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Experiences of Receiving Long-Term Care Services Post Stroke From the Perspectives of Indigenous and Non-indigenous People in the Taiwanese Community: A Focused Ethnographic Study

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Thesis submitted in fulfilment of the requirement of the degree of Doctor of Philosophy

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Abstract

Background: The Long Term Care (LTC) policy in Taiwan was developed in response to Taiwan’s ageing society and is aimed at addressing the increasing demand for healthcare services (Ministry of Health and Welfare, 2018). Stroke is often seen as an age-related disease. Medical advances have enabled an increase in the number of stroke survivors, and have consequently increased the population living in communities with long-term health conditions or residual complications post-stroke (Hsiao, 2010; Donkor, 2018). In Taiwanese society, adult children generally take care of their ageing parents. This generational relation bond in families stems from filial piety and a familial belief system that forms the backbone of the family caregiving system. Demographic changes in combination with more women joining the paid workforce have impacted negatively on the previously readily available but unpaid care work within the family, thus raising the demand and need for the provision of LTC services. The Taiwanese community comprises different ethnic groups, and insufficient attention has been paid to the specific healthcare needs of people from different backgrounds. This ethnography explores how stroke survivors and their family caregivers utilised LTC services from the perspectives of indigenous and non-indigenous participants.

Methodology and methods: A focused ethnographic approach was employed for this study. Data collection included non-participant observation of LTC service delivery and involved semi-structured interviews with 12 dyads of stroke survivors and their family caregivers. The research participants were from indigenous, urban-based indigenous and non-indigenous communities. Each ethnic group consisted of four dyads. Following transcription, the data were transferred to NVivo 12 for analysis. The data analysis reflected an inductive-abductive approach, drawing on Bury’s (1982) biographical disruption, Glaser and Strauss’ (2011) status passage theory, and in its later stages, Giddens’ (1984) structuration theory.
**Findings:** The findings show that post-stroke life was underpinned by the family caregiving system and LTC system in Taiwanese communities. Each dyad’s needs and expectations for their post-stroke lives informed their post-stroke recovery trajectory. The extent to which LTC coordinated the individual needs within the situated contexts of both the family and community shaped the nature and quality of recovery and this reflected the individual’s recovery trajectory. However, the coordination of care resources faced obstacles that resulted from social determinants. The predominant socioenvironments were the key factors that inhibited healthcare access. Urbanisation was a fundamental reason for the urbanised indigenous participants’ slower movement along the recovery trajectory. They seemed to be invisible in the LTC system, and their healthcare was not as well supported. They had lost their ethnic connection to the native tribes and administrative identity in the LTC system concurrently, as they detached physically from the tribal communities and sociopsychologically from the urban communities. The geographical barrier was an unconquerable distance preventing healthcare access for the indigenous people located in mountainous areas, as the need for transportation increased and impeded the accessibility of healthcare facilities. The LTC workforce served as an agency in overcoming some of these barriers and optimising the system organisation. The agency of the LTC workforce functioned in different patterns. In the non-indigenous context, the LTC workforce assumed a supplementary role of collaborating with other available resources in the community. Their agency was expected to be more skilful and independently applied in the mountainous indigenous context. In the urban-based context, this agency was enacted through information and resource linking.

**Conclusions:** The conceptual model illustrated how structuration theory (Giddens, 1984), biographical disruption (Bury, 1982) and status passage theory (Glaser and Strauss, 2011) could help to interpret the world of people recovering from a stroke and engaging with the LTC system in society. It identified socio-environments as the key barriers and the workforce agency as
the facilitator for LTC implementation. Therefore, LTC policy should not aim to achieve equal healthcare access; instead, it needs to draw support from flexible, adapted strategies in order to address healthcare equity for individuals.

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Lay Summary

Long-term care (LTC) policy in Taiwan was developed to address the needs of an increasing population living with long-term health conditions due to the ageing of the population and advances in disease treatments. Stroke is one of the common diseases that causes people to live with residual disability in later life. The family, which has long been the key support for caregiving, faces the limitation of bearing both household and employment workloads. Extensive research shows that stroke survivors encounter ongoing life transitions when living with complications in the community setting. In the meantime, they face barriers when utilising healthcare and social care services.

This study explored the care needs of those living with long-term conditions in Taiwanese communities by undertaking a qualitative inquiry and using the example of stroke disease. In this study, experiences of using LTC services post-stroke were collected from 12 dyads of stroke survivors and their family caregivers, taken from the indigenous, non-indigenous and urban-based indigenous populations. Each ethnic group provided four dyads. Data were gathered by observing the LTC service delivery in the community and residential settings and interviewing the stroke survivors and their family caregivers individually.

The findings showed that the family caregiving system and LTC system work concurrently and supplementarily to support post-stroke life in the Taiwanese community. The stroke survivors recovered in different patterns and at different speeds along their post-stroke recovery trajectory. The dyads’ life continued as the LTC system met their individual needs through coordinating them with the contextual conditions in the community. However, both the LTC and family care resources had weaknesses. The socio-environments where people live are the key barriers to healthcare access. Urbanisation issues increase the difficulty of negotiating individual needs with the wider population in the community. Urban-based indigenous people seem to be invisible from the LTC
system, as they lose their original social connections when they become urbanised. Healthcare access for the indigenous people living in mountainous locations was limited by an unconquerable distance gap, which reduced the availability of rehabilitation and transportation services. It was found that these barriers could be partially overcome by the assistance of LTC providers. They could adjust the service delivery methods to meet the individual needs in the socio-environments.

In conclusion, the study highlighted that the efficacy of the LTC system needs to build on individual needs and overcome situational barriers through flexible service adaptation and delivery. The first recommendation following the findings was to reconsider the family caregivers’ needs instead of subordinating their needs to stroke survivors. Second, it was suggested that the local organisation and the workforce supply should be strengthened in order to empower care providers’ capability in communication and collaboration with other resources to meet the expectations of care users.
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Chapter 1: Introduction

This chapter presents pertinent background details related to (1) the significance of long-term care throughout the globe; (2) an overview of the long-term care system in Taiwan; (3) a rationale for forming the research aim and questions; and (4) the organisation of this thesis.

1.1 Background: the significance of long-term care policy throughout the globe

Long-term care (LTC) involves a variety of services that address the personal, health and social care needs of individuals with functional disabilities or long-term conditions that chronically influence their everyday life (Wunderlich and Kohler, 2001). The need for LTC is not specific to the elderly population; it may also be required by individuals with disability in young and middle age (Sciegaj et al., 2019). However, the focus of this study is the older generation; as such, I am looking at LTC for older people and specifically post stroke. Many people experience significant declines in physical and mental capacity as they grow older (Milanović et al., 2013; Murman, 2015). Therefore, the World Health Organisation (WHO) and Organisation for Economic Cooperation and Development (OECD) usually elaborate on the LTC, aligning with the ageing phenomenon and the resultant care issues confronting the countries in their membership. WHO (2015, p. 34) defines the role of LTC as “to enable older population who have high risk of significant ongoing losses in capacity to maintain a level of functional ability consistent with their basic rights, fundamental freedoms, and human dignity”.

Between 2015 and 2020, the global population aged over 60 years, i.e. those recognised as older persons, has risen from 12 per cent to 13.5 per cent of the world’s population. The number is projected to keep rising and represent 22 per cent of the world’s population by 2050 (World Health Organization, 2020).
Across the developed OECD countries, the population aged 65 and above is projected to rise from 17.4 per cent in 2017 to 27.1 per cent by 2050 (OECD, 2019a). Factors including efficacious treatment, rehabilitation programmes and advances in disease management have resulted in a longer and healthy life expectancy but also the potential of a longer timespan living with disabilities. The latter point is, for example, true for some premature infants who are more likely to survive these days; however, many need intensive interventions and care support to overcome neurologic sequela or bronchopulmonary complications (Glass et al., 2015). At the other end of the age spectrum, pharmaceutical innovations such as applying statins and intravenous recombinant tissue-type plasminogen activators (r-tpa) in stroke treatment can reduce severity and increase survival (Flint et al., 2012; Chapman et al., 2014). As more patients survive these diseases, more people are living with long-term health conditions.

The phenomena of ageing and the increasing needs of LTC should target both retirement life for older people in the community and the care services supporting them to sustain independence and dignity. Therefore, the Global Strategy initiated by the WHO (2017) advocates that every country builds a system of LTC in order to deliver and coordinate resources that will enable the best possible trajectories and better experiences of living with capacity loss over time. The LTC system is constructed in varying ways in different places, depending on the configurations of demographic composition, policy and welfare structure, family ideology and responsibilities between the health and the social sectors (Ranci and Pavolini, 2013). A considerable number of countries position LTC as elderly care, as it targets the population aged 65 years or older (OECD, 2019a). Apart from biological decline and physio-psychological change, ageing is also co-affected by lifecycle transition, sociocultural transformation and national development in each country (Albert and Trommsdorff, 2014; Defo, 2014). In this regard, the definition of old age varies across the globe. Most developed countries currently accept the general recognition of ages 60-65 as the start of old age, congruent with the lifecycle
of retirement and reception of pension benefits (Asher and Kimura, 2015; OECD, 2019a; OECD, 2019b). However, this commonly applied definition might not be suitable for less developed countries, where 50 years has been determined for this classification in light of a combination of chronological, functional and social definitions (Kowal and Dowd, 2001; WHO, 2020).

1.1.1 Concept of Healthy Ageing

Despite the various definitions of old age across countries, the WHO (2015) has developed a Healthy Ageing Framework to comprehend people’s ongoing capacity loss in later life as well as their engagements with health services, long-term care and environments. ‘Healthy Ageing’ can be embodied as a process of developing and sustaining functional ability that enables wellbeing in older age (WHO, 2015). When considering the general population as a whole, this framework (see Figure 1.1) illustrates an individual’s capacity transformation in ageing life with two dynamic and ongoing trajectories, functional ability and intrinsic capacity, that progress in the course of biological ageing.
Healthy ageing refers to a positive way of ageing; it is widely used and significantly related to multidimensional concepts such as active ageing and quality of life. These are constructed from interdisciplinary perspectives including social sciences, politics, geography, health sciences and geriatrics, economics and technologies (Rojo-Pérez and Fernández-Ballesteros, 2021). The realisation of healthy ageing depends on contextually appropriate indicators and predictors and the configuration of various healthcare resources in the context (McLaughlin et al., 2012; Fuchs et al., 2013). Cardinal et al. (2008) present a conceptual framework that elaborates on the vision of healthy ageing with nine areas of intervention, comprising five actions on primary health determinants and four predictors of risk factors and health conditions (see Figure 1.2). However, the LTC policy in Taiwan is grounded in a
perspective that illustrates individuals’ ageing process as a trajectory divided into five phases: healthy, sub-healthy, frail, physically disabled/cognitively impaired, ill, and end-of-life status (Ministry of Health and Welfare, 2016). The LTC policy designates the position and role task of the care continuum according to the medical-oriented system, LTC system and institution facilities along the ageing trajectory. In terms of the policy development background, the WHO Healthy Ageing framework (2015) demonstrated in Figure 1.1 was drawn upon to contextualise Taiwan’s LTC policy (Ministry of Health and Welfare, 2016).

Figure 1.2 A conceptual model of perspectives for healthy ageing by Cardinal et al. (2008), cited from Dubuc et al. (2013)

*Cardinal and collaborators’ original version is in French. The English version is adopted from Dubuc et al. (2013).
This framework (WHO, 2015) helps to understand the role and engagement of health services, LTC and environments in influencing ageing life trajectory and the fulfilment of Healthy Ageing. An individual’s trajectory of functional ability and intrinsic capacity can be divided into three main stages: a period of relatively high and stable capacity; a period of declining capacity; and a period of significant loss of capacity. The boundaries of these stages cannot be classified simply by chronological age; the trajectory varies in different people. A person engages with LTC in varying patterns according to their biological ageing stage, health status and the environment he/she stays in. Figure 1.3 illustrates different trends of physical capacity that proceed along the biological time. For example, the trajectory of people with good health might show a flat, wide plateau followed by a sharp downward trend in the endpoint like the trajectory A in Figure 1.3. This illustrates that this group maintains a high and stable capacity for a long time and experiences functional loss in terminal life. Some people experience an acute disease event in middle age and live with complications in their older age. The trajectory B representing this group shows an interrupted trajectory, with a steep, nearly 90-degree drop as an event causes a sudden fall in capacity, followed by an upward trend when access to rehabilitation or health services supports the person in regaining capacity.
An LTC system aims to maintain older adults’ capacity for as long as possible by compensating for functional deficiency, supporting capacity-enhancing behaviour and ensuring a dignified late life (WHO, 2015). The LTC system can enable older people to receive day-to-day care that helps them to continue their life, maintain their basic rights and experience wellbeing regardless of decline in physical and mental capacity (OECD, 2013). In contrast to acute medical care, long-term care provides a diverse array of services over a sustained period, aiming to avoid families being overwhelmed by a demanding care load and huge ongoing care expenditures (Pot et al., 2017). Moreover, a system developed for LTC also coordinates with other resources such as housing and transportation systems to build a barrier-free, aged-friendly environment and thus optimise living conditions (Rowles and Bernard, 2012; WHO, 2015).
1.2 Context of the research: the LTC system in Taiwan

Each nation constructs the LTC system differently; this reflects different nations’ political ideology and social structure such as workforce composition, organisation and funding of healthcare and social care system. In this section, I focus on showing what the LTC system looks like in Taiwanese society. I first provide a brief overview of the demographic status. Subsequently, I outline the establishment of the LTC system in Taiwan in terms of aspects of the development process, the ideal ideology of actively ageing in place, and the structure of a three-tier community-based programme.

1.2.1 Demographic characteristics

The statistical data from the National Development Council (NDC) (2020) shows that the population over 65 accounts for 16.07 per cent of the general population in Taiwan. Taiwan is one of the fastest growing ageing societies in the world (Asian Productivity Organisation, 2011; Lin and Huang, 2016), as it only took 25 years to advance from an ageing society (with the elderly population accounting for 7 per cent) in 1993 to an aged society (with the elderly population constituting over 14 per cent) in 2018 (NDC, 2020). This time span is relatively shorter than predicted for other countries, as the global average transforming time from an ageing society to an aged society is 39 years (Asian Productivity Organisation, 2011).

This accelerated ageing society highlights healthcare issues in Taiwan, as the ageing phenomenon is accompanied by falling fertility rates and improvements in life expectancy (Ministry of Health and Welfare, 2016; NDC, 2020). Taiwanese life expectancy was 84.2 years for women and 77.7 years for men in 2020. The general fertility rate, referring to average number of live births per 1,000 childbearing-aged women, dropped from 1.116 in 2005 to 0.99 in 2020, ranking as the lowest in the world (Ministry of the Interior, 2021). The issue is further manifested in the imperative fact that deaths started to outnumber
births in 2020, as Taiwan’s general population decreased by 11,250 people, which was not related to the COVID-19 pandemic.

The proportion of the population with LTC conditions or residual complications from diseases is expected to increase within the community due to longer life expectancy and advanced medical and healthcare skills (Hsiao, 2010; Donkor, 2018). This transformation in disease trajectory will lead to an intensification of the demand for LTC services. This entails a heavy burden in terms of taking care of frail and disabled people. These transformations have a broad set of implications for every family, as there will be fewer family members sharing the responsibility to provide care. The ratio of the elderly population (aged above 65) dependent on younger adults (aged 15-64) is projected to increase significantly from 1:5.6 in 2016 to 1:1.2 in 2060 (NDC, 2020). Consequently, it can be expected that the demands for LTC services will be amplified because of the growth of illnesses and inadequate human resources (Wang and Tsay, 2012). These demographic projections demonstrate a greater demand for a labour-intensive LTC system.

### 1.2.2 Profile of the long-term care system

Taiwan’s LTC policy was developed to address the social problem of an aged society and the resultant demands for healthcare services. Compared with the existing well-developed medical-oriented health system, National Health Insurance (hereafter NHI), the LTC system is still in a developing stage (Chen and Fu, 2020; Yeh, 2020). The ten-year LTC plan (hereafter referred to as the LTC 1.0 plan) was implemented from 2007 to 2016. When the LTC 1.0 plan was due, a policy reform followed and targeted its limitations, including the inadequate coverage of the service and the fact that only a few eligible users knew about the subsidy programme (Yeh, 2020). The question of whether to go on with an insurance system or continue the publicly-funded system was debated during the policy reform. In 2017, the second ten-year LTC plan
(hereafter noted as the LTC 2.0 plan), which proposed a tax-funded community-based model, was agreed (Ministry of Health and Welfare, 2018).

‘Actively ageing’ and ‘Ageing in place’
Corresponding to WHO’s advocacy for Healthy Ageing, the LTC policy in Taiwan calls on the concepts of ‘actively ageing’ and ‘ageing in place’ (Lin and Huang, 2016). The initiative of actively ageing focuses on enabling older adults to maintain a level of physical and mental fitness that makes them capable of managing their daily living. The initiative of ageing in place refers to the location of LTC provision, which purports to extend the period during which older people can stay in their preferred place in the community as long as possible and avoid institutionalisation (Yap, 2008). The purpose of the LTC 2.0 plan is to actualise ideals of ageing in place and actively ageing by building a universal care system with multi-type and continuous services based on the spirit of communitarianism as the local governments are entitled to establish facilities and organise LTC service in their borough (Ministry of Health and Welfare, 2020). The LTC system in Taiwan has endorsed concepts of actively ageing in place, respecting familial beliefs, which are engrained in the need to establish community-based LTC services in order to support individuals staying in their preferred home settings (Hsu, 2007).

The phased model combining the personal ageing trajectory and the care continuum in society focuses on family- and community-based services (Ministry of Health and Welfare, 2016; Yeh, 2020). A variety of services and infrastructures are established and available to support older adults and their families in their transitions from health to illness and end-of-life. However, institutional care is only substituted for family care during terminal illness within the policy planning. Hence, although the LTC service is positioned as social welfare, to a certain degree the policymakers intend to draw on informal care resources from family members, for economic reasons (Rozario and Rosetti, 2012).
Target populations

To address the specific preferences of community-based and family-centred services (Lin and Huang, 2016), the LTC 2.0 plan has expanded the coverage of the targeted population and increased the flexibility of care services compared to the LTC 1.0 plan. The LTC 2.0 plan offers services to the following people: (1) people over the age of 65; (2) people of all ages with LTC needs, to be defined by activities of daily living (ADLs) and instrumental activities of daily living (IADLs); (3) mountainous region and plain region indigenous people over the age of 55; (4) older people aged above 65 with frailty; and (5) people with dementia aged over 50 (Ministry of Health and Welfare, 2017). Table 1.1 lists the targeted population and the corresponding eligibility requirement. Taking these objectives into account, the LTC 2.0 plan aims to provide care services for people with different health conditions and to extend its coverage to indigenous people aged 55 or above.
Table 1.1 Targeted populations and eligibility criteria

*Content in italic blue format identifies the expanded population in the LTC 2.0 plan

<table>
<thead>
<tr>
<th>Targeted populations</th>
<th>Eligibility criteria: functional limitations and age</th>
</tr>
</thead>
</table>
| 1. Older people with functional limitations of ADLs      | • aged 65 and above  
• daily living dependence and assistance required, including clothes changing, eating meals, showering, walking on the plainland                                                                                               |
| 2. People with disabilities                              | • aged 50 and above  
→ aged 49 and under (expanded to include the whole population with disability)  
• possessing disability identification and/or certification                                                                                                                                  |
| 3. Indigenous people with functional limitations of ADLs | • aged 55 and above  
• daily living dependence and assistance required  
• mountain indigenous people  
→ mountain and plainland indigenous people (expanded to include the whole indigenous population)                                                                                     |
| 4. Older people living alone with only limitations of IADLs | • aged 65 and above  
• daily living dependence and assistance required, including clothes changing, eating meals, showering, walking on the plainland                                                                |
| 5. Older people with frailty                             | • aged 65 and above  
• elderly with symptoms of frailty such as weight loss, lower extremity functions and reduced energy level  
• a scale of frailty is the determined tool                                                                                                                                                |
| 6. People with dementia                                  | • aged 50 and above  
• definite diagnosis or suspected symptoms of dementia, including degeneration in expression, memory, sleep disorder (disturbance of sleeping) or hallucination                                                                             |
Financial scheme and sustainability

The ongoing LTC system is a national level healthcare policy and administrative project by central and local governments (Yeh, 2020). This financial scheme uses a combination of tax-funded and partially means-tested co-payments to ensure a more comprehensive coverage of the targeted population and the sustainability of the care system (Pot et al., 2017). The financing resources include earmarked tax: ten per cent of the Estate and Gift tax and the Tobacco and Alcohol tax (Ministry of Health and Welfare, 2018). In addition to these tax resources from the central government, the local governments in each city and country are also obligated to commit a certain portion of local tax revenues to fund the LTC services. LTC users are classified into eight levels of service demand based on their dependency. Each level is entitled to a portion of subsidy from the LTC system, and the care users are required to self-pay a designated portion of the service charge, which is determined by socioeconomic ability. Table 1.2 below shows the entitled subsidy and portion of co-payments for service users.

Table 1.2 Allowance standard for the eight levels of LTC service demands

<table>
<thead>
<tr>
<th>LTC service demand level</th>
<th>Subsidy limits (New Taiwan Dollar)</th>
<th>Low-income household</th>
<th>Middle-income household</th>
<th>General household</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>2</td>
<td>10,020</td>
<td>0%</td>
<td>5%</td>
<td>16%</td>
</tr>
<tr>
<td>3</td>
<td>15,460</td>
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<td>5%</td>
<td>16%</td>
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<tr>
<td>4</td>
<td>18,580</td>
<td>0%</td>
<td>5%</td>
<td>16%</td>
</tr>
<tr>
<td>5</td>
<td>24,100</td>
<td>0%</td>
<td>5%</td>
<td>16%</td>
</tr>
<tr>
<td>6</td>
<td>28,070</td>
<td>0%</td>
<td>5%</td>
<td>16%</td>
</tr>
<tr>
<td>7</td>
<td>32,090</td>
<td>0%</td>
<td>5%</td>
<td>16%</td>
</tr>
<tr>
<td>8</td>
<td>36,180</td>
<td>0%</td>
<td>5%</td>
<td>16%</td>
</tr>
</tbody>
</table>
1.2.3 Structure of the LTC system in Taiwan

The preceding paragraphs have outlined the implementation of LTC policy in identifying the target populations and the financial scheme. The structure and organisation of the LTC system in the Taiwanese communities will now be presented, including the location of service provision, operating model, service types and care providers. The locations for care provision include community-based care, care in the home setting and institutional care programmes. Statistics show that only 11 per cent of LTC users opted for institutional care. Twenty six per cent relied on live-in foreign care workers, 23 per cent used LTC services, and 40 per cent of the care-demanding population relied solely on their family members (Executive Yuan, 2020). This suggests that most people still prefer to be cared for by family members and living at home is their first choice for care in later life. To promote actively ageing in place, a three-tier, community-based LTC system model has been established in Taiwan (Executive Yuan, 2018).

- The three-tier structure comprises community-based integrated service centres (Tier A, with one in every township or district), combined service centres (Tier B, with one unit in every school district) and neighbourhood LTC stations in alleys and lanes (Tier C, built in every third village).
- Tier A assesses the care needs of individuals, rationing and connecting available resources at the B-tier and C-tier units in the community.
- Tier B consists of service-delivering organisations such as residential care, rehabilitation facilities and assisted device support centres.
- Units at Tier C are expected to play a neighbourly role to LTC users; they are highly accessible and provide a venue for social activities and information consultation. In addition to acting as a social organiser, the responsible person at the Tier C unit can refer queries up to Tier B and Tier A. Figure 1.4 illustrates this three-tier operation model with its role functions.
Figure 1.4 A-B-C Tiers in the LTC system, adapted from Ministry of Health and Welfare (2018)

**Tier A - Community-integrated service centre**
- Coordinates and links care service resources
- Establishes a localised service delivery system that integrates and connects to Tier B and Tier C resources
- Operates pick-up and transport service connecting A-B-C service through community transport and care transport personnel

**Tier B - Combined service centre**
- Elevates community capacity to provide LTC services
- Increase diverse services for the public

**Tier C - Combined service centre**
- Provides respite service in the neighbourhood
- Implements primary prevention programme

**Explanatory key for terms:**
- The concept of the tier is termed from the policy-making perspective, indicating the LTC conduct from Tier A (client enrolment and care planning) to Tier B (professional care delivery) and Tier C (primary, preventive, and respite care).
- This is the same as the A, B, and C units described from the perspective of the care users in the later chapters.
- The terminological difference was attributed to the different perspectives. The care users understood the LTC by engaging with care providers from various units, while the policy focused on interactive processes across different levels of capability and authority.
Service organisation: public sector, non-profit and for-profit organisations

As elderly and dependent people require social, health, housing and transportation services, the three-tier (A-B-C) structure integrates medical healthcare, LTC services, housing and transportation, as well as social participation in the community. To address these different needs, multi-type services are required in the LTC system. Therefore, the system is strengthened by a collaboration between the public sector, for-profit sectors, and non-profit organisations in order to provide various health and care services. The central government mainly assumes a regulatory and guiding role in policymaking. Local governments provide incentives for organisations to stimulate their participation and provide subsidy for the expenditure. These organisations include healthcare facilities, professional industries and philanthropic organisations, which expands the diversity and scale of B-tier and C-tier units. When a case is enrolled in the A-tier unit, the care manager can link the user to the care services that are available and accessible in B-tier and/or C-tier units near their residences.

Workforce: informal and formal workforce

Taiwan’s eldercare relies on informal work, usually assumed by family caregivers due to familial obligation; formal workers include domestic workforce and migrant care workers. Comparing the choice of care pattern between 2016 and 2020 shows that utilisation of LTC services increased from 15 to 23 per cent as the percentage of households caring for disabled older family members without formal assistance decreased from 60 to 40 per cent (Chen et al., 2016; Executive Yuan, 2020). The statistics also show that Taiwanese households remain highly reliant on the support of migrant live-in care workers, usually from south-east Asian countries. According to statistics provided by the Ministry of Labour (2019), the population of foreign care workers increased from 183,826 in 2010 to 256,173 in 2018, with this group mainly originating from the Philippines, Vietnam and Indonesia. This population demonstrates an upward trend annually. In 2012, there were
189,373 migrant care workers in the care service compared to 7,079 Taiwanese, indicating that migrant care workers are not supplementary to the care system workforce; rather, they form a major and significant part of the workforce dealing with Taiwanese elderly care (Chen, 2015). This parallel existence of migrant care workers and domestic LTC providers not only shows the dual workforce system in Taiwan’s elderly care industry but also provides a more comprehensive viewpoint regarding the caregiving pattern in residential-dwelling environments. Each household makes decisions about the care service preferences best suited to their needs, taking into account multifactorial considerations influenced by socioeconomic ability and sociocultural beliefs (Chiou et al., 2009; Park and Ko, 2020).

1.3 Rationale for the research aim and questions

Drawing on the implemented LTC policy, the LTC system is essentially a social construct that reflects a combination of ideology, political beliefs and sociocultural underpinnings (Kane, 2005). From a macro perspective, the system was established to address the increasing health and social care demands of an aged society, structured by policymakers and experts from correlative departments. Humans are place-makers, and places make humans (Madden, 2017). The LTC policy has its own social specialities and cultural features. The current operation of the policy has essentially been shaped by demographics, ethnic and social features, and a number of concerns, as it is a social and healthcare system within the community.

From a micro perspective, the service recipients in this domain could be deemed to be a group of people with featured experiences and preferences for accepting services in the context of general welfare practices in the Taiwanese community. Additionally, the LTC system defines a specialised age requirement for indigenous people, relating to their relatively weak health status and shorter life expectancy. Thus, the indigenous population can be
regarded as a subgroup in the LTC system in terms of their perceptions of receiving care services. Therefore, understanding experiences of LTC services from the perspectives of both indigenous and non-indigenous people in the Taiwanese community needs to be investigated.

1.3.1 Why focus on stroke?

Stroke ranks the third in the global leading causes of disability-adjusted life years (DALYs), representing a time-based measure that combines years of life lost due to premature mortality and time lived with a disability (World Health Organization, 2019). The loss of healthy life years resulting from stroke is mainly prevalent in the ages group from 50 years upwards (Kassebaum et al., 2016). In Taiwan, the DALYs loss of stroke increased from 992.1 in 2010 to 1360.8 (Age-sex standardised DALYs loss/10,000 people) in 2017 (Venketasubramanian et al., 2017; Wu et al., 2021). Medical advances led to an increase in stroke survivors (Donkor, 2018). The annually age-standardised mortality rate of stroke decreased from 57.8 to 30.8 per 10,000 between 2001 and 2012; these facts indicate an increasing population with long-term health conditions or residual complications from stroke living in the Taiwanese communities (Hsiao, 2010). Stroke onset tends to occur suddenly. The acute event and the associated complications usually influence the whole family and stress both stroke survivors and the family. Hence, this study attempts to understand how the LTC system supports stroke survivors and their family caregivers in facing a sudden attack from stroke and ways of engaging with care services over time.

When a change takes place in a family, the disturbance can lead to the creation of a new position of balance in the structure. Chronic health conditions, such as stroke or its subsequent complications, may cause various levels of impairment, and, therefore, qualify as life-altering diseases (Buschenfeld et al., 2009; Gallacher et al., 2018). More than 20 per cent of the stroke survivors live with residual disability and are confined to their homes, relying on the support
of family members in daily living over an extended period (Smith et al., 2008). Both stroke survivors and family caregivers will go through a process of role transition in their daily lives. The ongoing transition of post-stroke life requires the family to deal with the caregiving task and unpredictability results from dynamic family relations, subjective and contextual situations (Milliken et al., 2019). The caregiving work at the early stage is particularly challenging and stressful (Hunt, 2003).

1.3.2 Why look at indigenous and non-indigenous people?

Inequality pertaining to health exists in Taiwanese society. The age requirement of LTC 2.0 Plan for indigenous people (aged 55 or older) is ten years lower than that for the non-indigenous population (aged 65 or older). This age-differential treatment is applied to compensate the gap in life expectancy between the indigenous and non-indigenous population. In 2019, the life expectancy of indigenous people was 73.10 years, i.e. 7.76 years shorter than the average life expectancy of the total population at 80.86 years (Ministry of the Interior, 2019).

The definition of the indigenous population’s identity is based on the Laws and Regulations of Status Act for Indigenous Peoples. According to the “Status Act for Indigenous Peoples” (Laws and Regulations Database, 2008),

“The term ‘indigenous people’ herein includes native indigenous peoples of the mountain and plain-land regions. Status recognition, unless otherwise herein provided, is as provided in the following:
Mountain indigenous peoples: permanent residents of the mountain administrative zone before the recovery of Taiwan (1945), moreover census registration records show individual or an immediate kin of individual is of indigenous people descent.
Plain-land indigenous peoples: permanent residents of the plain-land administrative zone before the recovery of Taiwan, moreover
The interplay of ethnicity and social class in relation to family health is significant. The combined influence of these two variables is profound, especially for the indigenous people in Taiwanese society. Reasons for which different service requirements are provided in LTC 2.0 Plan for Taiwanese indigenous peoples can be explained and discussed from a historical context, from the context of ethnicity, lifestyle, and socio-structural perspectives. The island’s 550,000 indigenous people, who constitute two percentage of Taiwan’s 23 million population (Ministry of the Interior, 2018), are frequently neglected in geopolitical assessments regarding Taiwan. Indigenous people in Taiwan witnessed the conquest, pacification, and rule of several foreign regimes, including imperialist and colonialist ones. Due to four centuries of political marginalisation and competition with dominant ethnic groups, the indigenous Taiwanese have gradually become minority and disadvantaged groups, who belong to the lower-middle class socio-economic group in Taiwanese society (Huang and Liu, 2016). The household income of the indigenous population is only 63 per cent of the average income of general households in 2017. Moreover, 81.59 per cent of indigenous households rely on paid work, which is much higher than 65.96 per cent of the households in the general population. In addition, income resources other than paid work (such as rental income and investment revenue) accounted for 6.42 per cent of the total income for the indigenous households, vis-a-vis 19.28 per cent for the general households (Council of Indigenous Peoples, 2018).

The combined effect of lower socio-economic stability, lifestyle factors and healthcare utilisation are represented in the household expenditure. According to the economic status survey of indigenous people in Taiwan (Council of Indigenous Peoples, 2018), the expenditure on medicine and healthcare in
indigenous households was 5.75 per cent in 2017, which is very much lower than the average national household expenditure of 15.25 per cent (Council of Indigenous Peoples, 2018). Indigenous people accounted for about one fifth of the expenditure on healthcare, compared to the average level. With respect to the household expenditure on cigarettes, alcohol, and betel nut, it accounts for 5.03 per cent for the indigenous population in 2017, and slightly less than 5.22 per cent in 2014. However, the proportion remained considerably higher than the national household average of 1.20 per cent (Council of Indigenous Peoples, 2018).

1.3.3 The study aim and research questions

This focused ethnographic study aims to explore and describe the experiences, perceptions and beliefs pertaining to LTC services from the perspectives of indigenous and non-indigenous people in two geographical regions in Taiwan: an indigenous administrative region and an urban region respectively.

The research questions are as follows:

- **How does the current long-term care policy meet the needs and expectations of stroke survivors and family caregivers experiencing LTC from different ethnic or cultural backgrounds?**

- **What are the facilitators of and barriers to long-term care for stroke survivors and their family caregivers who are experiencing care in their community?**

This thesis details the development of the research, the methods and the analysis of the data and elaborates on life transitions in the post-stroke recovery trajectory by contextualising social relations among individuals, the LTC system and environments.
1.4 Organisation of the thesis

This thesis comprises seven chapters. Chapter 1 provides background context about LTC for the research context and the rationale for forming the research aim and questions with a focus on stroke survivors. Chapter 2 provides an analysis of the literature examining the LTC system. Chapter 3 justifies my research design and a justification of my focused ethnographic approach. A series of reflexive practices were applied during the research preparation, data collection in the field and the process of data analysis. The chapter presents my reflections and experiences when completing this research in the real-world context. Chapters 4 and 5 present the research findings of this study. Chapter 4 focuses on my principal analysis of biographical continuation in the post-stroke recovery trajectory by contextualising social relations among individuals, the system and environments, while chapter 5 analyses the themes and subthemes relating to the coordination and operation of the LTC system. Chapter 6 provides an overarching discussion of the post-stroke recovery trajectory and the LTC system engagement with a conceptual model. The conceptual model navigates the integrated LTC system in a three-context structure through capturing the concepts of social interactions: individual-system, individual-collective, and identity-place. The three-context levels are identified as the predominant macro context for policy implementation, the meso context for tension coordination, and the micro context for adapted service practice. Chapter 7 presents the conclusion of this PhD study, including implications and recommendations for future LTC policy refinement regarding an aged-friendly environment, co-payment fee scheme reconsideration, workforce recruitment and organisation integration.
Chapter 2: Literature Review

2.1 Introduction

In the previous chapter, the international status of long-term care (LTC) policy and its implementation in Taiwan were discussed. The background chapter illustrates that the LTC system is a social construction framed by the associated demography, policy vision, financial scheme and LTC structure in Taiwan. This chapter presents a retrospective literature review based on the data analysis, and focuses on what will actually be discussed in the thesis. Initially, as I developed my thesis, I looked into family nursing and focused on dyads of stroke survivors and family caregivers. I read around the topic broadly as a foundation for my research study. However, as I explored my data, I realised I did not have an adequate way to analyse it. It was the analysis that inspired me to reach out and look at more diverse sociological explanations and other frameworks and models to explain my data. This was how I came to the theoretical perspectives of biographical disruption (Bury, 1982), status passage theory (Glaser and Strauss, 2011) and structuration theory (Giddens, 1984). Here, I present a more structured approach to the research studies I reviewed as my data analysis focus became more apparent. This approach is not uncommon in qualitative research, which is primarily inductive and then abductive.

Specifically, the literature review is divided into three main parts. The first part considers life transition post-stroke, and analyses individual, relational and healthcare aspects. The second part analyses the tensions involved in LTC implementation within social structures. I debate the factors in these social structures that may impede transition, including the tension between family and society, the tension between familism ideology and political ideology, and the tension between social determinants and health accessibility for indigenous groups. Finally, the third part looks at the theoretical underpinnings from the literature upon which I draw and through which I further justify the
rationale of abductive reasoning in Chapter 3 and the finding of presentations in Chapters 4 and 5.

2.2 Literature search methods

The function of a literature review is to gain an overview of what is known as well as identifying a knowledge gap that sets the stage for data interpretation in the later process of the research (Charmaz, 2006). To review relevant research studies I used the PRISMA statement, which includes a 27-item checklist and a four-phase flow diagram, as a tool to help to systematically search the literature (Liberati et al., 2009). I carried out the literature search using electronic databases including CINHAL Plus, Medline, Sociological Abstract, Psycho INFO and EMBASE. Search terms included ‘stroke’ OR ‘family caregivers’ AND ‘rehabilitation’ OR ‘recovery’ OR ‘community life’ AND ‘long-term care’ OR ‘indigenous’ OR ‘aboriginal’ OR ‘minority groups’ AND ‘qualitative research’ OR ‘interview’ OR ‘observation’ (see Appendix A for the details of the combined search terms and the number of results).

In addition, a social welfare dimension emerged from the above search results that spurred me on to carry out another search with search terms including ‘welfare regime’ AND ‘long-term care policy’ in the Sociological Abstract database. Hence, I manually identified relevant publications relating to long-term care policy in European and East Asian countries. Since the LTC 1.0 plan was initiated in 2007 (Ministry of Health and Welfare, 2018), the timeframe for the literature search was from 2007 onwards. The search was limited to full-text journal articles and published in English. The literature was searched in order to explore post-stroke life, interacting with LTC and care resources in families and communities. Therefore, the inclusion criteria were identified as being relevant to stroke care, family caregiving, long-term care, elderly care, or minority groups in community settings. Literature aimed at tool examination were excluded. Figure 2.1 presents the process of extracting research via databases and the criteria for the retrieved and excluded literature.
Figure 2.1 Flow diagram of literature identification via databases, adapted from PRISMA 2020 statement

Identification

Potentially relevant articles identified (N=413)

Articles screened after duplicates removed (N=396)

Articles screened by titles and abstracts (N=396)

Screening

Articles excluded (N=238) for these reasons:
(1) irrelevant to stroke, long-term care (LTC) or elderly care
(2) not in a community or home setting
(3) unclear data

Eligibility

Full-text articles assessed for eligibility (N=158)

Articles excluded (N=85) for these reasons:
(1) focused on tool examination
(2) irrelevant to family caregiving, minority groups, healthcare in remote area, European or East Asian countries, or social determinants
(3) unclear data

Included

Full-text articles assessed for inclusion retrieval (N=73)

Articles included for these reasons:
(1) specific population relevant to the research context, including indigenous or Taiwanese
(2) identified support for family caregivers
(3) LTC policy or LTC system

Articles included (N=25)

Articles identified through the first set of search terms:
- CINAHL (N=4)
- Medline (N=21)
- Sociological Abstract (N=274)
- EMBASE (N=8)
- Psycho INFO (N=2)

Articles identified through the second set of search terms:
- Sociological Abstract (N=104)
2.3 An overview of transition in post-stroke life

I examined the literature relating to post-stroke transition in the life trajectory, from the personal embodiment of body, self and identity to relational dynamics and health needs transformation across the care continuum post-stroke. The concept of transition was one theme that emerged from my literature review and was widely discussed in the published articles and conceptualised in various forms, including biographical disruption (Bury, 1982), the chronic illness trajectory (Corbin and Strauss, 1992) and transition theory (Meleis, 2000). This section analyses the stroke survivors’ and their families’ life transition and engagement with healthcare across the care continuum, based on these theoretical concepts.

2.3.1 Transition in the sense of body, self, and identity

The efficacy of intravenous r-tPA and improved diagnosis protocols have lowered the occurrence of severe and recurrent strokes (Chapman et al., 2014; Qureshi et al., 2017). Medical advances have reduced the risk of fatal symptoms and thus limited the morbidity and mortality associated with stroke (Jauch et al., 2013). According to the statistics on stroke disease registration data in the National Health Insurance database in Taiwan (Chiou, 2018), 61.2 per cent of stroke patients face functional disability one month after stroke onset, while 51.72 of them remain disabled six months after the stroke. Among discharged patients, 92.9 per cent are discharged to their home (Chiou, 2018). This implies that a considerable percentage of stroke survivors live with disabling motor, cognitive or language deficits as well as social and psychological changes associated with residual conditions post-stroke. It highlights the urgent need to extend the post-stroke care and rehabilitation scheme into the community sphere.

Changes in health status lead to a process of transition. “Transition is a result of and a result in changes in lives, health, relationships, and environments”
(Meleis et al., 2000, p. 13). Timothy et al. (2016) revealed conflicting embodiments of body and self-identity post-stroke in their constructivist grounded approach (Charmaz, 2006) that interviewed seven stroke survivors one month after discharge from rehabilitation units. The stroke survivors were in transition between the state of ‘a divergent body-self’ and ‘a cohesive body-self’, both reflecting a sense that ‘it is all me’. The fluctuation took place within moments and over time; it reflected the physical environment, social environment and wherever comfort could be embodied (Timothy et al., 2016).

According to Nasr et al. (2016), whose narrative inquiry study recruited five stroke survivors and three family caregivers in the UK, stroke onset not only caused physical limitations but also influenced psychological wellbeing. The narratives in this study unpacked the central way the stroke survivors’ changed bodies influenced their role function and identity exertion in their household, occupation and social context. The altered perception of body-self is a stressful situation and becomes meaningful to stroke survivors' life stories. Other people who are not involved may not empathise with this changed embodiment. Bury (1982) coined the phrase ‘biographical disruption’ to describe a disruptive perception change from what one knows about the body, self and identity to a new form that one does not yet know. This elaborates on the disruptive effect brought on by sudden stroke onset, which leads to physical and life transitions for stroke survivors and the surrounding people who co-experience the event.

2.3.2 Transition in identity and relationship

Stroke survivors’ families are likely to have an understanding of the changed body and its physical vulnerabilities as they are the primary sources of support underpinning the limiting body in daily life (Nasr et al., 2016). Family as the frontline support for care demands is strengthened in the work of Kitzmüller (2012), who applies hermeneutic and phenomenological methodology to understand the long-term experiences of family life after stroke from 37 stroke survivors and their spouses. The central theme emerging from their narrative
is that of the family as a lifebuoy. As the survivors and their families co-experienced the changes resulting from the limiting body, they were usually considered a unit when comprehending the illness trajectory of stroke (Kitzmüller et al., 2012). Families act on and react to changes in their family dynamics, especially when family members encounter health issues or when LTC transformations take place with periods of remission and deterioration. In order to gain a balance between stability and change, an additional role as family caregiver usually emerges, as the family often takes on the responsibility of caring for the sick family member during their illness (Kaakininen et al., 2015; Shajan and Snell, 2019). Cameron et al. (2013), in their framework methodology study on family caregivers’ support needs, defined a family caregiver as a family member or friend primarily responsible for providing and/or coordinating a stroke survivor’s post-hospital care without financial compensation.

The impact of any disruptive health event can cause a shift in familial relationships as members become care receivers and caregivers (Anderson et al., 2017). Long-term reliance on family caregiving impacts marital equilibrium and alters the parent-child relationship (Kitzmüller et al., 2012). In their constructivist qualitative approach, Anderson et al. (2017) interviewed 18 dyads of stroke survivors and spousal caregivers. The couples described three types of marriage transitioning: reconfirming their pre-stroke marriage; recalibrating it around care; and their parallel relationship. The parallel relationship was embodied as the couples’ disconnected lives due to divergent expectations and being unable to reach consensus on reciprocal roles. Three couples were unable to reconnect and subsequently separated. Dynamics occurred around the couples’ family caregiving responsibilities and marital relationships. The concept of biographical disruption (Bury, 1982) can explain the difficulty of role transitions in marriage. However, it has limitations in conceptualising the continuity after a disruptive event and the discontinuity regarding the different processes and outcomes of transitions (Cott et al.,
2007), for example, finding an agreeable balance between marriage and care, and the three different types of marriage continuity.

2.3.3 Transition in the care continuum

As mentioned before, medical advances have enhanced the survival of stroke disease (Jauch et al., 2013) but also increased the number of people living with long-term health conditions (Krueger et al., 2015). They have also transformed the way that dyads of stroke survivors and family caregivers engage with healthcare across the continuum of intense rehabilitation, community-based care, and transition to LTC institutions along their life trajectory.

Rehabilitation

Rehabilitation resources are front-loaded in enabling post-stroke recovery and usually begin within the first two weeks of stroke onset (Coleman et al., 2017). Teasell et al. (2012) reviewed the efficacy of randomised controlled trials (RCTs) across the continuum of stroke rehabilitation management lasting six months or longer. Although an age profile and illness severity were not provided, the article showed that rehabilitation in RCTs ranged across broad categories including motor function, cognitive function, medical interventions, out-patient therapy, psychosocial disorders and community reintegration. The majority of RCTs evidenced the positive effects of rehabilitation. Of the total 339 RCTs, 256 rehabilitation interventions were related to motor function recovery, while only 19 (less than six per cent) were related to community reintegration and psychosocial issues such as depression. Motor function recovery is apparently paid more attention than psychosocial recovery and community reintegration on the continuum of rehabilitation. However, recovery from divergent body-self to cohesive body-self should rely on a sense of wholeness and familiarity anchored in knowledge, positive attitudes and the environment (Timothy et al., 2016). A stroke survivor’s confidence to display motor function when exerting social identity is directly related to their physical
and social environments. Therefore, it is important to provide psychosocial rehabilitation in the community in order to build on their knowledge, experiences and positive attitudes regarding coping with environmental conditions and reconnecting social links.

A similar situation was observed by Vincent et al. (2010), who deployed a questionnaire survey to investigate rehabilitation services available to stroke survivors aged 65 years and older (N=295). The results showed that rehabilitation offered within care facilities tended to emphasise motor capabilities, and services offered in the community focused on local motion and mobility. Vincent et al. (2010) attributed this phenomenon to the fact that motor function recovery can improve a person’s mobility, while reducing the burden of family caregiving from a socioeconomic viewpoint. Benefiting from functional recovery, dyads of stroke survivors and family caregivers are more likely to have a good quality of life if they are functionally and socially active (Morris and Williams, 2009; Mweshi, 2016). Socio-psychological dimensions seem to be less valued in the continuum of post-stroke rehabilitation, even though stroke complications impact on individuals’ physical bodies and social roles concurrently. Although stroke survivors can demonstrate their body control using the skills and knowledge they have developed in motor rehabilitation to cope with environments, they occasionally feel strange about their body-self again when faced with unfamiliar environments. In this regard, they will need to seek physical function, rehabilitation assistive devices, and mental support from long-term rehabilitation resources when facing changing situations over time. More attention is warranted in order to understand the need for chronic stroke care and long-term rehabilitation in the community (Teasell et al., 2012).

**Transition from hospital to community**

Abrahamson and Wilson (2019b) applied multiple case study research in three sites in England in order to understand stroke patients’ post-stroke needs. The study explored how these needs were addressed by the six-month review and
compared them to policy aspirations in order to investigate whether the policy objectives corresponded with the participants' perspectives. Interview data were collected from 46 stroke survivors and 28 professionals, including stroke nurse specialists, coordinators, support workers, physio/occupational therapists, service managers and general practitioners. Many stroke patients expressed their needs for community rehabilitation even after their illness had stabilised. However, the therapists tended to withdraw the rehabilitation scheme when the patients' symptoms were alleviated, as the patients had become ineligible according to policy guidelines. Consistent with other literature, the stroke patients' expectations of continuing long-term rehabilitation after being discharged into the community were not actualised in the policy scheme (Morris and Williams, 2009; Teasell et al., 2012; Mweshi, 2016).

Balakrishnan et al. (2017) carried out a photovoice study in the US with 17 stroke survivors who had experienced stroke onset within the past five years. The participants presented photos that described their post-stroke life and their perceptions in three photovoice sessions. A journey of recovery and adaptation to life post-stroke was illustrated visually through the participants' subjective expressions. The participants conveyed their recovery from stroke in three stages. In the first stage, they learnt to navigate the initial physical and emotional impact of the stroke. Secondly, they coped with newfound physical and emotional barriers, and thirdly, they experienced a long-term adaptation to physical impairment and/or chronic disease. This study presented post-stroke life using a stage-based model that showed varying degrees of success and identified barriers and facilitators to the process. It echoed Kitzmüller’s (2012) and Anderson’s (2017) findings and evidenced that the post-stroke transition is a long-term process, resulting from a combination of ongoing physical and psychosocial states and familial relationships. The subjective expressions from the participants portrayed a multi-challenged post-stroke life in the community. The stroke survivors needed to keep adapting to the ever-changing situations in their lives, but the positive experiences from prior
adaptions could alleviate the stress of the next transition (Balakrishnan et al., 2017).

Chou et al. (2015) conducted a quantitative study to examine the factors associated with LTC users’ (N=30,680) choices among four main LTC models in Taiwan: institutional care, community and home-based care, live-in migrant care, and family care. The statistics showed that 72.6 per cent of older adults (aged 65 and above) required personal care provided by live-in family members, while 12.5 per cent were cared for by live-in foreign workers. The institutional care and community/home-based care accounted for 10.3 and 2.6 per cent, respectively. As the long-term conditions changed along with age and the illness comorbidities (Faircloth et al., 2004), the families were compelled to determine how to transition along the trajectory of living with long-term conditions.

Corbin and Strauss (1992) proposed the chronic illness trajectory framework, which divided illness into the following stages: pre-trajectory, trajectory onset, crisis, acute, stable, unstable, downward, and dying, based on the medical and pathological characteristics of the chronic disease. The formation of this trajectory framework utilised professionals’ knowledge, patients’ experiences and intervention protocols (Burton, 2000). This model collates commonalities in predicting the occurrence of the disease before diagnosis and describing the ups and downs between illness deterioration and condition stabilisation. However, as more stroke survivors are living longer lives in the community, this framework has a downside, in that it is weaker at understanding post-stroke care needs in community life. In addition, the stroke survivors studied by Nasr et al. (2016) perceived the occurrence of the illness differently. Some of them described the onset of stroke as a sudden disruptive event, but others regarded it as a normal result of ageing. This embodiment was also implied by the stroke survivors studied by Faircloth et al. (2004). They described their stroke experiences as a series of contextual events and normalised them as part and parcel of old age. Therefore, Faircloth et al. (2004) endorsed
biographical flow, which involves constructing stroke experiences by integrating various social contingencies to form a biography that flows across time and space.

Chou et al. (2015) showed that the majority of older adults in Taiwanese society were cared for by their families, as they maintained good health and functioning ability. Families and patients would face situations requiring transition in care patterns when their care needs are overloaded. In this regard, whether a person interprets illness as a component of ageing or a disruptive event does not influence the fact that the family and the patients need to make the decision in order to maintain their biographical flow. This implies that long-term conditions do not necessarily lead to a biographical disruption. It is a biography that patients and families co-experience as a 'biographical we', containing many social contingencies, when reconsidering health issues and changing care needs in their collective lives (Aasbø et al., 2016).

**Transition from home to LTC institution**

Policymakers envisage family-based care as fundamental to supporting an ill person’s transition on his/her LTC trajectory. Institutionalisation at an LTC facility is usually a last resort when the individual’s capability declines and the family cannot bear the load. Konietzny et al. (2018) interviewed 13 Canadian informal caregivers in order to understand their experiences of transitioning an older adult into LTC institutions in southern Ontario, Canada. The engagement with LTC services showed the caregiver’s sense of control during the transition process and its alignment with transition theory (Meleis et al., 2000). The caregivers’ experience of transitioning to institutionalisation involved the stages of ‘before the transition’, ‘during the transition’, and ‘after the transition’. The consideration of institutional care was often marked by a progressing illness, a significant health decline in the older adult, or unsafe events such as falls. The pre-transition period was usually sustained by the caregivers’ personal sacrifice until they became aware that the services and amount of time they devoted to caregiving could not guarantee quality of life and safety
of care. The caregivers discussed their burden and constant worry before transition, their feeling of loss of control, and their concerns about being ignored if they refused to settle in a less preferred institution during the transition. In the end, they felt relieved and prepared for future transitions.

The caregivers experienced complex perceptions and fluctuating emotions during the transitional process. Transition theory, developed by Meleis et al. (2000), depicts the dynamic nature of transition experiences as having multiple facets including change triggers, properties, conditions and patterns of response. It is widely applied as a middle-range theory, principally integrating theory with empirical research (Merton, 1957; Meleis et al., 2000), as a philosophy or theory is often too abstract to find overarching concepts for analysing the operation of social processes or the essential features of the social structure. Transition theory (Meleis et al., 2000) classifies four transition properties: developmental, health and illness, situational, and organisational transitions. Timespan, process, disconnectedness, awareness, and critical points are the main properties that shaped the transitions. The theory helps identify types of transition, universal natures, facilitators and inhibitors, and transition patterns in order to explain the complexity of the transitional experiences (Meleis et al., 2000). In the study of Konietzny et al. (2018), caregivers reflected on their simultaneous experiences of developmental, health and illness, and situational transitions. During the transition, the stressful interaction between caregivers and healthcare providers made the family caregivers feel their hands were tied; it was thus described as an unhealthy transition (Konietzny et al., 2018). The experiences of care pattern transitions in Konietzny et al. (2018) and Chou et al. (2015) both implied that the transition to institutional care featured the circumstance of ‘choice of no choice’ in the long-term care continuum. It also suggested that patients and their families tend to become vulnerable during their transitions when interacting with healthcare facilities, which seem to hold power in terms of rationing resources (Konietzny et al., 2018).
Health-related issues make patients and family members more vulnerable when facing life changes (Meleis et al., 2000; Milliken et al., 2019). Transition theory has shown the potential to prompt nurses to identify strategies, patterns, and critical and vulnerable points in order to support patients and families during transitions of universal but defined types, natures and conditions. Milliken et al. (2019), in their exploration of complexity in transitions, investigated family caregivers’ complex coping strategies on public and personal levels. Some family caregivers actively took part in public policy advocacy in order to make sure their loved ones could have what they needed. However, they sometimes experienced losses in personal life that limited their application of coping strategies. Their distress could not be alleviated by friends or relieved through taking a break from the caregiving life.

Although caregivers’ advocacy at an organisational and policy level can serve as a coping strategy and a relief, the study further found that family caregivers of individuals with long-term conditions or age-related disabilities seem to make shorter appearances and have less influence in policy advocacy than caregivers of individuals with intellectual and developmental disabilities. Transition theory observes transition from nurses’ therapeutic viewpoint (Meleis et al., 2000), which raises a query about the extent to which it can authentically and equally reflect advocacy by care users and family caregivers.

**2.3.4 Infrastructure enforcement to optimise care transition**

The initial stage of post stroke care focuses on medical treatment and intense motor rehabilitation (Chapman et al., 2014). As the condition stabilises, stroke survivors' care engagement transforms from intense motor rehabilitation, addressing functional recovery, to long-term rehabilitation, focusing on function maintenance and social life establishment (Mohd Nordin et al., 2014). Mohd Nordin et al. (2014) conducted focused interviews with 15 rehabilitation professionals and eight stroke survivors in Malaysia. Their findings highlighted the urgent need to establish a community-based stroke rehabilitation centre.
The opportunity for continuous access to rehabilitation provided information and individualised instruction that supported stroke survivors coping with environmental barriers (Mohd Nordin et al., 2014). The findings from Balakrishnan et al. (2017) also stated that facilities in disrepair and disabled-unfriendly discourage participation in outdoor activity, even though people actively engage with them. This implies that the transition of stroke survivors and family caregivers within the community cannot simply be managed by family caregiving support. Their transitions within the community simultaneously build an environment with disabled-friendly infrastructure and a systematic consideration of their physical and psychological needs.

The extent of community reintegration is based on mobility and accessibility in the community (Nanninga et al., 2015). Nanninga et al. (2015) applied an ethnographic approach to understanding the post-stroke rehabilitation process by interviewing 33 stroke survivors in the Netherlands. Their study highlighted that community rehabilitation should focus on the stroke survivors’ movements between locations and their reconnection to meaningful places. As stated beforehand, current rehabilitation resources and community care programmes focus on functional recovery. Inadequate attention has been paid to the significant psychosocial recovery needed to prepare stroke survivors for transitioning from a non-disabled to a disabled body-self and the acceptance of the renewed body-self (Cott et al., 2007). Accessibility and mobility are the fundamental requirements for enjoying a meaningful social life in familiar environments outside the community rather than limited to home settings (Nagginga et al., 2015). Without disabled-friendly environments that prepare stroke survivors to exert their renewed body-self after disease, it is unrealistic to expect an all-around recovery when the multifactorial interplay of physical social and mental states has not been captured and addressed in the care continuum.
2.4 Strategies to enhance post-stroke transitions

2.4.1 Community-based, family-centred support programme

The vast majority of the literature identified that rehabilitation should not only provide functional training but also cover knowledge preparation and social role reconstruction (Vincent et al., 2010; Timothy et al., 2016). Moreover, transition did not feel natural to the stroke survivor, and their caregivers also faced transitions, which were often related to caregiver stress and physical challenges (Kitzmüller et al., 2012; Cameron et al., 2013). Research with stroke family caregivers indicates that there should be more support programmes from the healthcare system that address family caregivers' specific needs and that this support should be available across the care continuum post-stroke (Park and Han, 2010; Cameron et al., 2013; Tseung et al., 2020).

Tseung et al. (2020) interviewed 43 healthcare professionals, comprising LTC specialists, rehabilitation specialists, education coordinators and regional district programme directors, and highlighted the importance of implementing a caregiver support programme. Their findings revealed that a caregiver programme would help prevent caregivers from being overwhelmed, and thus improve patient care outcomes (Tseung et al., 2020). The study also identified the barriers to and facilitators of caregiver support programmes from various perspectives. In the operational aspect, healthcare systems tend to address the caregivers' role in providing care but rarely consider their personal needs. For example, the LTC system in Taiwan provides respite care for family caregivers, taking into consideration their caregiving workload. However, it does not have a support programme or education in place at the system level, and so caregivers are usually underprepared for their role and lack confidence to carry out skilled tasks (Ministry of Health and Welfare, 2016).

In the aspect of care system organisation, it is unclear who would be responsible for implementing the programme; this constitutes a barrier to
incorporating a caregiver support programme into healthcare system cross-disciplines and across the care continuum. Park and Han (2010) surveyed 70 nurses and held focus group interviews with 16 nurses at a daycare centre in Korea in order to understand their experiences of caring for elderly patients with stroke. The study revealed that quality care support for stroke survivors and family caregivers tends to be impeded by the ambiguity of the roles and tasks of healthcare providers, as implementing a caregiver support programme is not a mandate of the healthcare system (Park and Han, 2010). Discontinuity of responsibility between different care facilities and systems were found in the support provision. Therefore, Tseung et al. (2020) suggested that identifying the timing of support in the post-stroke trajectory would be a pragmatic way to clarify the responsibility for caregiver support among healthcare systems.

Moreover, Abrahamson and Wilson (2019b) identify the unmet needs by the six-month review as the continuity of care and support from community services, quality of communication, and adequate information. The findings emphasised the importance of tailoring individual needs over time by acknowledging the varied contextual factors instead of adhering to a uniform timeframe and approach. Moreover, according to Park and Han (2010), the survey data showed that skilled nursing services, functional recovery and general health counselling were considered the most significant services for stroke survivors at day care centres. Five themes that emerged from the analysis data were identified as barriers, including: (1) providing the same standard of care; (2) lack of partnership with family caregivers; (3) conflict with other staff and ambiguity over roles and tasks; (4) lack of proper education and training; and (5) need for quality control and monitoring. The study stressed that quality and appropriateness of services are usually overlooked, due to the preference for adopting a fixed scheme with a fixed quantity of service and a fixed subsidy scheme in an administrative-friendly system. The need for quality control instead of evaluating the quantity of services was emphasised. Individually tailored, direct nursing care is key to better recovery and rehabilitation in the post-stroke care continuum. The study indicated a need to
re-examine the stroke survivor’s condition in order to tailor the care service in a timely manner.

According to Tseung et al. (2020), the optimal timing to provide a caregiver support programme in a community-dwelling environment is at the rehabilitation stage, as family caregivers individually take on the primary role of caregiving tasks along the post-stroke trajectory. Milliken et al. (2019) interviewed 54 family caregivers who were caring for individuals with physical disabilities, developmental disabilities, ageing or chronic health conditions in the U.S. From the perspective of family caregivers, support is only supportive when delivered at the right time in the right way. Complicated application processes or lengthy waits to organise support are not regarded as supportive (Milliken et al., 2019).

### 2.4.2 Timing-oriented transition programme

Considering the dynamic characteristics of post-stroke care, Cameron et al. (2013) applied the ‘Timing It Right’ framework (Cameron and Gignac, 2008), which defines the stroke recovery trajectory as having five phases: event diagnosis, stabilisation, preparation, implementation and adaption. Although the ‘Timing It Right’ framework was created as a conceptual framework to guide the understanding of phase-specific needs of family caregivers across the post-stroke care continuum, it is actually a useful timeline that contains a description of what is happening in each phase. However, it provides inadequate conceptual thinking to comprehend the life transitions in a physical and psychosocial sense. The first two phases take place during acute care, the third phase tends to occur in the course of acute or in-patient rehabilitation, and the last two phases occur in the community. Phase-specific needs can facilitate family caregiver preparedness, ease the psychological stress of confronting unpredictability, and enhance the stability of the transitioning process in order to reduce negative health outcomes. This study conforms to a suggestion from Tseung et al. (2020), who recommended timing
identification as a pragmatic solution for clarifying the tasks and responsibilities of the caregiver support programme among health professionals in different professions and on different points of the care continuum.

As Meleis et al. (2000) stated, illness and health issues tend to make an ill person and their family more vulnerable during a transition. In this regard, they expect stable and sustainable resources from the healthcare system in order to support them in their transitions. The literature conceptualises various aspects of transition. It shows the significance of identifying the all-round care needs of dyads of stroke survivors and family caregivers by equally valuing biological and sociopsychological aspects, and by taking timing and environmental factors into consideration in order to construct a plan for a successful transition. An individually tailored plan for stroke survivor support focused on family caregivers’ personal needs can contribute to a smoother transition. In the following section, I review the literature and discuss issues that might reduce the capacity of the dyads’ transition.

2.5 Factors that influence post-stroke transition

A family-centred and community-based programme should be flexible enough to incorporate the dynamic of transitions in biophysical, psychological and sociological aspects. However, factors associated with social context impact on individuals’ engagement with LTC services in the community. This section discusses the barriers to effective transition caused by the following aspects: (1) tension between family and society; (2) tension between familism ideology and universal welfare ideology; and (3) tension between social determinants and equitable access.

2.5.1 Tension between family and society

The family caregiving system is based on support and reliance between family members; therefore, it is suggested that the family is viewed as a unit
consisting of unique persons with different needs and responsibilities (Kitzmüller et al., 2012). However, this system can be challenged by tensions from outside the household and inside the unit, because that is what happens in a chronic illness situation where one needs constant care.

**Transformation of familial belief**

From an individual perspective, the situated social context and disadvantaged conditions also transform older people’s expectations of family support. Suen and Thang (2018) interviewed 19 informal caregivers from low-income households in Singapore in order to explore their challenges and coping strategies. The participants expressed feelings of guilt due to the inability to provide care for their elderly parents, which they saw as a filial duty. The concept of familism, which values immediate family members’ reciprocity and obligation (Sayegh and Knight, 2011), combined with the filial piety involved in Confucian social ethics, make healthcare systems in Asian countries (such as Japan, Taiwan, South Korea, Singapore and China) different from many other welfare systems (Hikoyeda and Wallace, 2002; Coburn, 2004). Filial piety inculcates a strong belief that it is the responsibility of the entire family to care for older adults (Sun, 2014; Suen and Thang, 2018); therefore, social care and social safety nets are conventionally developed on the basis of family support (Rozario and Rosetti, 2012).

This long-lasting belief has been challenged within contemporary society. Sun (2014) revealed a changing value on reciprocity based on the narratives of 55 older Taiwanese immigrants in the US. These elderly people did not want their children to be stressed by the need to balance childcare and eldercare as they themselves had been; therefore, they reconfigured their traditional familism beliefs in reconciliation with social challenges (Sun, 2014).
Women's multiple responsibilities for work and caregiving

Mehta and Leng (2017) researched 30 adult family caregivers and 15 live-in foreign workers, who also reported the stresses and dilemmas faced by family caregivers in Singapore. They had to balance work and caregiving in order to commit to the filial responsibility of caring for parents. Of the 30 adult family caregivers in the study, 21 were female family caregivers, constituting more than twice the number of men. In terms of employment status, 21 out of 30 family caregivers were employed. This shows that the family caregiving role tends to be assumed by women, and they are likely to take on multiple workloads as in the full-time occupation and majority of caring responsibility.

These characteristics were evidenced by the study of Alpass et al. (2017), which surveyed 1,036 working participants (aged over 55 years) in New Zealand to understand their perception of reconciling work and caregiving responsibilities. The findings showed that, among the participants who identified themselves as caregivers (N=157) in the survey responses, women were more likely to take a caregiving role than men; they accounted for 18 per cent and 12.3 per cent, respectively, of their gender groups. As for the indicator of work-care status transition over time, 65.6 per cent of the participants continued caring and working simultaneously. Moreover, the caregivers were noted to have negative psychological wellbeing, poor mental health and a higher propensity for depression symptoms.

Sandwich generation

In reviewing the literature, the term ‘sandwich generation’ was traced back to Miller (1981), referring to a cohort of people who are sandwiched between eldercare and childcare and are thus subjected to a great deal of stress. This is because the adult children have a prominent position in decision-making and providing support for both their elderly parents and their younger children within the family system. However, the reliable family caregiving system has been challenged by social transformation (Suen and Thang, 2018). Suen and
Thang’s qualitative study, based in Singapore, interviewed 19 family caregivers; they reported that adult children usually felt sandwiched, as they faced the multiple tasks of providing health, economic and emotional support for both their older parents and their own children. These family caregivers faced emotional burdens such as a sense of loneliness and loss of freedom due to their multiple roles and tasks, as described by Kitzmüller et al. (2012). Buschenfeld et al. (2009) interviewed seven partners of stroke survivors who were undertaking family caregiving responsibilities for spouses, ageing parents and children while simultaneously working as breadwinners to sustain their households (Buschenfeld et al., 2009). Instead of considering the dual responsibilities between work and caregiving as wholly negative, some spousal caregivers in the study of Buschenfeld et al. (2009) attached meanings to their work. They placed great importance on the role of work in their lives as they re-configured their sense of self and retrieved their identity through their work and connection to social life.

Keene and Prokos (2007), in their investigation into the preferred working hours of this sandwich generation in America, showed that members of the sandwich generation are less likely than other workers to want to reduce their working hours. Keene and Prokos (2007) explained that this generation are parenting dependent children, and may also want to work more in order to prepare for the financial costs of the expected increase in eldercare. An accumulation of financial and social factors places burdensome responsibilities on this group. It also reflects the insufficient social support systems in place. The phenomenon of changing social values resulting from an overloaded sandwich generation, a greater number of female family caregivers engaged in paid work, and changing values towards the older generation have led to a reconfiguration of the family caregiving system in Taiwanese society (Sun, 2014; Alpass et al., 2017). This tension has challenged the family caregiving system’s capacity to continue providing quality support for LTC transition (Mehta and Leng, 2017). It is important to note that an LTC system should be sufficiently robust and flexible to fulfil the
demands of the family utilising the service, as well as the transformation in the social structure. Finch (2003, p. 43) stated:

“The aim of policies should be to facilitate flexibility in family life, rather than shape it into a particular form... to ensure that people have maximum opportunity to work out their own relationships as they wish to suit the circumstances of their own lives.”

2.5.2 Tensions between familism ideology and universal welfare ideology

Engagement with the LTC system exists not merely in terms of ADLs or medication but also in the dynamic family relations and personal and contextual situations that the users and family caregivers encounter (Milliken et al., 2019). Family caregiving capacity has been weakened due to social transformation. Hence, the LTC system, which endorses a family-centred and community-based programme, has developed a residual model to supplement the insufficient care provided by families (Rozario and Rosetti, 2012; Yeh, 2020). However, the LTC system in Taiwan is funded by taxation. The tax-based model is often adopted in universalistic LTC models and implemented in welfare states such as in the Scandinavian countries (Ranci and Pavolini, 2015). This fact supports the argument that the contemporary welfare structure implicitly emphasises community-based home care, but in practical terms relies on informal caregiving networks to fulfil the LTC implementation (Ranci and Pavolini, 2015). Policies regulate the formal care infrastructure and workforce resource, but also shape informal networks by stealth in both Eastern and Western countries (Kodate and Timonen, 2017).

Taiwan’s long-term care policy is meant to provide a better ageing life for the older generation by prolonging their stay in a familiar environment. However, this initiative, in turn, increases the workload on families due to dramatic
demographic changes and gender-related unequal responsibilities, as more women are engaged in formal paid work and hence unable to shoulder any informal caregiving work at all. The conflict between political ideology and the family caregiving system means that care users and their family caregivers are encountering challenges that are inherent in the healthcare system (Milliken et al., 2019). Arguably, more research on the views of family caregivers caring for individuals with long-term conditions or age-related disabilities needs to be carried out in order to make this population visible in policy advocacy.

2.5.3 Tensions between social determinants and equitable healthcare access

The literature demonstrates that the concept of transition has long been acknowledged in studies and in LTC practice. Individuals living with stroke perceive a divergent sense of body-self, which impacts familial and social relations along the post-stroke trajectory. This is because of the generational relations between individuals and the family system and the inextricable relations in the social structure. The positions of care users and their families in the social structure determine their relationship and the way they influence each other. The distinctive characteristics of the diverse populations in Taiwan require more attention in order to ascertain their engagement with the LTC system during life transition. The next section elaborates on these social determinants and their impact on healthcare accessibility and health equity in terms of the following aspects: (1) socioeconomic influence on healthcare utilisation; (2) cultural awareness of caring for ethnic groups; and (3) indigenous people’s transition in an unfamiliar context.

Socioeconomic influence on healthcare utilisation

Socioeconomic status can be an essential determinant of health in many ways, such as the distribution of healthcare resources, psychosocial conditions,
health behaviours, and access to and quality of healthcare (Seccombe, 2000). The plight of low-income caregivers is more likely to be compounded by contextual challenges such as fractured family relationships, role conflict and perceived barriers in their institutional environment (Suen and Thang, 2018). The more affluent an individual or family, the better their living conditions; they will have greater access to preventive and therapeutic health care services. Consequently, they will enjoy a better health status (Chou et al., 2015).

Households with stable income are usually more resilient to life changes and more capable of transitioning through these changes. According to Chou et al. (2015), the majority of older adults are cared for by their families, as they maintain good health and functioning ability. Better-off households in Taiwan are more likely to hire a live-in worker who supports the family 24 hours a day by staying in the family house. However, lower-income families have no choice but to involve themselves in the caregiving role and sometimes sacrifice their work (Chou et al., 2015). Referring back to the tension between familial and political ideologies discussed above, many governments have focused on policies that recommend ageing in place and a community/home-based care model in order to reduce the societal expense (Ranci and Pavolini, 2015; Kodate and Timonen, 2017). A family caregiving system is shaped on the basis of policy ideology/reliance, sociocultural beliefs and individual preference. Regarding the LTC policy in the Taiwanese context, the cultural beliefs about filial piety and familial responsibility shape the population’s care preferences. In the meantime, the LTC policy and the generational support provided by the family caregiving system have transitioned along with social structure changes. The increase of women in full-time employment has weakened the family caregiving system, as there are now fewer people in households who can manage growing care demands. In this regard, individuals can only make a preferred decision from among the available choice(s). In other words, individuals’ preferences and perceptions of healthcare systems are constructed in a context shaped by social culture and the social structure.
Cultural awareness of caring for ethnic groups

Central or core values typically determine a family’s priorities at a time when family caregivers have to manage a set of healthcare demands. The perception of a visible minority in the community was emphasised by Hou and Kuo (2019). They interviewed ten public care managers in order to understand LTC services’ utilisation by indigenous people in Taiwan. Indigenous people experience home care services differently from non-indigenous people because of their different views about formal care and welfare services. The complex process of service applications, which includes contracts, signatures and identification, differs from the verbal agreements they usually make.

Moreover, there are challenges relating to unfamiliarity with service content, language barriers, co-payments and cultural discomfort that discourage indigenous people from using home care services. It is suggested that the healthcare system should systematically remove instrumental and cultural barriers in order to enhance service appropriateness for these ethnic groups. To echo the emphasis of Milliken et al. (2019), supportive support is actualised when it is delivered at the right time in the right way.

Yeung et al. (2015) utilised the ‘Timing it Right’ framework (Cameron and Gignac, 2008) to analyse narrative data from five stroke survivors and 13 caregivers. Their qualitative study aimed to explore the experiences of post-stroke reintegration into the community from the perspectives of Chinese-Canadian people, a visible minority group in Canada. It was found that Chinese stroke survivors and family caregivers required more Chinese-language educational resources to be made available, and preferred staff and therapists who spoke Chinese in care environments. The literature on support programmes for stroke family caregivers shows that the language barrier is an important factor that influences the healthcare-related knowledge or literacy of minorities, and further determines their perception of the health services being provided. This was evidenced by Tseung et al. (2020), who stressed the need to provide care that included a cultural awareness of the First Nations, the
groups of Canadian indigenous people studied in their research. Accordingly, the following measures were suggested: preparing information leaflets/brochures in different languages; recruiting personnel who were able to communicate in different languages; and maintaining a better understanding of the ethnic group’s culture. These would enable care users to feel more comfortable accessing the healthcare system and seeking help.

Furthermore, Chinese-Canadians are strongly affiliated to their traditional medical theory and treatment (Yeung et al., 2015). The influence of the Chinese socio-cultural background on the healthcare system was also shown in Yeung et al.’s (2011) phenomenological study, where the concerns of Chinese stroke survivors during hospitalisation and in their transition to the home environment were explored. It was found that fatalism is perceived as a common coping strategy in Chinese culture, arising from the typical Chinese belief that fate or transcendental forces dominate the life experiences of a person. This appears to be interpreted as allowing nature to assume its own course. The fatalistic coping strategy is a pervasive concept that strengthens the mind-body-spirit resilience of Chinese patients (Yeung et al., 2011).

Indigenous people’s transition in an unfamiliar context
Indigenous people age and live with long-term health conditions in a more complex environment than the mainstream population (Pace, 2020). They need to cope with life changes and transition along the illness trajectory in a context that does not fit into their native environment after experiencing centuries of colonialisation and competition with the mainstream population (Anderson et al., 2016; Santos et al., 2021).

Santos et al. (2021) carried out a narrative review of stroke incidence, risk factors and treatment in indigenous peoples worldwide, including in Australia, Canada, Chile, Ecuador, Norway, Taiwan and the United States. The review reported that stroke and its outcomes interplay with disease pathology, biology, lifestyle, socio-environmental-economics, human rights and non-modifiable
demographic factors across individual, social and healthcare system levels. In addition, it indicated that cardiovascular risk factors are generally more prevalent amongst the indigenous population than the non-indigenous population in Australia, the United States and Canada, but not in Chile, Ecuador, Taiwan or Norway (Hung et al., 2016; Santos et al., 2021).

This might contribute to the high coverage of national health insurance in Taiwan, with a national average of 99.9 per cent and a 94.05 per cent enrolment amongst the indigenous group by March 2012 (Council of Indigenous Peoples, 2013; Huang and Liu, 2016). The government promoted a policy project that specialised in subsidising the indigenous population's enrolment in national health insurance; consequently, insurance coverage among the indigenous population reached more than 99 per cent by 2020 (Council of Indigenous Peoples, 2021). Although universal health access coverage for indigenous people has risen to the average level, the fact that there was originally an enrolment gap shows a health inequality among Taiwanese indigenous people (Huang and Liu, 2016). Owing to their poor financial condition (see section 1.3), unlike other ethnic groups, indigenous people might not be able to afford healthcare expenditure at the level they require, which poses a major problem in terms of equal access to healthcare. According to the population study of Anderson et al. (2016), cultural and material losses relating to colonisation are a significant cause of disadvantage in lifestyle, biological and socio-environmental-economic risk factors for indigenous people. Due to their weaker socioeconomic status, a great proportion of the indigenous population reside in a remote rural area. According to Hou and Kuo (2019), care services in rural areas are not as accessible as in urban areas, because it is hard for a care provider to benefit from delivering a service that only covers a limited number of clients and requires long travelling hours.

The misalignment of health between indigenous people and the healthcare system, as well as their loss of connectedness with land and identity, enlarges
the health disparity between indigenous and non-indigenous people (Santos et al., 2021). This argument is strengthened by Pace (2020), who has carried out a photovoice project with accompanying narratives in order to explore the embodiment of ageing and health transition from the perspective of the NunatuKavummiut, an indigenous population in Canada. The study shows the pronounced impacts of natural environment and culture on indigenous people’s health promotion and care trajectories. Healthy ageing is considered a combination of active engagement with the environment, good health, a positive attitude and close social connections. Ageing in place is understood as maintaining a close connection with natural environments. The older participants in Pace’s (2020) study explained that they constantly used their minds to perceive nature and interact with the environment. They found new and familiar experiences related to land and nature and old life routines. Unwillingly accepting healthcare services away from the community is not conducive to older people’s wellbeing.

Due to their experience of centuries of competition with mainstream culture and oppression by the non-native population, indigenous people, to a considerable degree, have departed from their original life and native land (Anderson et al., 2016). This, along with communication barriers (Tseung et al., 2020) and lack of culturally appropriate awareness in institutional structures (Hou and Kuo, 2019), has possibly led to a post-stroke transition that is more challenging and a more vulnerable situation for the indigenous population.

2.6 Theoretical underpinnings for this study

Life transition and tension in the social context are the focal points of argument in the literature review. During the process of developing this research, a variety of theoretical perspectives were taken from the extensive literature. In this study, the idea of researching experiences of post-stroke life transition and
tension while engaging with the LTC system in the social context was inspired by the concept of biographical disruption (Bury, 1982), and the status passage theory (Glaser and Strauss, 2011) was adopted in order to explore the interaction with the social and healthcare system. The structuration theory (Giddens, 1984) is conducive to explaining social interaction and tensions in social structure by applying the concepts of duality of structure and agency, time-space-power, and macro-meso-micro.

2.6.1 Biographical disruption

The first perspective was inspired by biographical disruption (Bury, 1982), which addresses negotiation between biomedical illness trajectory and psychosocial trajectory. Biographical disruption refers to the changes brought about by chronic illness and long-term conditions as an embodiment of changed body-self, referred to as a lived entity and social identity (Bury, 1982; Kelly and Field, 1996; Williams, 2000). The changed body makes stroke survivors unable to sense their ‘self’, as they cannot control their body or make it behave in a way that allows it to exert their old social roles. Not until they experienced their stroke occurrence did they perceive the existence of lived body and the concept of self. The lived entity, which used to be overlooked, became perceptible and tangible as it disappeared. Bury (1982) highlights that chronic illness is experienced as a disruptive event, and suggests three key elements of this disruption. The first relates to the disruption of taken-for-granted assumptions and behaviours, with the significance of the condition subverting previously held personal perspectives. The second pertains to “profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person’s biography and self-concept is involved” (Bury, 1982, p. 169). The third element highlights that people will mobilise resources and endeavour to address this altered situation.

However, Bury’s concept of biographical disruption is inadequate for supporting the justification of the biographical continuation of stroke survivors
and family after they are discharged from the hospital and return to the community. Bury (1982) originally conceptualised chronic illness as a disruptive event, using the experiences of rheumatoid arthritis patients, whose illness trajectory generally first showed a noticeable drop when they suffered the pain and were informed about the diagnosis. A flattened downwards trend followed after it was acknowledged that the illness would cause persistent pain, gradually erode physical ability, and eventually influence social and career life.

In contrast to the gradual onset observed by Bury in the illness trajectory of rheumatoid arthritis, the impact of a stroke is quite different. The post-stroke illness trajectory first presents with a dramatic and acute episode when the stroke occurs, followed by survivorship under medical treatment (Chapman et al., 2014; Qureshi et al., 2017), but resulting in the loss of physical and social ability (Chiou, 2018). Stroke survivors partially regain their capability under rehabilitation (Kirkevold, 2002) and transition their focus from motor function to long-term psychosocial rehabilitation on the care continuum (Vincent et al., 2010; Teasell et al., 2012). The life transition post-stroke involves a continuous process of embodiment in terms of what the disease has brought to the corporeal body and psychological sense, flowing from a divergent body-self to a cohesive body-self, and an attempt to develop a new form of normal (Faircloth et al., 2004; Cott et al., 2007; Timothy et al., 2016). It necessitates a multifaceted interaction with social actors in social contexts across time and space (Faircloth et al., 2004). Therefore, Bury’s concept provides an analytical dimension: the illness trajectories can progress differently, and accordingly the post-onset life and the recovery trajectory develop differently. I evidence the concept of biographical disruption with Bury (1982) and note that it helps explain some data but is not sufficient to understand the data’s complexity with regard to biographical continuation post-stroke. Therefore, I draw on biographical disruption and conceptualise it as the start of a continuous life transition following disease onset and long-term health conditions.
2.6.2 Status passage

Properties elaborated in the status passage theory (Glaser and Strauss, 2011) can help conceptualise the dynamic life transitions and ongoing biographical flow that take place in the social context. Status passages “entail movement into a different part of a social structure; or a loss or gain of privilege, influence or power, and a changed identity and sense of self, as well as a changed behaviour” (Glaser and Strauss, 2011, p. 1). The social contingencies of status passages are characterised by the absence or presence of properties such as reversibility, temporality, desirability, shape, circumstantiality, pattern of passage (solo, collectively or in aggregation), communication, degree of control, legitimisation, clarity, and disguise. The centrality in a passage and the length of time that the passage will engage with each individual’s life course is interrelated with the properties. The concept of the status passage resonates with the complexity of life transitions. It plays a role in defining a transitional status and explaining how this transitional status has come about as a result of social events such as illness and careers (Cott et al., 2007; Glaser and Strauss, 2011).

The status passage is conducive to focusing on both individual and collective passages with other agents, since family are usually involved in life transitions when people have health issues (Sayegh and Knight, 2011; Kitzmüller et al., 2012). It is suggested that two or more passages/agents will make passages more competitive when the stakeholders have a high degree of interrelation and interaction. The transitions in familial relations cause the passages to juggle time, goals and commitments (Glaser and Strauss, 2011). Thus, societal resources are available to support a transitional status helping individuals to articulate their competing status passages. Several theoretical frameworks highlighting the individual needs appear to be applicable; however, the focal points of the theoretical perspectives are not entirely compatible with this individual-focused and context-based study. For example, patient-centred care (Genteis et al., 2003) involves eight core dimensions to address individual needs: (1) respecting patients’ values, preferences and communication of care
needs; (2) information and education; (3) access to care; (4) emotional support; (5) inclusivity of patients and families; (6) coordination; (7) physical comfort; and (8) continuity and transition between healthcare settings (Genteis et al., 2003). Patient-centred care focuses on the interaction between patients and professionals, ranging from individual to system-level issues within the acute hospital setting (Cott, 2004; Davis et al., 2005). Although patient-centred care emphasises the coordination of care inclusive of the patient and his/her family, it does not provide sufficient conceptual thinking for theorising an individual’s needs in a social context. The status passage theory helps to understand the life transition by interacting with social actors and mobilising societal healthcare resources within the social structure where the transitions are embedded. It suggests that the degree to which societal healthcare resources originate from individual embodiment in the social contextual situation relates to the efficacy of the status passage (Cott, 2004).

2.6.3 Views of structuration theory

The literature and policy background have shown that the LTC system is embedded in social structure and constructed due to societal needs. The social structure where the LTC system is embedded plays a considerable role in the transitioning stages. In addition to adopting biographical disruption and status passage theory to analyse the chronic illness life trajectory, the structuration theory (Giddens, 1984) is used to highlight the duality of structure and agency; the essential constituents of time-space-power and the positional practices across macro-meso-micro are drawn upon to underpin the data analysis and findings presentation.

Duality of structure and agency

The structuration theory proposed by Giddens (1984) suggests that human agency and social structures are recursively linked and mutually developed due to their co-presence. Giddens (1984) termed this ‘duality of structure’, as it specifies that human actions occur in structures while the agency of human
actions sustains and reproduces the structures. Structuration is an ongoing process characterised by the properties of the social structure and system, as they are both the medium and outcome of recursive social interactions among actors (Giddens, 1984; Stones, 2005). The actions of human actors occur along a continuous length of time that involves a repetitive occurrence of practices in an ongoing flow of social life (Giddens, 1984). The structuration theory has been challenged for its concept-led approach, which provides general, abstract concepts but lacks the detail of empirical works (Orlikowski, 2000; Pozzebon and Pinsonneault, 2005; Stones, 2005). Notwithstanding the critics, when its strengths are adopted and its shortcomings addressed, Giddens’ concept of duality of structure and agency underlies the significant proposition that social structures and systems are dynamic and in the process of development. The concepts of time-space-power and macro-meso-micro set out by the structuration theory (Giddens, 1984; Stones, 2005) help understand for whom and under what circumstances the situation occurs (see Figure 2.2).

Figure 2.2 Concept map of time-space-power and macro-meso-micro, adapted from Giddens (1984)
Time, space and power
Life transitions are grounded in the continuous and reflexive understanding of the purpose of actions and tensions from the social system within the transitional process. The concepts of time, space and power help understand the interactive process of system structuration. They are everywhere, and exist as social constructs before coming into contact with social actors. Social actions are constituted in time and space and give meaning to situations of co-presence and situatedness of interaction (Giddens, 1984). In this sense, time and space possess subjectivity; they become lived time and lived space with meaning imbued by social actors. When social relations shift, power thus becomes visible in the relational context (Giddens, 1984). Understanding the social process of transition and tension in post-stroke life in relation to a specific time, place and power helps to identify the social contingencies of life transitions and the engagement of the LTC system. Systems, resources and social relations emerge on the spans of time and space under the structuration process played by structural properties and human agency (Giddens, 1984). Thereupon, power reflects social relations to coordinate the engagement of LTC systems with other available societal resources.

Aspects of power
As a construct element in social science, power has been presented in diverse forms in social theories and influences the social world with its various appearances, such as the power of knowledge (Foucault, 2000), hegemony in international relations (Cox, 1983), agency power (Giddens, 1984) and symbolic power (Bourdieu, 1991; Wacquant, 2013). Power appears to be everywhere, but it is still ubiquitous. Therefore, the significance of the power dimension is to explore where power is grounded, how it is generated, and how it can be visible. Although the social structure is virtually framed by time-space-power, its existence can be observed through relational control and its impact on social events and social roles (Giddens, 1984). The properties and positional practice that the social roles play mark the social relations in the
virtual time-space-power structure. Power also becomes visible when social relations shift in the ongoing process of structuration.

Tensions in engaging healthcare resources for life transitions occur in the interweaving structural properties between institutional and cultural ideology (Rozario and Rosetti, 2012; Kodate and Timonen, 2017) and family and social systems (Sun, 2014; Mehta and Leng, 2017). As explained in Chapter 1, the NHI and LTC systems are the main societal resources that Taiwanese people use for healthcare support when they experience disease and long-term health conditions (Chen and Fu, 2020; Yeh, 2020). Interactions with these systems can drastically shape dyads’ life transition experiences in living with healthcare issues. From Giddens’ (1984) standpoint, the mutual interaction between individual and structure constrains and enables individual action. People’s life transitions occur in an environment framed by time and space with regularised resources, energy, available time, and approachable places for social activities and human actions.

Power appears in dynamic social relations and instantiates as a force that enables coordination to reconcile the tension in the LTC context. When stroke survivors and family caregivers seek support from society, a smooth engagement with care resources lies in the definite coordination of the human perception of time-space and the system organisation of time-space. Power appears as a force that enables coordination. The force of coordination is grounded in the collective goals between the care systems and individuals’ expectations, and is fulfilled in time-space coordination. When coordination between the individual and system is not achieved, the failure to attain the collective goals appears as a tension between the individual and system (Giddens, 1984). Therefore, power is visible as the empowering and oppressing forces for social coordination in this study. Mobilising resources to fulfil the shared goals of individuals and collectives serves as an agency and is regarded as an operation of power relationships (Jones and Karsten, 2008). The power of coordination can drive everyday life and enable engagement with
the care system and social environment. In this regard, if the power of coordination cannot be attained, its agency to alleviate the tension and fuel the life transition cannot be exerted. The resulting factors thus substantiate the oppressing side of power.

**Macro, meso and micro**

Extending from the duality of structure and agency in structuration theory, macro structures are recursively interrelated with micro practices (Carter, 2013). Giddens (1984) does not seem keen on the concepts of micro- and macro-sociology, which he exemplifies by stating his concerns: first, one particular approach might hierarchically be regarded as more fundamental than the others; and second, micro-sociology might be overly deemed as an approach specialising in exploring the day-to-day activities of individuals from the perspective of viewing things as trivia. He considers macro- and micro-sociology to be mutually interactive and reconstructive; thus, it is improper to prioritise one over another. Although Giddens (1984) does not entirely endorse the concepts of micro- and macro-sociology, he accepts that radically empirical micro-foundations are significant in the reconstitution of macro-sociology and the progression towards successful sociological science. Collins (2014) argues that macro-sociology is reconstituted based upon empirical micro-sociology translation via a seriality of micro-translation of social phenomena. Giddens (1984, p. 181) suggests that “social reality, then, is ‘micro-experience’; it is the numerical temporal and spatial aggregations of such experiences that make up the macrosociological level of analysis”. Resonating with the duality of structure and agency, a structure that contains both the outcome and medium of agency acts as the fundamental building construct of the structuration theory (Giddens, 1984; Stones, 2005).

Corresponding to Collins’ (2014) and Giddens’ (1984) views, human behaviour and life experiences are characterised by the individual’s practice in a micro context, which takes place in the associated conditions of time and space in the macro context. The macro context reflects the sociological properties of
historical, geographical, institutional, and socialisation evolution across time and space. Drawing on the sociological critique that Giddens’ structuration theory lacks methodological details (Stones, 2005; Parker, 2006; Elbasha and Wright, 2017), the meso-level context develops as an ontological existence linking the macro abstract context and the micro conduct context. The meso context focuses on the hinge between structure and agency that explores the phenomenon and power of agency exerted by structurally situated actors (Stones, 2005; Parker, 2006). The meso context, which is referred to as intermediate temporality (Parker, 2006), reflects the situated condition where structure and agency interplay in the ongoing structuration process. In addition, it also reflects the social actors’ minds and knowledge, which drive the agency and power exertion (Giddens, 1984; Foucault, 2000). The meso context is an intersection zone of reality situated between sociological and institutional systems and individual actions. Strengthened by the concept of the meso context, the coordination and tension embedded in context can benefit from combining the social structure position with social actors’ practices (Bhaskar, 2013).

In conclusion, the theoretical perspectives of this study were inspired by biographical disruption and underpinned by the status passage theory and the structuration theory. The theoretical perspectives of biographical disruption (Bury, 1982) and status passage theory (Glaser and Strauss, 2011) provide the analytical details for contextualising the post-stroke life course transition. The structuration theory (Giddens, 1984) provides the analytical concepts to decontextualise, re-contextualise and theorise the intention and situation of social actions. These theoretical perspectives justify the analytical reasoning in Chapter 3 and the findings presentation in Chapters 4 and 5.
2.7 Summary of this chapter

Transition and tension are two significant concepts in stroke survivors’ and family caregivers’ lives. The literature review has set the scene for the study’s context by conceptualising ‘life transition post-stroke’ and ‘tension of LTC implementation in a social structure’. Post-stroke life experiences involve a transition from non-disabled to disabled self-image (Cott et al., 2007), uncoordinated body-self (Timothy et al., 2016), biographical disruption (Bury, 1982), biographical flow (Faircloth et al., 2004), and so on. No single theoretical perspective dominates the discipline, but all of them display a continuous theoretical strand that enables me to explore the post-stroke transition across biological, familial and social life.

Based on timing-efficient, community-based and family-centred initiatives, the LTC system has been found to be supportive of the post-stroke life transition. The implementation of the LTC system is limited by tensions amongst the institutional, socio-cultural and socioeconomic levels of the social structure. None of the published literature or theories are sufficient for theoretically constructing an individual’s transition and interaction with the LTC system within a social structure. There is a gap for conceptualising the interaction process between the post-stroke transition and the tension of the LTC system in the social structure. Therefore, this study has adopted the relevant theoretical perspectives identified from the literature to support the abductive reasoning of the inductive data. The related theoretical concepts underpinning this study were: biographical disruption (Bury, 1982); status passage theory (Glaser and Strauss, 2011); and structuration theory (Giddens, 1984). Their application will be detailed in Chapter 3.

The next chapter, focusing on methodology and method, proposes to improve the understanding of the LTC experiences and needs of people from different contexts. I adopt social constructionism, which emphasises that knowledge is produced by exploring and understanding the social world of the people being studied, focusing on their meanings and interpretations (Young and Collin,
2004; Ritchie et al., 2013). This perspective supports the development of a research design that adopts an ethnographic approach in order to understand individuals' perceptions in their situated context and thus explore the research questions:

- *How does the current long-term care policy meet the needs and expectations of stroke survivors and family caregivers experiencing LTC from different ethnic or cultural backgrounds?*
- *What are the facilitators of and barriers to long-term care for stroke survivors and their family caregivers experiencing care in their community?*
3.1 Introduction

In this chapter, I present the considerations leading to the adoption of the chosen methodology to guide the research design and answer the research questions outlined in section 3.2 and section 3.3. In section 3.4, I present an explanation of the reflexive practices underpinning this study. In section 3.5, I justify the philosophy of reality (ontology) and knowledge (epistemology) related to this project and the adoption of focused ethnography. I then explain the rationale for the research methods in section 3.6 and the logic of the data analysis in section 3.7, and justify the quality of the study in section 3.8. Following this, I present the ethical considerations and strategies undertaken in this study in section 3.9. Lastly, I conclude this chapter with a discussion of the limitations of the research design in section 3.10.

3.2 Research aim and questions

This study aims to explore and describe the experiences, perceptions and beliefs pertaining to long-term care (LTC) services from the perspectives of indigenous and non-indigenous people in two geographical regions in Taiwan, an indigenous administrative region and an urban region respectively. The research questions are as follows:

- *How does the current long-term care policy meet the needs and expectations of stroke survivors and family caregivers experiencing LTC from different ethnic or cultural backgrounds?*

- *What are the facilitators of and barriers to long-term care for stroke survivors and their family caregivers experiencing care in their community?*
3.3 Negotiating methodology

The project approached the research aim and questions using three main principles, leading to the methodology and methods subsequently employed. First, a fundamental principle of this ethnographic study was to explore the opinions and narratives of stakeholders who take part in the LTC system and are involved in the process of LTC service delivery in a diverse Taiwanese society comprised of people from different ethnic backgrounds. It was intended that participants’ concrete and detailed descriptions of facilitators and barriers in this context or during the practices of LTC services in the community would be sought and understood instead of attempting to find universal trends through quantitative statistics. The current study design aimed to explore contextual circumstances. From the outset, it was established that the research project would be descriptive, exploratory, and embracing of conversation, which is another root principle of various community and informal dialogues. A qualitative inquiry thus appeared to be an appropriate approach for orienting this study.

Second, the study aimed to explore stroke survivors’ and their family caregivers’ lives in multiple varied regions. By using a multi-site design, I was better able to familiarise myself with and understand the sites and people of interest, by being there and staying with them. With this proposition, on-site fieldwork was an essential and key method in this study.

Third, as an active member of the field under investigation, the inevitable mutual influences of the researcher, hereafter writing in the first person, and participants in this qualitative approach cannot be ignored. I have had to make an all-out effort to strengthen and expand the advantages of the chosen methodology and reduce the possibility of bias. An awareness of reflexivity and a series of reflexive practices, described in section 3.4 below, were applied during the process of study design, data collection and data management. Reflexivity has kept me aware of my involvement and the interplay of my role in this focused ethnographic research; in this regard, I have attempted to avoid
using innocent statements implying that a researcher can play an objective, neutral role. The extent of the involvement and the influence of a researcher are relative properties (Madden, 2017). Thus, I wish to contextualise my practice in the subject area, rather than othering it as a neutral position, and to place myself in the picture as an involved member or co-participant.

3.4 Reflexivity

To align with the three main principles declared above, especially the third, an awareness of the influence of the researcher and the potential biases due to my involvement has run through the full journey of this research. Gobo and Molle (2016, p. 80) described reflexivity “as the process of confronting and expecting to be, to a certain extent, biased by prejudice”. Preconceptions are unavoidable, since any of us can make pre-assumptions and pre-judgments, whether positive, negative or both. Nevertheless, those assumptions also become a cognitive tool for people; our overall reasoning capability may be more or less influenced by them, and this is a prejudice (Gobo and Molle, 2016). Hence, I regard the attitude of confronting these biases, and noticing the preconception rooted in human lives and inevitably surrounding human study, to be reflexivity.

It has also been suggested that reflexivity is people’s conscious thoughts, showing the theories they use while perceiving and acting in the world (Schon, 2008). Shacklock and Smyth (1998) explained reflexivity as the conscious revelation of the role of the beliefs and values held by a researcher in the process of selection of research methodology for the generation of knowledge and its production as a research account. In *Ethnography Through Thick and Thin* by Marcus (1998), reflexivity was outlined in four dimensions, namely (1) the basic or null form, (2) sociological reflexivity, (3) anthropological reflexivity and (4) feminist reflexivity. Madden (2017) further classified the first two forms as methodologically-focused sociological reflexivity, which indicates that the researcher engages in reflections on the subjective and objective elements of
the methodological approach. The other two forms were more likely represented as personal-political reflexivity, which indicates reflection on the position and the influence of one’s own social, occupational and contextual identity on the processes of fieldnote collection and generation.

Reflexivity in this study was performed using a combination of Madden (2017) and Marcus (1998); the rigour of the research process and data analysis has been structurally strengthened, and the integrity to be aware of the preconceptions resulting from my personal, political stances has been internally presented. Therefore, I have acknowledged the biases, and have deliberately called attention to and made use of conscious thoughts during the whole research process, from the outset of research design, ethics preparation and the data collection process, to data interpretation and findings’ generation. In other words, in this study, reflexivity has been embodied in philosophical stances, methodological selection, methods practices in real context, ethics preparation, data analysis, and the consequences of unexpected issues confronted during the process. Drawing on Madden (2017), O’Reilly (2012) and Alvesson and Sköldberg (2000), the roles of reflexivity at each stage of research and the way they were applied to be reflexive are summarised briefly in the following paragraphs and will be elaborated in detail in the corresponding sections in the latter part of this chapter.

(1) Philosophically, I have incorporated the statement of Seale (1999, p. 25), who states that “philosophy positions can be understood by social researchers as resources for thinking rather than taken as problems.” The role of philosophy is regarded as a tool for thinking reflexively and systematically. Sections 3.5.1 and 3.5.2 elaborate on my relativist ontology and social constructionist epistemology stances, which underpin this research.

(2) Methodologically, I endorse the significance of relativism, which indicates that truth is partial and not absolute, and that the researcher’s view is only one among many and has no more legitimacy than the opinions of the people being
studied (Guba, 1990; Rubin and Rubin, 2005). Therefore, the methodological reflexivity in this study draws on Alvesson and Sköldberg (2000, p. 246), who advised researchers to “avoid empiricism, narcissism and different varieties of social and linguistic reductionism”. Therefore, I carried out this focused ethnography through multi-sited fieldwork by putting myself into the contexts in order to explore insider and outsider, and subjective and objective, perspectives, instead of believing that I could maintain neutrality and/or investigate with real-life objectivity. The participatory characteristics of this focused ethnography and positionality of myself are elaborated in Section 3.5.3.

(3) Practically, various social actors’ perspectives in the field need to be gathered and balanced to fulfil the significance of equal representation. For this reason, non-participant observation and individual semi-structured interviews were applied as complementary data-collecting methods to ensure that correlative members of the LTC system would have adequate discursive rights and appropriate opportunities to express themselves. I needed to be aware of language power/authoritative voice in the real-world context, for example in the observational sessions when LTC recipient and provider coexisted, especially for the vulnerable populations that tend to be muted in the community. The rationale for the research methods, including study setting, sampled population and data collection, are justified in section 3.6.

(4) With regard to data management, the word ‘conscious’ is to some extent compatible with ‘selective’, usually described as selective subjectivity, to entail the fact that fieldnotes are unavoidably captured by the ethnographer’s intention. Elite perspective in the notetaking process needs to be noted and deliberately reflected in order to avoid claiming any view to be more trustworthy or representative than others; this study explored human experiences, which are considerably discourse constituted. By writing myself into the fieldnotes and recognising that I was engaged in persuasion within a social and consequently a political context, I was able to avoid narcissism and self-
centredness (Alvesson and Sköldberg, 2000). A reflexive practice for balancing insider and outsider perspectives in fieldnotes and the research diary is presented in section 3.6.5.

(5) During data analysis, I applied abductive reasoning to negotiate the emic and etic perspectives, interrogate my analytical thoughts, and value outlier cases equally. “The idea of reflexive interpretation is to allow room for elements other than the problematisation of text-authority relations, and to avoid the latter dominating. A totalisation or privileging of the rhetorical-textual dimension is rejected, not least because the empirical material does not get a fair chance” (Alvesson and Sköldberg, 2000, p. 249). I applied the concept of biographical disruption (Bury, 1982), the status passage theory (Glaser and Strauss, 2011), and the theoretical framework of the structuration theory (Giddens, 1984) during the processes of data decontextualisation, abstraction and recontextualisation. Section 3.7 presents the data analysis processes and a reflexive turn guided by the emerging phenomenon from empirical data that corrected my preconceptions.

(6) Ethically, reflective and reflexive awareness of problems help to reduce difficulties and possible damages. A process of commitment to ethical considerations and supervisory meetings are also practical methods of being reflexive with the assistance of other actors. I also reflected on challenges encountered in the course of the ethics applications discussed in section 3.9, realising that tacit ethical issues faced by the minority group hinted at an unbalanced social structure.

With these practices, reflexivity can also be a way of validation; it brings revelation to methodology, sensitises the ethnographer, examines the research methods, makes links amongst formal and informal discourses with research participants, and thus improves the trustworthiness of data analysis and the ethnography itself.
3.5 Philosophical stances underpinning this study

Corresponding to the first step of reflexive practices, I considered that the philosophy of social science could improve my ways of thinking and strengthen the performance of reflexivity in this ethnographic research (Seale, 1999; O'Reilly, 2012). I needed an in-depth understanding of stroke survivors and family caregivers’ experiences in utilising LTC services and their circumstances in terms of interacting with the social system, which in turn would reflect the real-context implementation of the LTC system in different socio-cultural environments. In this section, I justify my perspectives of relativist ontology and social constructionist epistemology, which underpinned this study and guided the research process.

3.5.1 Ontological stance

Ontology is concerned with “the study of being” (Crotty, 1998, p. 10) or “the nature of reality” (Guba, 1990, p. 18). An ontological stance represents what we believe constitutes social reality, claims about what exists and what it looks like (Blaikie, 2019). This study focuses on exploring the LTC system in Taiwan, which is based on a national LTC policy to address the increasing care needs of the growing ageing population (Ministry of Health and Welfare, 2018) and the reduction of family caregiving capability in Taiwanese society (Lin and Huang, 2016). The existence of the LTC policy is in response to demands from social actors, including elderly people, the population with functional limitations, and their families. The age requirement for the indigenous population is different from the general population, due to their shorter life expectancy (Ministry of Health and Welfare, 2015). This reflects the reality that the construction of the LTC policy is highly correlative with the social world, and its implementation is grounded in the context of multiple social interactions. Guba (1990, p. 27) asserts that realities in relativism “exist in the form of multiple mental constructions, socially, and experientially based, local and specific, dependent for their form and content on the persons who hold them”. In this sense, regulations of LTC policy in itself are not ‘meaning-attached’. Once the
services are linked with social actors such as recipients and providers under the mechanism of human behaviours, or the LTC system is implemented within a context, the LTC policy becomes functional and meaningful. Those social actions and interactions reveal experiences, thoughts and facts about the LTC services and further link to more in-depth understandings of socio-cultural-political phenomena within the LTC policy. This has enabled the appearance of the research target, the implementation of the LTC policy, as the field of this ethnography.

Moreover, the LTC services are meaning-attached not only when people utilise them but also in the circumstance that people do not utilise the services or forsake them. According to relativist ontology, reality is a finite subjective experience, and nothing exists independently of thoughts or experiences (Denzin and Lincoln, 2005). Therefore, I take the position that the fact of LTC utilisation can only exist in context, and can only be sense-making of the human thoughts, consciousness, conceptions, and interpretations embedded in context (Ritchie et al., 2013). Our experiences lead to different ways of seeing the world and diverse expressions of fact. Thus, a relativist ontology allows me to understand the subjective experiences of social actors by considering the social-constructed, context-dependent and subjectively perceived reality and facts in the field of LTC.

3.5.2 Epistemological stance

Epistemology is related to ontology, but refers to a theory of knowledge involving how it is I can know the fact (Blaikie, 2019). Epistemology is concerned with “how we know what we know” (Crotty, 1998, p. 8) or “the nature of the relationship between the knower (the inquirer) and the known (or knowable)” (Guba, 1990, p. 18). As I took up the connotations of relativism, I realised that the facts about the LTC field needed to be approached by ascertaining what people meant, through hearing their experiences and making sense of the situation. Social constructionism supports the epistemological stance of this study in two dimensions: first, how it is I can
know the fact about the LTC field; second, that the process of this ethnographic study itself represents social constructionism. It implies that social reality cannot be understood independently from individual human beings, as is the case in interpretivism and constructivism (Ritchie et al., 2013). Instead, it needs to make sense with a group of social actors and in the context where it is socially constructed.

This research attempts not simply to be interpretive toward individual experience, but also to probe ‘how people experience LTC from different ethnic or cultural backgrounds’ given that people with different ethnicities residing at different geographical and contextual environments are involved in the LTC system. I value not only individual experiences but also the way a context or a community facilitates or impedes people’s experiences of receiving or delivering care services. In this sense, I believe that the experiences of LTC utilisations are socially constructed meanings that need to be understood in the process of sustained social (inter)action of their particular society or culture. This corresponds to the ideology of social constructionism, which has a social focus on culture and communities rather than an individual focus (Young and Collin, 2004; O'Reilly, 2012).

Social constructionism indicates that “social phenomena and their meanings are continually being accomplished by social actors. It implies that social phenomena are not only produced through social interaction but are in a constant state of revision” (Bryman, 2016, p. 29). On the other hand, social constructionism also includes the notion that researchers’ accounts of the social world display a form of social construction (Bryman, 2016). Constructionism emphasises that knowledge is produced by exploring and understanding the social world of the people being studied, focusing on their meanings and interpretations (Ritchie et al., 2013). In this sense, constructionism identifies how the world and knowledge can be learnt and approached. With regards to active involvement as an investigator, knowledge is actively built by human beings, instead of being passively received by them.
(Ritchie et al., 2013); as such, the ways my approach to obtaining knowledge and my fieldwork experiences correspond with the epistemological stance is a process of social construction.

### 3.5.3 Methodological stances

Methodological practice refers to the question of “how should the inquirer go about finding out knowledge” (Guba, 1990, p. 18). Extending from the relativist ontology and social constructionist epistemology, I believed that my understanding of the LTC system needed to be constructed by learning from social actors’ thoughts and contextualising their everyday life. I continue to explain how the methodology reflected my philosophical stances, supported my theoretical perspective and informed my choice of research methods (Crotty, 1998). With regards to the aim of this study, a focused ethnography was able to facilitate my exploration of the LTC system and enable me to obtain a comprehensive view of the real lives of stroke survivors and their families, and their engagement with the LTC in different contexts. Below, I continue to explain the methodological stance used to answer the research questions. I first describe ethnography in terms of general qualitative inquiry. Second, I justify the rationale of a focused ethnographic approach to this study. Third, an account of my positionality is reflected in terms my research journey, and then I present the logic of my research methods.

#### 3.5.3.1 The place of ethnography within qualitative inquiry

The general characteristics of qualitative inquiry depend on its attempt to explore phenomena in an everyday context and to understand these phenomena through meanings brought about by research participants (Savage, 2006; Ritchie et al., 2013). These characteristics distinguish ethnography from other approaches, making it valuable for researching healthcare issues; this value lies in its participation in context, drawing attention to everyday action and interaction and accounting for their interplay.
with broader cultural formations (Hammersley and Atkinson, 2007; O'Reilly, 2012). Ethnography is applied broadly, in every domain from anthropology to sociology (Madden, 2017), and throughout the whole research process. Ontologically, ethnography possesses its connotations within the successive phase through the following aspects: naturalist ethnography, realist ethnography, modernist ethnography, and an epistemological encompassing that allows the production of critical ethnography, feminist ethnography, and more (Savage, 2006). Besides its philosophical significance in the holistic research process, ethnography is illustrated as a collaborative and participatory methodology, representing a process of production and a product, usually a book (Agar, 2008).

Spradley (1980) thus defines ethnography as the work of describing a culture to understand another way of life from the native’s point of view. Roper and Shapira (2000) consider ethnography to be a research process of learning about people by learning from them. Lambert et al. (2011) adopted ethnography as a methodological technique to explore the nature of communication between patients and health professionals in a hospital setting. In this ethnographic practice, six trademark characteristics were identified and suggested for consideration when applying the ethnographic approach: naturalism; contextualisation; focusing on small case numbers; employing multiple modes of data collection; presenting multiple perspectives; and considering the ethical implications. These characteristics echo the core values of the ethnographic approach to: (1) conducting fieldwork in natural settings with minimal influences from the researcher; (2) understanding social phenomena from intense human behaviours at fieldwork sites; (3) gathering a thick description of a targeted group by applying multiple data collection methods; and (4) reflecting on ethical issues immediate in their emergence (Roper and Shapira, 2000; Atkinson, 2015).
3.5.3.2 Rationale of a focused ethnographic approach in this study

These diverse descriptions of ethnography explain two key features: field-orientated activity and cultural interpretations. In Cruz and Higginbottom’s (2013) and Roper and Shapira’s (2000) adoption of ethnography in nursing studies, what most clearly distinguishes focused ethnography from conventional ethnography is its promising effectiveness in studying specific phenomena in distinct cultures and subcultures of clients or professionals. Focused ethnography is applied in order to explore preselected research questions focused on certain issues for a particular small population within a specific context (Roper and Shapira, 2000). Morse (1994) suggests that focused ethnography can be used to describe the topic-oriented small groups ethnographies found in the nursing literature. This describes the practices or specific situations within a larger social scene (Munhall, 2007). Thus, prospects of investigation within a cultural context make ethnography valuable for nursing studies’ researchers to understand patients’ experiences in the environment where they use healthcare services (Cruz and Higginbottom, 2013) and to enhance their understandings about illness and healthcare phenomena (Wolf, 2007; Lambert et al., 2011).

Muecke (1994) further demonstrates the features of focused ethnography and its application in characterising social phenomenon as follows: the conceptual orientation of single research; a focus on a discrete community, organisation or social phenomena used in academia and for development in healthcare services; the involvement of a limited number of participants, which is problem-focused and context-specific as participants usually hold specific knowledge; and episodic participation observation. With its problem-focused and context-specific characteristics, the following features differentiate focused ethnography from the conventional approach: (1) shorter field visits; (2) ethnographers with background knowledge; (3) versatility in terms of making use of video or audio recordings; and (4) data analysis intensity, in contrast to the experiential intensity of conventional ethnography (Knoblauch, 2005). Drawing on a relatively practice-based explanation from Muecke (1994) and
Knoblauch (2005), this study placed value on the identified features and justified its reasons for applying focused ethnography with properties as follows: the philosophical concept, the problem-focused field, the context-specific population, the subgroups/subcultures in the population fields, and ethnographic practice in data collection.

The study’s philosophical stances can be briefly summarised: knowledge and reality are deemed as socially constructed, and reality is not necessarily the only reality or one’s own reality. The field was identified as the implementation of the LTC policy that addresses the healthcare demands resulting from social phenomena. A focused ethnography would allow data generation on a predefined topic within the field and within the cultural context of the population, which were taken from different geographic regions with multi-ethnicities involved. Furthermore, the ability to explore the LTC service system, which relates to multiple social systems among general healthcare practices in Taiwanese communities, could be explored. Focused ethnography would fulfil the intention of this study, allowing the analysis of subgroups of people or those within a subgroup of social and healthcare practice. LTC services are carried out in residential settings in communities. Understanding the way of life in residential settings, usually a closed environment, could only be facilitated by the researcher playing a participatory role and building rapport throughout the whole journey of ethnography. It could not be ignored that the data collection would benefit if the researcher were present and close to LTC recipients and providers, staying with them and experiencing the moment when LTC practices unfolded. It was considered that in exploring the research aim, focused ethnography would be a promising methodology to assist with the conduct of such a healthcare study, as it would be able to address specific aspects of fields in highly differentiated organisations, and capture data on specific topics of importance to individual stroke survivors, family caregivers, and their LTC specialities (Knoblauch, 2005).
3.5.3.3 Reflection on insider and outsider positions in my ethnographic journey

Furthermore, studying a subculture in mainstream society or a specific context within a larger social scene yields insider and outsider positions, and emic and etic perspectives. Participation in the field sites enables the ethnographer to understand ‘how others see’ as Madden (2017, p. 182) asserts that an insider perspective is “not about looking participants in the eye; rather it is an attempt to see the world through their eyes”. Insider and outsider perspectives are not incompatible; they are mutually informed and sustained (Madden, 2017). Focused ethnography allows social reality to be elicited through changing positions between insider and outsider, and viewing social phenomena between emic and etic perspectives (Coffey, 2018). It is hard to set out a definite boundary between these positions. However, during ethnographic fieldwork, the tension between the insider and outsider positions enabled me constantly to question, immerse in and distance from data, and to understand social fact through synthesis of different perspectives.

My original research interest was to assess the experience of nurse-led discharge planning for stroke survivors and their family caregivers, to understand how the strengths and limitations of nurse-led discharge planning influence community care, and to view how discharge planning programmes fulfil the healthcare needs of post-stroke patients over time. However, after trying to find the types of resources that people could access within the community, I realised that LTC services provide the primary care system for people with long-term conditions residing in that community. As a result, I shifted my research interests towards gaining an in-depth understanding of the LTC system, which cares for households with elderly, dependent or disabled family members who require long-term care services.

My positions varied constantly and depended on which social role in the LTC system I was encountering or had encountered during the study. I acted as an individual researcher during the whole process. I belong to the non-indigenous
population. I used to be a clinical nurse taking care of stroke patients in a tertiary hospital in the Taiwanese community. Regarding ethnicity, I was an outsider among the indigenous population but an insider among the non-indigenous participants. With my nursing background, I had an insider’s knowledge in terms of understanding the healthcare demands of care users. Furthermore, I shared a background with LTC service providers as a care provider. However, my background knowledge was hospital-based, with different standards of healthcare. What is standard in the hospital might not be pragmatically applicable in residential environments. Within this study, I filled both the insider and outsider roles and found myself at different points along the continuum at different times. Therefore, I acknowledged my active role in the field and recorded myself in the field notes (Agar, 2008). My ways of seeing the world in the real context are influenced by my ethnic identity (a Han Chinese), occupational background (a nurse), and the situation that has led to the formation of this inquiry, which is a researcher (Reinharz, 1997).

Things have their attached meaning at the moment they happen (Vygotsky, 1980). The ways I interpret a condition has an essential meaning generated from past experiences (Young and Collin, 2004). Thus, my understanding of LTC services could be expected to be constructed following many interactions with key informants and participants in the real context. Experiences and gathered information from research participants would influence the lenses through which I saw the participants. The consequence of this premise is the overt acknowledgment that a researcher is not a neutral observer of action and the collector of data, but instead an active co-participant whose values will inform the research project (Bryman, 2016). Neither the fieldwork nor the interpretative activity of the ethnographer can be considered neutral or innocent. It was a fundamental principle to put myself in the position of the participant under study, for empathetic reasons. Furthermore, I needed to be self-aware of the influence that results from the researcher’s involvement. Due to ethnography's key methodological stances and characteristics, finding the relationship between the emic and etic perspective is not simply a matter of
balance. Instead, it involves synthesising these two ways of seeing to explain particular human phenomena on a broader canvas (Madden, 2017).

3.6 Research methods

Signposting
With the methodological stance justified above, I considered that the LTC field could only be explored by delving into the LTC recipients’ experiences and understanding their ways of thinking in the context of care needs and delivery. In this section, I present the rationale for the research methods in sequence of: (1) identifying the study setting and sample; (2) gaining access through ethics and gatekeeper negotiations; (3) on-site recruitments; (4) non-participant observation and semi-structured interviews for gathering multiple perspectives; (5) a data management process to follow the ethics considerations and ensure the comprehensibility of the anonymous documents; and (7) an iterative data analysis process in abductive reasoning.

3.6.1 Rationale for study setting and sampling methods

The aim of this focused ethnographic study was to explore the utilisation of LTC services from people of different socio-cultural backgrounds and ethnicities. An appropriate study setting and samples with adequate and corresponsive representations in the LTC system were the foremost considerations (Marcus, 2002). The representation of the relevant population in the field was such that I was able to choose a study sample that could represent the whole group and allow me to explore LTC users’ experiences by studying the most appropriate group of people on the most appropriate occasions. The study settings were located in three fieldwork sites, in three different administrative regions in middle-southern Taiwan.

A purposive sampling strategy allowed me to recruit participants pertinent to the research questions (Bryman, 2016) and provided enough information to help me understand the points of interest in the phenomenon (Creswell and
Plano Clark, 2017). In the general scope of LTC policy, six populations, classified by functional limitations and age requirements, are listed: (1) older people (≥ 65 years old) with functional limitations of ADLs; (2) people (of any age) with a disability; (3) indigenous people (≥ 55 years old) with functional limitations of ADLs; (4) older people (≥ 65 years old) living alone with only limitations of IADLs; (5) older people (≥ 65 years old) with frailty; and (6) people (≥ 50 years old) with dementia (Ministry of Health and Welfare, 2020). The differentiated requirements reflect not only the varying degrees of dependence and required assistance among care users, but also the health inequalities between indigenous and non-indigenous populations (Ministry of Health and Welfare, 2016). The selection of the sample in this study also reflected sociocultural features including long-term illness conditions, caregiving types and ethnicities.

This study included indigenous, non-indigenous and urban-based indigenous people in order to facilitate an equal representation of perspectives from the mainstream and minority groups. The selection criteria for the indigenous population were dyads of stroke survivor and carers. Participants needed to be adults (over 20 years old) who were currently residing and receiving LTC services in an indigenous administrative region (Council of Indigenous Peoples, 2002) and qualify as either Mountain Region Indigenous Peoples or Plain Region Indigenous Peoples based on the Status Act For Indigenous Peoples (Council of Indigenous Peoples, 2001). The selection criteria for the urban-based indigenous population were adults (over 20 years old) who identified as one of the two abovementioned indigenous groups and currently resided and were receiving LTC services in any region not classified as an indigenous administrative region (Council of Indigenous People, 2002). The selection criteria for non-indigenous populations were adults (over 20 years) who neither qualified as indigenous people nor resided in an indigenous administrative region.
The indigenous dyads were recruited in an indigenous administrative township in a mountainous region. The non-indigenous dyads were recruited in non-indigenous townships in a plainland urban region. For the urban-based indigenous dyads, the study setting was split between two types of community: one type was situated in non-indigenous townships in plainland, while the other was a post-disaster community in a township adjacent to a mountainous indigenous administrative township. Table 3.1 below presents the sampled population of this study with group characteristics.

**Table 3.1 Study population and sample characteristics**

<table>
<thead>
<tr>
<th>Study population and sample characteristics</th>
<th>Indigenous population</th>
<th>Urban-based indigenous population</th>
<th>Non-indigenous population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mountainous indigenous administrative region</td>
<td>Post-disaster community in the region adjacent to the indigenous region</td>
<td>Communities in the plainland non-indigenous region</td>
<td>Non-indigenous administrative region in plainland</td>
</tr>
<tr>
<td>Fieldwork site</td>
<td>1st</td>
<td>1st</td>
<td>3rd</td>
</tr>
<tr>
<td>Stroke survivors</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Family caregivers</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

For the study sample with different socio-demographic features, I decided to include participants with similar long-term conditions who needed support from the LTC system. As a stroke usually constituted a sudden change to a family (Hawkins et al., 2017), I set the stroke occurrence as a sampling criterion for the long-term condition of participants in order to understand the engagement of LTC services in stroke survivors’ lives in different sociocultural contexts. Moreover, due to the intimate bond between care users and their families in the Taiwanese community (Hsu, 2007; Yeh et al., 2015), this study
concurrently focused on the families’ perspectives and experiences of the LTC services. Therefore, stroke survivors with a family member as their primary caregiving support was set as an inclusion criterion in order to understand how the implementation of LTC services could support households with a dependent family in an unexpected and urgent situation.

The adoption of purposive sampling also enabled me to select participants flexibly, choosing those who could share their experiences in an articulate, expressive and reflective manner (Spradley, 1979; Bernard, 2011). Hence, stroke survivors with dementia were excluded from the recruitment, since the cognitive ability of the patients was uncertain. Equally, as it was necessary to understand the family caregivers’ perspectives of utilising the LTC system, families who sought help from assisted care workers were precluded. Furthermore, among the targeted populations in the general LTC policy, those who were not stroke survivors, those who did not have a primary family caregiver, and those who might be cognitively impaired were excluded.

All participants had to be aged 20 years or above, as 20 is the legal age of majority in Taiwan according to the Civil Code (Laws and Regulations Database, 2020); this legally ascertains whether an individual is capable of civil action and can make decisions without parental permission. The participants had to be able to communicate fluently in Mandarin or Taiwanese in order to express their complicated experiences of adaptation and explain whether LTC services had been able to help them work through that process.

The sample size was 12 dyads in total, including dyads of stroke survivors and family caregivers from three ethnic populations: indigenous, urban-based indigenous and non-indigenous populations. There were four dyads from each ethnic population. It is always difficult to determine how many interviews will be required in qualitative research, since data sufficiency is often the criterion for deciding data size (Morse et al., 2002). When a sufficient depth of data is obtained to describe the phenomenon fully and to represent the targeted
population adequately, interviewing and observation is discontinued (Fossey et al., 2002; Vasileiou et al., 2018). Bernard (2011) states that 30 to 60 data collection sessions may be required for an ethnographic study with the aim of discerning the essence of experiences. Creswell (2013) recommends interviewing four to five knowledgeable people when carrying out a case study of lived experiences or any well-defined cultural field. This study recruited four dyads of stroke survivors and family caregivers from each of the three ethnic populations mentioned above; thus, it was clear that at least 24 individual interviews would be conducted. Combined with the non-participant observation, which was scheduled to take place at least three times a week and to continue for two months (24 non-participant observations), it was consequently estimated that 48 data collection sessions would take place during this focused ethnography. The strategies of purposive sampling, snowball sampling, and asking for contacts from social acquaintances were all adopted, due to the challenges in finding adequate, eligible participants for the study. A detailed and transparent account of the process of participant recruitment is presented later in this section.

3.6.2 Gaining access to the research populations

Given that my study involved indigenous populations that are classified as a minority and as a sensitive and vulnerable population, I required several gatekeepers to help me access the targeted population. With regards to the known challenges, I sought to identify data collection sites before submitting the applications for ethics approval. Ethics applications and access seeking with respect to the field were an integral part of my ethnographic study, which involved multiple layers of permission requests. Finding fieldwork sites and requesting legal access from administrative units were the first steps. Next, ethics approval was essential. To gain access to the indigenous population, I contacted and sought permission from the relevant administrative units in Taiwan and ascertained their willingness to allow an individual researcher to carry out data collection in their boroughs. The Health Bureau of a county in
middle-southern Taiwan, with an indigenous township in its borough, gave verbal consent with prerequisites, which were set out as follows:

- Obtainment of ethical approval from one of the IRB/REC institutions based in Taiwan and,
- Seeking approval from the Council of Indigenous People (hereafter CIP), since all studies relevant to the indigenous population have to be reported to that specialised supervisory department.

It took a great deal of additional work to obtain this permission, since a proportion of the research participants in my proposal were indigenous people, who comprise a vulnerable population and an ethnic minority in Taiwan. In April 2018, I gave a presentation about the study to the LTC supervisors, the Chief of the Health Section and the Vice Deputy of the Health Bureau in order to strengthen access and affirm a cooperative relationship. They granted their permission and requested a report on the findings as a reciprocity. The length of this access and ethics process took six months; below I detail this process as it has been key to the progress of this ethnographic research.

**Ethics applications**

Ethics applications were sought from February to July 2018 by contacting three institutions: the Research Ethics Committee (REC) at the University of Edinburgh (UoE) in the UK, the REC at National Cheng-Kung University (NCKU) and the Council of Indigenous People (CIP) in Taiwan. Within the official institution of CIP, the Project Management Centre for human studies involving the indigenous population and the Department of Education and Culture were involved in negotiating the ethical approval. The REC at NCKU gave formal approval on 21 June 2018, and the counterpart at the UoE gave approval on 2 July 2018 (see Appendix B). On 10 July 2018, CIP gave verbal consent for me to access the indigenous region and conduct data collection, on the condition that I completed the pathway of ‘Regulation of human research consulting for indigenous population assent and business profits agreement’, determined by NCKU. The process of negotiating ethical
approvals with correlated sectors is illustrated in Figure 3.1 and elaborated upon in the following paragraphs.

**Figure 3.1 Ethics application process**

The two institutions in Taiwan, NCKU and CIP, needed to complement each other, which enabled the obtainment of ethics approval for this indigenous-related study. The role of the NCKU’s REC, parallel to the UoE, was to ensure that the research design considered the rights and potential risks of harm and that participants were well-informed and received language-appropriate documents before making the decision to take part in the study. These documents, including an information sheet and informed consent in both Mandarin and indigenous language, are presented in Appendices C and D. CIP is a specialised governmental institution dedicated to ensuring that the rights and autonomy of indigenous people are considered. However, the Research Ethics and Project Management Centre at CIP also requires support from a REC to scrutinise the research process and provide affirmation that a study is human-body-related and applicable to CIP’s authority. For example, if...
a piece of research collects the biomedical information of indigenous people, collective consent from the indigenous community needs to be granted, as the research results might reveal the health status of the targeted population in general. If a piece of research produces profitable results, the derived interests need to be shared with the indigenous population. In this regard, research that falls under an administrative regulation, ‘Consultation for acquiring indigenous consent and regulations for agreed commercial interests and its applications’ which is based on the ‘Human Subjects Research Act’ (Laws and Regulations Database, 2017), needs to go through the process of the CIP panel.

For this reason, an obstacle was encountered, as the committee of NCKU determined this study to be non-human-body-related research (as it would not involve invasive procedures or seek biological information from the participants, and would be low-risk with regard to the targeted population), and so considered it unnecessary to apply to the CIP. I contacted the CIP for their opinion regarding the decision of this exemption from the NCKU. The CIP staff indicated that they were unable to approve my access to the indigenous population because the NCKU’s determination of the study as non-human-body-related research put it outside the purview of the CIP. After making several attempts to attain this ethical permission and raising the issue through an online public query pathway, the issue was subsequently referred to the relevant unit, the Education and Culture Department. I spoke on the phone with an administrative staff member, who enquired about the research purpose, data collection methods (for instance, would the research process involve indigenous people’s land enclosures?), data utilisation, etc., and eventually conveyed his verbal agreement for me to access the indigenous people.

At the same time, I prepared an indigenous language version of the informed consent document in the light of advice from the ethics committee boards (the UoE and the NCKU) with help from an indigenous language teacher, in case the Mandarin version could not be read by elderly people in the indigenous area. To evaluate this version of the document, the NCKU committee also
sought assistance from another indigenous language teacher. I was informed of a few concerns regarding grammar and language usage by the language representative from the NCKU and passed on these concerns to my language consultant. After I communicated her explanations and justifications to the committee, the ethics application of the study was approved. The complicated process of these ethic applications made me reflect on the appropriateness of asking a REC to cooperate with an indigenous-specialised unit to supervise the ethics of an indigenous-related study. In section 3.9.5, I will reflect on the question of ‘to what extent a pre-fixed ethics protocol can supervise and support an ethnographic study’ and explain the rationale of balancing structured ethical codes in my ethnographic practices.

**Gatekeepers from administrative departments and service provision units**

From July to August 2018, I again requested permission from one of the gatekeepers, the newly-appointed chief executive director of the health bureau in the county, shortly after he came on board. He checked all the documents, including the ethics approvals from the UoE and NCKU. I explained all the procedures which had been undertaken, including the conversations and contacts with the CIP and NCKU. The director eventually agreed to the study, but indicated that he would need to scrutinise the thesis and relevant publications before release. Information that could possibly disclose geographical details was to be delocalised and blurred to an unidentifiable level.

However, consent from the gatekeepers did not ensure acceptance by the other social actors or by the study participants that this focused ethnography intended to access through engagement with the given community. The initial entry success did not guarantee continued access. Further frustrations and obstacles were encountered when I contacted the service provision units. In order to carry out observations by accompanying LTC service providers, I also sought permission from the Centre of Residential Care Services, subordinated
under a hospital, since the residential LTC services in the indigenous area were outsourced from this institution. The research proposal and the consent form for the LTC provider were delivered to the unit. The director of the service provision unit was essentially concerned about whether the data collection process would influence the service provision schedule. I emphasised that data collection would be conducted via non-participant observation and would not intervene in the service delivery, and that the unit would not have to modify its schedule of residential services. It took three more weeks to complete this round of contacts, await the gatekeeper’s reply, furnish explanations, and go through one more round of internal discussions.

### 3.6.3 Process of recruitment

Obtaining ethical approvals from the REC institutions and being granted permission from the gatekeepers only meant that I could personally visit the fieldwork sites. The research participants were scattered throughout the communities, and I needed to find ways to approach them. My ethnographic fieldwork involved diverse methods of access to potential research participants: connections with people who played different roles in the LTC system, as well as contacts I made in the places I attended in order to familiarise myself and build rapport with the research participants. I contacted people who assisted with meetings involving the administrative gatekeepers, the supervisors of the residential care attendants, the coordinators of the LTC services and the A-unit LTC manager. The places I considered included neighbourhood LTC stations and correlative facilities, such as rehabilitation centres used by another care system. Also, I took advantage of the social acquaintances (relations) I built in the communities, which linked me with further potential research participants.

Due to the uncertainty of recruiting ethnic minority groups, I decided to prioritise and start recruitment in the indigenous region in the mountain and then move on to the less contentious non-indigenous region in the urban...
plainland. During recruitment, it turned out that the urban-based indigenous population were scattered throughout the community; therefore, I started seeking eligible participants from the key informants and acquaintances I had made since I came to the indigenous region. In this section, I will first describe the access methods with respect to the three fieldwork sites and the logic behind applying them. Differences in seeking and attaining access to potential research participants subsequently manifested. I will explain the reasons that led to the challenges I encountered in finding eligible participants, and then contextualise the phenomena/dimensions that I observed during the process of data collection.

3.6.3.1 The indigenous region: the first fieldwork site

I mainly accessed the indigenous population through connections from care providers (residential care attendants and supervisors) and gatekeepers (the administrative and supervision departments); permission for this was ascertained as soon as I reported every contact to the correlative departments, the CIP and NCKU. On 19 August 2019, I made my first contact with LTC recipients who utilised residential care services, as I was accompanying the supervisor of the residential care attendants in a local hospital, Kinkichiho Hospital (pseudonym), while she renewed contracts with the clients. I was able to catch a glimpse of six of the potential participants on my roll, which had been provided by the LTC coordinator, while the supervisor and I shuttled across the southern villages of the indigenous region, including the Kawazu, Aomoriken and Chiba villages (all names are pseudonyms).

I noticed that she went to the tribal culture and health station (referred to as the neighbourhood LTC station in the non-indigenous region) in the Kawazu village to renew contracts of residential care services with the clients, and learnt that two stroke survivors had continued to attend the LTC station regularly. Because the Kawazu village contained six of the 13 total stroke survivors on my roll, I selected this village as the initial observation site. I
regularly attended the activities at the LTC station two days per week for a month. Of the six stroke survivors, five were not recruited into this study due to difficulties with hearing (two stroke survivors); problems with expression after stroke attack (one stroke survivor); hospitalisation (one stroke survivor); the absence of a family caregiver (one stroke survivor); and resettlement in another township (one stroke survivor). The stroke survivor who was resettled in a post-disaster reconstruction community was recruited as a participant in the subgroup of urban-based indigenous people.

Due to the ineligibility of the stroke survivors in the Kawazu village, I subsequently focused on accompanying the residential care attendants to visit stroke survivors who lived in other villages, one by one. The supervisor of the residential care services gave me the contact numbers of four residential care attendants and helped me by giving them a notice that a researcher would contact them. I then had to introduce myself and explain my research process through text messages and phone calls with four residential care attendants. As a result, I obtained their permission to go along and observe at a distance when they provided their services. Eventually, four dyads of research participants categorised as in the subgroup of the indigenous population were purposively identified; they were located in the Soglio, Arashiyama, Aomoriken and Chiba villages (all names are pseudonyms) respectively. Table 3.2 outlines the biographical details of the indigenous people in the mountainous indigenous region.

The dyads recruited in this study varied in age, occupation, level of disability and socioeconomic background. These conditions influenced the LTC service demand level they were allocated, which resulted in different types of service utilisation. I provide each participant group’s biographical details in a table. In the mountain-based indigenous group, the stroke survivors were aged between 73 and 84 years, with a mean age of 79 years. The family caregivers were aged between 38 and 72 years, with a mean age of 43.25 years. Three stroke survivors, Andrew, Novia and Yuri, were placed at level 3 of care.
demand, which reflected their level of disability resulting from an occlusive stroke. However, Bridget was placed at level 6, as she had suffered a haemorrhagic stroke with higher severity and greater challenges in recovery. During the LTC engagement, every care recipient had interacted with one of the A units in the community after they applied for LTC services. Their engagements with B and/or C units depended on the services they required in daily living.

### Table 3.2 Biographical data of the mountain-based indigenous group

<table>
<thead>
<tr>
<th>Code</th>
<th>Fieldwork site/ Pseudonym of living community</th>
<th>Pseudonym</th>
<th>Age</th>
<th>Kinship relationship</th>
<th>Occupation</th>
<th>Service utilisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1S</td>
<td>1st/ Soglio</td>
<td>Andrew</td>
<td>73</td>
<td>Husband</td>
<td>harvesting labourer</td>
<td>Level 3/ AB/ general household</td>
</tr>
<tr>
<td>A1F</td>
<td></td>
<td>Georgia</td>
<td>72</td>
<td>Wife</td>
<td>farmer/ BBQ vendor business</td>
<td></td>
</tr>
<tr>
<td>A2S</td>
<td>1st/ Arashiyama</td>
<td>Bridget</td>
<td>84</td>
<td>Daughter</td>
<td>B&amp;B business</td>
<td>Level 6/ AB/ general household</td>
</tr>
<tr>
<td>A2F</td>
<td></td>
<td>Deborah</td>
<td>61</td>
<td>Mother</td>
<td>farmer</td>
<td></td>
</tr>
<tr>
<td>A3S</td>
<td>1st/ Aomoriken</td>
<td>Yuri</td>
<td>83</td>
<td>Daughter-in-law</td>
<td>farmer</td>
<td>Level 3/ ABC/ General household</td>
</tr>
<tr>
<td>A3F</td>
<td></td>
<td>Molly</td>
<td>40</td>
<td>Mother</td>
<td>LTC provider</td>
<td></td>
</tr>
<tr>
<td>A4S</td>
<td>1st/ Chiba</td>
<td>Novia</td>
<td>76</td>
<td>Daughter-in-law</td>
<td>harvesting labourer</td>
<td>Level 3/ ABC/ General household</td>
</tr>
<tr>
<td>A4F</td>
<td></td>
<td>Beryl</td>
<td>38</td>
<td>Mother</td>
<td>cook</td>
<td></td>
</tr>
</tbody>
</table>

#### 3.6.3.2 The non-indigenous region: the second fieldwork site

Access in this region relied on social acquaintances. The research participants were recruited from their social venue, the LTC station and the rehabilitation centre. I contacted an A-unit LTC manager who was in charge of a private LTC
institution in Fukuiken, through a connection with a professor at the university where I completed my bachelor’s degree. In the non-indigenous group, the age of the stroke survivors ranged from 43 to 79 years, with a mean age of 66.35 years. All of them were assessed as level 4 of LTC demand. Table 3.3 contains the details of the non-indigenous groups. That professor linked me with the A-unit LTC manager, who was studying for her master’s degree under the professor’s supervision. I contacted her and briefly explained the type of research participants I was looking for, especially stroke survivors who had an indigenous identity and resided in non-indigenous regions. She expressed a willingness to assist and to help find eligible participants. Hence, I scheduled a date to visit her and had a face-to-face discussion with her at her office in the LTC institution, which she runs. The manager initially offered to screen out four dyads in a straightforward manner; these would comprise people who were easy-going, according to her impression, and hence more likely to agree to take part in my research. In order to fulfil my research design and commit to ethical practices with respect to finding four proper dyads among six to eight households, I declined her kind assistance, explaining that my research needed to screen the research participants from a greater number of households in order to gain a wider view and a more nuanced understanding of LTC service utilisation.
### Table 3.3 Biographical data of the non-indigenous group

<table>
<thead>
<tr>
<th>Code</th>
<th>Fieldwork site/ Pseudonym of living community</th>
<th>Pseudonym</th>
<th>Age</th>
<th>Kinship relationship</th>
<th>Occupation</th>
<th>Service utilisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>N1S</td>
<td>2nd/ Fukuiken</td>
<td>Julian</td>
<td>43</td>
<td>Husband</td>
<td>Self-employed technician</td>
<td>Level 4/ ABC/ General household</td>
</tr>
<tr>
<td>N1F</td>
<td></td>
<td>Ginger</td>
<td>36</td>
<td>Wife</td>
<td>Company employee</td>
<td></td>
</tr>
<tr>
<td>N2S</td>
<td>2nd/ Fukuiken</td>
<td>Hobart</td>
<td>68</td>
<td>Husband</td>
<td>Retired insurance clerk</td>
<td>Level 4/ AB/ General household</td>
</tr>
<tr>
<td>N2F</td>
<td></td>
<td>Clara</td>
<td>64</td>
<td>Wife</td>
<td>Part-time job/ homemaker</td>
<td></td>
</tr>
<tr>
<td>N3S</td>
<td>2nd/ Mieken</td>
<td>Leonard</td>
<td>75</td>
<td>Father</td>
<td>Retired from cleaning squadron</td>
<td>Level 4/ AB/ General household</td>
</tr>
<tr>
<td>N3F</td>
<td></td>
<td>Louis</td>
<td>50</td>
<td>Son</td>
<td>Driving coach</td>
<td></td>
</tr>
<tr>
<td>N4S</td>
<td>2nd/ Fukuiken</td>
<td>Driscoll</td>
<td>79</td>
<td>Husband</td>
<td>A Taoist spirit medium Homemaker</td>
<td>Level 4/ AB/ General household</td>
</tr>
<tr>
<td>N4F</td>
<td></td>
<td>Delia</td>
<td>71</td>
<td>Wife</td>
<td>Homemaker</td>
<td></td>
</tr>
</tbody>
</table>

**Recruitment in the neighbourhood LTC station**

The manager subsequently told me that a few stroke survivors (five, to be precise) regularly attended the neighbourhood LTC station on the ground floor of the LTC institution; therefore, I attended the facility three days a week in order to: (1) conduct the initial non-participant observation with potential research candidates; (2) enhance my familiarity with the stroke survivors; (3) determine their eligibility for individual interviews; and (4) seek the possibility of further observations in residential settings. Of the members in the LTC centres, only one stroke survivor and his family caregiver, Julian and Ginger
(N1), consented to participating in the study. One stroke survivor was excluded because he was not quite capable of answering questions coherently. Of the other three dyads, my request for participation was declined by either the stroke survivor or the family caregiver.

Recruitment in the rehabilitation centres
The rehabilitation centres were additionally identified as appropriate settings for recruitment, extending from rapport with existing research participants. When I started the fieldwork, I made extensive use of the research participants’ social circles, introducing myself and my work and demonstrating what I would like to do at the rehabilitation centre in the non-indigenous region. I discovered the rehabilitation centres’ potential for recruitment when engaging with Julian, the first stroke survivor recruited from the non-indigenous group. I originally came to know about Julian’s daily routine when he told me, “I attend the neighbourhood LTC station every Tuesday and Thursday, and carry out the rehabilitation exercise in a hospital on every Monday, Wednesday, and Friday”. His description of his regular attendance and utilisation of facilities in the community triggered my interest in his daily life among the stroke survivor community. Therefore, I asked to observe the rehabilitation exercise, and he agreed.

During the course of observation, I found that several stroke survivors regularly attended the rehabilitation centre, accompanied by residential care attendants. They told me that they applied for residential care services from LTC units so that a residential care attendant would accompany them. I realised that rehabilitation is also an LTC service delivery setting; stroke survivors require assistance during the process of rehabilitation exercise and movements in hospital settings. Considering the limitations I had encountered in finding potential stroke survivors in the neighbourhood LTC station, I decided to spend more time seeking out potential stroke survivors at the rehabilitation centre; four more stroke survivors were identified there. They utilised the same LTC services (the residential care services) and adhered to a similar family-
caregiving pattern (with a female spouse as a caregiver) so I decided to recruit only two of them: Hobart (N2) and Driscoll (N4). To increase the diversity of the stroke survivors, I found Leonard (N3), another stroke survivor who took an active part in his post-stroke care and had a different caregiving pattern in relation to his family (adult son as the caregiver). The family caregivers’ willingness to allow my home visiting was first inquired about and communicated by the stroke survivors themselves. After obtaining their verbal consent for further interaction, I visited them and provided further information about my research. Their agreement to take part in the research was conveyed either through the stroke survivors or directly through a phone call. I then visited them again to complete the informed consent.

3.6.3.3 Recruitment of urban-based indigenous people in the first, second and third fieldwork sites

In contrast to immersing myself in the geographical environments or social living circles of the research participants in the indigenous and non-indigenous groups, the access and recruitment processes with regard to the urban-based indigenous people were relatively individual and discrete: I contacted each dyad individually. I relied significantly on connections made through social relationships and acquaintances, while my familiarity with and understanding of the contexts had been built up in the course of the long-term fieldwork. The eligible dyads were recruited from three geographical regions in total, which are distinguished as three fieldwork sites in the following paragraphs. Two dyads were recruited from the post-disaster resettlement community in the first fieldwork site. The other two dyads were recruited from the second and third fieldwork sites respectively. Table 3.4 lists biographical data of the urban-based indigenous group. The biographical details show that the age of the stroke survivors in the urban-based indigenous group ranged from 47 to 64 years, with a mean age of 56.25 years. Of the stroke survivors, two participants were placed at level 5 of care demand, and the other two at level 4. Comparing the biographical data, the urban-based indigenous people had experienced
their stroke onset at a younger age than the other ethnic groups, with a mean age of 66.25 years in the non-indigenous group and 79 years in the mountain-based indigenous group. Moreover, the only two dyads that belonged to low and middle-income households were in the urban-based indigenous group.

Table 3.4 Biographical data of the urban-based indigenous group

<table>
<thead>
<tr>
<th>Code</th>
<th>Fieldwork site/ Pseudonym of living community</th>
<th>Pseudonym</th>
<th>Age</th>
<th>Kinship relationship</th>
<th>Occupation</th>
<th>Service utilisation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Urban-based indigenous group</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>U1S</td>
<td>1st/ Tottoriken/ a post-disaster resettlement community</td>
<td>Linda</td>
<td>52</td>
<td>Younger sister</td>
<td>Village officer</td>
<td>Level 5/ ABC/ General household</td>
</tr>
<tr>
<td>U1F</td>
<td></td>
<td>Prima</td>
<td>57</td>
<td>Eldest sister</td>
<td>Harvesting labourer</td>
<td></td>
</tr>
<tr>
<td>U2S</td>
<td>1st/ Tottoriken/ a post-disaster resettlement community</td>
<td>Ella</td>
<td>62</td>
<td>Wife</td>
<td>Harvesting labourer</td>
<td>Level 5/ AB/ General household</td>
</tr>
<tr>
<td>U2F</td>
<td></td>
<td>Bob</td>
<td>63</td>
<td>Husband</td>
<td>Harvesting labourer</td>
<td></td>
</tr>
<tr>
<td>U3S</td>
<td>2nd/ Fukuiken/ Communities in the plain land non-indigenous region</td>
<td>Hank</td>
<td>64</td>
<td>Father</td>
<td>Company employee</td>
<td>Level 4/ AB/ middle-income household</td>
</tr>
<tr>
<td>U3F</td>
<td></td>
<td>Ivy</td>
<td>30</td>
<td>Daughter</td>
<td>Manufacturin g worker</td>
<td></td>
</tr>
<tr>
<td>U4S</td>
<td>3rd/ Aichiken/ Communities in the plain land non-indigenous region</td>
<td>Dora</td>
<td>47</td>
<td>Cohabitant</td>
<td>Carer in care facilities</td>
<td>Level 4/ ABC/ middle-income household</td>
</tr>
<tr>
<td>U4F</td>
<td></td>
<td>Maxwell</td>
<td>58</td>
<td>Cohabitant</td>
<td>Unemployed</td>
<td></td>
</tr>
</tbody>
</table>
I was not able to undertake a general observation for the group of urban-based indigenous group at the initial stage of access and rapport-building, since eligible dyads (comprising a stroke survivor and family caregiver) were hard to find due to the invisibility of urban-based indigenous people in society, as well as a couple of further reasons explained below. The recruitment of urban-based indigenous people relied far more on relationships with professional acquaintances, and the research participants were recruited one by one. I ended up contacting them and requesting their agreement to take part in the study at different points along the ethnographic fieldwork timescale, as I could only do so once a common acquaintance connected us. This method of data collection meant that I did not achieve my ambition of finding eligible dyads among a larger number of households: six to eight households were planned in the research design, but this was successfully achieved only in the other two groups.

**Recruitment in the post-disaster resettlement community**

The reasons which I came to identify the first dyad of urban-based indigenous people, Linda and Prima (U1), were as follows: first, my increased understanding of the context of the post-disaster relocation communities; and second, the relationship I established with a residential care attendant. Linda, the first stroke survivor in this group, was originally on my roll of names of those who resided in the Kawazu village. Initially, I had believed that this stroke survivor was no longer eligible after her LTC service was suspended (when she moved to the Tottoriken community to live with another family caregiver); however, a residential care attendant inadvertently mentioned the name in relation to her services provision schedule in the Tottoriken community when we were on our way to the LTC recipients' houses in the indigenous region. The residential care attendant explained that Linda's residential care services had been suspended due to her change of residence and a shortage of workforce, but had resumed after new staff joined the service.
The scenario unfolded as follows: the residential care attendant explained that the transfer time was much longer when providing service in the mountainous areas, and she generally had to drive between 30 and 90 minutes from one household to the next. Incidentally, she mentioned that a new recipient in the Tottoriken community had been added to her schedule. After completing her service in the Tottoriken community, a post-disaster community in a plainland area, she needed to drive for 40 minutes to reach the villages in the mountainous region. Thus, I queried the conditions of the new service recipient. The residential care attendant explained that “she is also a stroke survivor, who used to live in the Kawazu village but now moved to the Tottoriken community.” I learnt more about the post-disaster community from the dyad of Andrew and Georgia (A1), who resided in the Soglio community. They told me that “many people opted for relocating to the Tottoriken community in the plainland area. But they just wanted to stay in the mountainous area, and as a result, they fought to have their native place as their permanent housing community, because of weather, livelihood and familiarity”. This information from Andrew and Georgia enabled further contextualisation of the information about the communities: post-disaster relocations were made into what are locally known as permanent housing communities, made up of disaster-stricken households.

In contrast to the conventional distanced living style, the post-disaster relocation communities for the indigenous population featured amalgamated and multiple-family-dwelling units that looked new, well-designed and concentrated. Among these post-disaster reconstructions, the Tottoriken community, with 155 households located in a plainland area outside of the indigenous region, was found to be the most populated community among the urban-based indigenous people residing in the plainland region. With the information from the residential care attendant and the contextual knowledge obtained from Andrew and Georgia, I was able to identify the stroke survivor, Linda, and her eldest sister, Prima (U1), who was currently residing in the post-disaster community in the plainland area and were eligible for my research.
Among the 155 households in the Tottoriken community, I further identified a second dyad, Ella and Bob (U2), from a connection with an LTC service coordinator.

Recruitment through social acquaintances in the plainland community
After completing the recruitment and data collection of six dyads (four dyads from indigenous populations and two dyads of urban-based indigenous people), I decided to seek a further ethnographic field work site, as I realised there was a limited chance of finding further eligible urban-based indigenous people in the first fieldwork site, and I also needed to start working on access to the non-indigenous group in the plainland region. I applied for an amendment to my ethics approval when I decided to seek another area for fieldwork site. I initially focused on a particular borough in order to gather data within the same scope of jurisdiction. However, only four dyads of urban-based indigenous people in total were identified in this borough, including two recruited dyads who resided in the post-disaster reconstructions mentioned above. The other two dyads were ineligible for the study because the stroke survivors were not capable of expressing themselves. This cemented my decision to change to another fieldwork site. Therefore, I had to make contact with an LTC institution manager in another geographical region in Taiwan (the A-unit manager I mentioned when discussing my access and recruitment in the non-indigenous region).

The second fieldwork site was a borough containing one indigenous district and 27 non-indigenous districts. I found one dyad, Hank and Ivy (U3), through a connection with the LTC manager, who phoned them to inform them of my project. They agreed that I could observe their LTC service and also gave consent to being individually interviewed. The last dyad of urban-based indigenous people, Dora and Maxwell (U4), was recruited from the third fieldwork site, also with assistance from the social acquaintance. Through this connection, I was able to find this dyad in Aichiken. I looked for eligible
participants using two contacts: a staff member who worked in a Cultural Tribal and Health Station; and a residential care supervisor of an LTC institution that provided services in my third fieldwork site. The same dyad was screened out by both contacts. The dyad regularly attended the Cultural Tribal and Health Station (the neighbourhood LTC station), engaging in social participation and utilising residential care services from the LTC institution.

To sum up, I identified and recruited two of the urban-based indigenous dyads purposively from the administrative unit, and two through snowball sampling by making enquiries of people with connections to either the residential care attendants, the LTC manager, or other acquaintances.

3.6.3.4 Gap between original logic and the reality of sample recruitment

The incidences and challenges I encountered during the process of accessing and recruiting participants revealed that I had an inadequate understanding of the sample and naïve expectations about finding eligible and adequate research participants in a single borough. The initial logic of recruitment was to carry out fieldwork in a borough in southwestern Taiwan in order to attain an equal understanding of different populations' perceptions of the services running under the same LTC system. However, it did strengthen the advantages of the ethnographic approach. Due to the fact that I stayed close to the field sites and populations, all the challenges and interludes were recorded, which enriched the data and reflected the partial social phenomena among different socio-ethnographic groups. They became a part of the resources for analysis (see section 4.7), stating the significance of socio-context in system organisation and human behaviours; this is elaborated in Chapter five.
3.6.4 Data Collection

This focused ethnographic study used non-participant observation and semi-structured interviews during data collection. Here, I justify the strategies and processes used to gather my data.

3.6.4.1 Non-participant observation

The aim of collecting data through observation is to gain a close and intimate familiarity with participants and their life within a context, through more consistent involvement with people in their natural environments (Hammersley and Atkinson, 2007; Atkinson, 2015; Madden, 2017). It is the research participants’ everyday environment. Ethnography takes place in the everyday environment of participants. Forming a field purports to guide an ethnographer’s enquiries into a human group or real-world context, leading the ethnographer’s thinking and practice-based process instead of controlling the behaviours or thoughts of the participant group. My non-participant observation mainly involved four important processes: (1) rapport-building with ethical considerations; (2) the observation process; (3) gathering diverse perspectives from informants; and (4) field note-taking. The observational lens transformed from a detailed description into a topic-focused format during the course of observation. Non-participant observation (n=24) was employed and combined with individual interviews (n=24) as part of the data collection method. This section explains how non-participant observation was conducted and the type of information obtained in field note-taking.

Rapport-building with ethical considerations

As Coffey (2018) stresses, productive fieldwork depends on an ethnographer’s relationships in the field, which are built on shared understanding and a trusting atmosphere. In the recruitment preparation and initial observation, I aimed towards rapport-building and creating familiarity through my presence with the LTC providers, care recipients and their families. This rapport-building process guided the way I embodied my presence and my changing positionalities over
time; at that point, I introduced my engagement to the participants in the LTC settings. Their interpretation of a researcher’s existence would influence their behaviour and interactions. The details of contacting the LTC units and providers and gaining access to the participants’ homes have been explained in ‘Process of recruitment’ (see section 3.6.3, p. 86). I address the ethical issues and considerations when conducting non-participant observation in ‘Ongoing consent of consent’ (see section 3.9.2, p. 135).

The observation process
The meaning of data is reflected in its setting; thus, the understanding of data is best linked to the setting (Emerson et al., 2011; Coffey, 2018). Considering that the LTC service provision usually took place at home or in a closed setting, I was better able to understand the providing-receiving process of the LTC services through observation. It provided me with an opportunity to learn about this social and healthcare system, live, in its real context. In contrast to the all-round, full-engagement role played by researchers in participant observation, in my non-participant observation I adopted a fly-on-the-wall approach (Caldwell and Atwal, 2005) in order to remain partially detached when observing things in their natural state (Swanwick, 1994). Utilising non-participant observation enabled me to fade into the background and avoid disrupting things taking their normal course, except in the ways that ordinary people influence each other (Alder and Alder, 2000; Bryman, 2016). Therefore, this non-participant observation had great potential to uncover contextualised data and help with the approach to the research objectives.

I carried out the non-participant observation by following the LTC providers, mainly the residential care attendants and physical therapists, when they delivered care services in the care recipients’ houses or rehabilitation settings; this enabled me to observe the real-life scene of service operation. In each participant group, I observed six to eight households and took the opportunity to identify potential participants for individual interviews. I carried out at least
four observation sessions with the participants recruited for individual interviews before arranging an interview session. Due to the fact that I was shadowing the LTC providers, each observation session lasted from the beginning to the end of service delivery. Thus, the exact observation duration depended on the LTC service that each participant required; it generally ranged from 1 to 1.5 hours. The observation at the beginning was more descriptive (Spradley, 1980), as I needed to gather the general features and contexts of the LTC settings. This included contexts such as service conduct, housing environment, and interactions and conversations among service providers, stroke survivors and families. Subsequently, more focused and selective observations were carried out when participants conducted particular activities or specific services in which I had not been involved before. Thus, I transformed iteratively between general/focused and descriptive/selective observation in light of the condition of the settings.

The transitions between different observation methods are exemplified by my experiences in the non-indigenous context. According to my gatekeeper’s log, I commenced general observation at the rehabilitation centres, where several stroke survivors received support from the residential care attendants in order to attend post-stroke rehabilitation. I carried out rapport-building and initial non-participant observation in the public environments. Details of the recruitment process are described in section 3.6.3.2 (see p. 89). After Julian (N1S) mentioned the residential reablement service provided in the residential setting, I inquired about the possibility and obtained his consent to extend my observation from the rehabilitation centre to his house. Therefore, my observation started from the descriptive lens in a public setting and selectively transitioned to a residential setting in order to focus on a particular service that I had not observed before. Moreover, my perspective during the observation process shifted depending on my interaction with participants. If the participants mentioned the social links in the rehabilitation facility, I paid attention to this topic-focused perspective during the following observation. When I realised that the adapted service meant a lot to indigenous people who
could not access a rehabilitation centre, I selectively observed how the other two participant groups interpreted the limitation and valued the adapted service.

**Diverse perspectives from informants**

I was able not only to observe the different aspects of the LTC services with less care intervention but also to clarify my queries and expand small findings by asking questions of the group members at the time or by learning more about the service activity through group discussions. Furthermore, the LTC professionals’ opinions and perceptions could be explored through informal conversation during observation events, which was a good way of utilising their presence, since they were not recruited as interviewees in the proposed research design. The informal conversation covered a wide range of topics, including the way LTC recipients’ condition transformed over time, the LTC professionals’ negotiation with the care recipients, the way they incorporated the LTC and community resources and the means by which they reported individuals’ needs to the care supervisory system and other LTC workforces. It was generally easier for a respondent to describe an event while it was happening than before or after it took place. For instance, I asked the physical therapist who was treating Julian (N1S) why he had increased the volume of residential rehabilitation services from three times a month to six times a month. I was inspired to raise this question because Julian had expressed that his pain was not as bad now that the physical therapist was visiting him more often. The therapist explained that he believed Julian had the potential for improvement because he was still young. Therefore, the therapist had developed a rehabilitation plan and applied for service escalation from the rehabilitation supervisory unit in the LTC system.

Moreover, the LTC providers revealed detailed information about their working conditions and shared opinions that they tended to avoid mentioning in front of the dyads. For example, a residential care attendant indicated that a relatively
low payment for a long transportation and travel time and the invested efforts to access remote areas had reduced their willingness to provide care in the remote areas as they were not remunerated for the travel hurdles and time. These informal conversations enabled a more comprehensive understanding of the LTC service operation and helped to organise the observational field notes.

I was able to observe what people actually did, as opposed to what they thought they did or would have liked others to think they did (Caldwell and Atwal, 2005; O'Reilly, 2012). Observation methods tend to offer a more direct view of social action or interaction, while interview methods glean the interviewee’s real perception through relatively indirect means. Applying non-participant observation as the preliminary method of data collection allows a researcher to gather a range of information that can be explored and provide direction for subsequent individual interviews. Therefore, observation can be combined with interviews, which can become complementary in data solicitation.

Field note-taking
The aim of ethnographic fieldwork is to get close to the everyday life experiences of people by living and being part of the context (Atkinson, 2015). I took notes on the activities of LTC service workers in keywords or simple sentences during the course of observation (Sanjek, 1990; Emerson et al., 2011; Bernard, 2017). I jotted down these notes in public quickly, instead of going into more extended detail, in order to lessen the impact on the flow of observation. Some participants involved in observation might feel uncomfortable when the ethnographer takes notes, and this can intentionally or unintentionally influence their activities and behaviours (Jackson, 2019). The jotted notes captured significant and/or minor matters that would be easy to lose. The observation sometimes revealed the relations and interactions of LTC operation in situ and offered valuable opportunities to ask questions in the
settings. Thus, I also recorded the particular scenarios that drove me to ask questions. I usually expanded the on-site jotted notes in proper descriptive notes the day after I finished an observation session and returned to my accommodation, as my memories were still fresh and I could expand on the detail.

Aspiring to a higher level of detail, expanded notes should include a description of physical context, conversational context, verbal and non-verbal communication, and as many perspectives as possible from the people involved (DeWalt et al., 2011). I produced observational field notes that emphasised context, response, sketches and reflexivity in the hope that an organised approach would stand me in good stead throughout my ethnographic study. In other words, it helped to recreate the atmosphere in which conversation and behaviours took place; this was conducive to including multiple voices and identify ignored aspects that were significant. Becoming involved in and finding out about the daily lives of others are vital parts of the ethnographic method (Emerson et al., 2011); materials cannot be understood independently from the context in which they were found (Gubrium and Holstein, 1997). Therefore, I recorded and described contexts that contained the life pattern, background of post-stroke resettlement, living arrangements, focus of the dyads’ lives, and the situation of their involvement with the LTC services. In addition, I recorded the situations in which individual responses including subjective experiences, emotional reactions, and behavioural responses took place. I marked information and verbatim quotations from different informants in different colours: information from LTC providers in green and from the dyads in purple; preliminary analytical thinking in grey; and explanatory content or tacit knowledge that I gleaned from other observation sessions in orange.

After more contact, I sketched out a few analytical points I had obtained from the observational sessions, which complemented the selective lenses explained beforehand. The expansion of descriptive field notes is a process of
selection based on the researcher's decisions; I transformed social life and social discourse into written work (DeWalt et al., 2011; Emerson et al., 2011). The interaction between the field notes and my headnotes created the ethnography (Ottenberg, 1990). I recorded my perceptions, self-reflection and justification for the decision-making process separately in the personal diary in order to facilitate the reflexivity of my qualitative study (Deggs and Hernandez, 2018). These issues and focuses were different in field note descriptions that significantly or implicitly utilised a variety of lenses to frame and interpret the materials. The reflexive notetaking shows a reflexive consciousness while taking into account my positionalities as a researcher and as a healthcare professional, as well as an awareness of my preconceptions. The reflexive notetaking was carried out throughout the observations, interviews and data analysis. I tried to identify the insider and outsider perspectives by recognising my existence in the fieldwork. A portion of my reflexive notetaking will be presented in the next section (see p. 108).

3.6.4.2 Semi-structured interviews

Semi-structured interviews were performed as a complementary technique in association with observation in this focused ethnographic study. Interviews, when combined with observation, can result in the interviewer being told different things at different times (O'Reilly, 2012). The process of prolonged engagement in the field and the ongoing development of the relationship, from rapport to trustful, enables a willingness among participants to talk and facilitate the credibility of the data. Due to the participatory characteristics of this focused ethnographic study, informal chats, opportunistic discussions and impromptu questions asked during observation led me to identify the more specific questions that needed to be asked in a quiet, uninterrupted and private environment. The interview technique is considered to enable a formal and collaborative conversation between the interviewee and the interviewer, allowing them to explore themes together (O'Reilly, 2012), and to help the interviewer adapt to unexpected research problems and work out how to
proceed in a new direction with the engagement of the research participants (Rubin and Rubin, 2005). The responsive interviewing model, as it is termed by Rubin and Rubin (2005), can be combined with the suggestions of O'Reilly (2012) to form the view that the interviewee and interviewer are both collaborators in the study rather than merely informants, and that the interviewer is not just a listener or recorder.

Drawing on my claim that knowledge is likely to be subjectively perceived, socially constructed and contextually dependent on the situation (Ryen, 2016), responsive interviewing specifies a few characteristics essential for keeping interview questions close to the interviewee and producing grounded and credible findings. First, the mutually influenced relationship between interviewer and interviewee should be paid adequate attention; it should not just be considered a means for the researcher to maintain neutrality. Secondly, interviewers need to take on deep ethical obligations as a close relationship with and in-depth understanding of the interviewee develops. Thirdly, the responsive interviewing model emphasises the significance of maintaining flexibility throughout the project to achieve the goal of receiving grounded answers and generating deeper understanding (Rubin and Rubin, 2005; Madden, 2017). In the following paragraphs, I explain the purposes of adopting semi-structured interviewing and carrying out individual interviews with the stroke survivors and family caregivers separately; in short, this was to overcome any potential influences between participants and obtain credible data, as suggested by Madden (2017) and Rubin and Rubin (2005). With regard to ethical obligations, the procedures that I applied in order to highlight ethical considerations and avoid violating ethics principles during data collection and data management are elaborated upon in section 3.9.

The purpose of this research was to give voice to the vulnerable groups under study and broach sensitive topics that would have been silenced in the course of the observational sessions. This is related to the fact that the nuanced voice is silenced in a hierarchy or social structure with uneven power distribution.
(Sheridan et al., 2015; Holroyd-Leduc et al., 2016). Power issues in group hierarchies and family dynamics are believed to influence interviewees’ manners of expression in front of other people (Aléx and Hammarström, 2008). People who need assistance or are dependent on others tend to be relatively vulnerable within a group and also unintentionally or intentionally quieter. In other words, people who are more powerful within a group are more likely to dominate or take control of the discourses/conversations. Moreover, individuals can find it burdensome to share their real thoughts and feelings in front of someone close to them, even without considering the possibility of saying something negative. People tend to keep their real thoughts to themselves, and refrain from saying negative things in front of other people. Therefore, I was responsible for providing a proper opportunity for the research participants to speak out in a more private setting, with fewer chances of interruption from other people and unfolding events. Conducting separate interviews with each individual from the dyads separately provided me with the opportunity to gather in-depth information and ascertain the truth from each member of the dyad about their experiences of using LTC services.

Moreover, I adopted semi-structured interviews, which provide room to accommodate new information and provide flexibility for the research participants to construct knowledge or clarify their stories. Spradley (1979) views the ethnographic interview as a key form of verbal exchange in ethnography. As a compromise between the predefined and non-variable questions of a structured interview, and the non-predefined questions and full conversational space for participants in an unstructured interview (Gibson and Brown, 2009; Bernard, 2011), semi-structured interviews are conducted with a prepared list of questions that include the themes and topics that need to be covered, not necessarily in a particular order. In addition, I opted to question interviewees in an open-ended way, with the expectation that the prepared list of questions would not only subtly steer the interview but also allow the participants to make expansions and clarifications (Madden, 2017). Appendix E provides the interview guides. Interviewing sessions could be (or tended to
be) paused or could wander off opportune as the research participants suggested topics, concerns and meanings that were important to them (Rubin and Rubin, 2005). Therefore, the flow and structure of the verbal exchanges (conversations) proceeded hand in hand by means of a prepared list of questions practised in a flexible order, as the research participants collaboratively took part in constructing my understanding of the LTC field. Concrete descriptions conveyed by research participants can ground answers in ways that provide nuance and precision, context and evidence simultaneously; this fulfilled my intention to ascertain the experiences of different people as interpreted through the interviewees’ own cultural lenses.

Applying reflexivity in note-taking

In this study, I have applied reflexive practice to the methodological appropriateness and rationale of research methods, and have questioned the influence of the positionality of the ethnographer on the creation of the text. In terms of interacting with data, the conscious thoughts that generate a sense of reflexivity have been applied more deliberately in order to avoid selective subjectivity and to remain aware of the ways that I have influenced the research. A sense of reflexivity in managing fieldnotes can provide a space to negotiate insider-outsider perspectives.

A reflexive diary was kept throughout the whole research process. Writing a reflexive diary helped me to self-reflect on my role, and to record the formation and transition of viewpoints in their contextualised background (O'Reilly, 2012). Through this diary, I realised that my decision to study the implementation of LTC services among indigenous, urban-based indigenous and non-indigenous people was a result of my keenness to understand the healthcare systems used in the community to prepare for an ageing society. My diary reflected on the fact that the contradictions that emerge from insider-outsider positions and tensions between a service provider and a recipient, official policy and routine care practices, and the social and health domains can be sensitised. I was able to become more aware of my ambiguous political and ethical position,
and of the need to pay more attention to the relationship between knowledge society and power. Furthermore, I also realised the difficulty in identifying enough LTC users with an indigenous identity residing in urban regions, and that this reflected the actual healthcare utilisation of urban-based indigenous people. In this regard, a personal diary constitutes a memorandum for retaining the viewpoint of an outsider and an etic perspective as a researcher. I regarded it as a daily routine that allowed me to stand back, maintaining a distance, in this focused ethnography.

Writing my diary and fieldnotes together constituted an early stage of data analysis. I intended to distinguish my insider and outsider perspectives by sorting them into fieldnotes and diaries. It was anticipated that the subjective nature and objective nature would be seen individually and analysed collectively. Observational fieldnotes and interview transcripts demonstrating an emic perspective can enrich the data diversity and supported understanding of the concerned phenomenon in collaboration with an etic perspective built on the personal diary, analytical memo and theoretical framework applied in analysis. I present the process of data analysis in section 3.7. With these practices, reflexive notetaking was also a validation method, as it sensitised my conscious thoughts. It enabled me to examine the research methods, make links between formal and informal conversations with research participants, and prevent the findings from being biased by my preconception (Emerson et al., 2011); as such, it improved the trustworthiness of data analysis and the ethnography itself.

3.6.5 Data management

In order to ensure uniformity of data generation, I created a procedure for data management. The first step was the documentation of data sets of observational notes, interview audiotapes and transcripts. The documentation procedure involved entering data collection details such as origin, time references, geographic location and access conditions into the data dictionary,
and subsequently assigning each research participant an identifier to ensure anonymity. Second, I recorded identifiers in the dataset index and stored it as a separate, encrypted file both on my personal laptop and in the UoE DataStore space.

**Storage**

My personal encrypted laptop was the primary data storage facility. All new primary material generated, such as observational notes, interview transcripts and consent forms, was scanned, stored and subsequently archived in a standardised manner. To reduce the risk of information loss, I ensured that the data were backed up daily on my personal secure server space. All the data collected from fieldwork were backed up and stored on a portable hard drive, which was password-protected. This study took place abroad; therefore, a few steps were proposed before I left the university in order to help me manage data security issues while travelling. I set up a VPN to connect remotely to my personal private space on the University's DataStore space, which was the third place where I stored and backed up fieldwork data. After collection of informed consent and other important files, I scanned and uploaded all copies of the files to the network location affiliated with the University of Edinburgh network drives, in order to safeguard against hardware problems. These facilities provided support for encryption and daily backup where required.

**Transcription**

The semi-structured interviews were audio-recorded in .mp3 format. I transcribed the audio recordings into Mandarin and stored them in .doc form using oTranscribe, a free web app for transcription. Three excerpts from the interview transcripts, two from the indigenous group and one from the non-indigenous group, were translated into English line-by-line and viewed by my supervisors to evaluate the quality of data, maintain the consistency of the coding process, and ensure the correctness of the analytical thoughts. Further excerpts of the remaining Mandarin transcripts were translated into English and uploaded into the computer-assisted qualitative data analysis software.
(CAQDAS) such as NVivo 12 application for collaborative analysis. CAQDAS can manage indexes, codes and ideas on one surface that was convenient for retrieval. Therefore, it supported insight development and data visualisation (Bazeley and Jackson, 2013; Maher et al., 2018). Observational fieldnotes and interview transcripts were anonymised (following the pseudonym and codes shown in Table 3.2, Table 3.3 and Table 3.4) when I created the storage files and imported them into NVivo 12.

**Translation issues**

Data quality is maximised when an analysis retains the original language of the data for as long as possible (Van Nes et al., 2010). Some narrative excerpts or utilisation of metaphor contain cultural meanings that only make sense within the source language (Polkinghorne, 2005; Lakoff and Johnson, 2008). Language is socially constructed, with cultural meaning attached within the social context; this needs to be realised within the original context of language formation. For example, one of my participants, Clara, used a metaphor to express her anxiety: “I got my nerve strained”. This described how her body reacted when she felt anxious about not being with her dependent husband, the stroke survivor. In Mandarin, this metaphor expresses the way her psychological and emotional state influenced her physical senses; however, it does not make sense in English. Therefore, during the initial coding, which was the first step in preparing the data for analysis, I decided to keep the source data in Mandarin to minimise the chance of losing meaning. The labelled excerpts were then translated into English for the subsequent stage of descriptive coding and categorisation. To minimise meaning loss in translation, I made efforts to re-contextualise the meaning by providing fluid descriptions for each code. Details of the coding and analysis process are further explained in section 3.7. I sought a proofreader who was fluent in both Mandarin and English and had experience working with interview transcriptions to ensure the accuracy and comprehensibility of the translation. Thus, this study involved two languages; the interviews were conducted in Mandarin as the source language, while the findings are presented in English.
The English-translated excerpts and developed codes were shared and viewed by the supervisors in order to evaluate the quality of data, maintain the consistency of the coding process, and ensure the correctness of the analytical thoughts.

### 3.7 Data analysis

**Signposting of this section**

The analytical procedure of this study originated from the data gathered from formal conversations in the interviews and data from observational sessions, including my fieldwork notes and informal conversations. Data analysis was undertaken alongside data collection and management. Analysis took place in a spiral way from data analysis to writing up to reintegration of the data, as O'Reilly (2012, p. 180) stated: “ethnographic research is iterative-inductive. This is a practice of doing research in which data collection, analysis and writing up are not discrete phases, but inextricably linked”. This section first justifies my practice of initial and descriptive coding methods as I reduced a large data set into smaller, manageable units. Second, I explain the tactics of code mapping to visualise the relation of codes with the research participants and contextualise them within the fieldwork sites (see section 3.6.3). Third, I explain the application of abductive reasoning to conceptualise codes and categories with the concept of biographical disruption (Bury, 1982), status passage theory (Glaser and Strauss, 2011), and the theoretical framework of the structuration theory (Giddens, 1984). Subsequently, I further reflexively question and reshape my analytical thinking by iteratively observing commonalities and differences within and between the individual dyads in the sample groups in different regions, and the LTC users in their socio-demographic environments. Figure 3.2 illustrates the analytical process and approach used for this study.
3.7.1 Coding methods applied to identify potentially meaningful data

I started by reviewing the research questions explored to guide my focus:

- How does the long-term care policy meet the needs and expectations of stroke survivors and family caregivers experiencing LTC from different ethnic or cultural backgrounds?
- What are the facilitators of and barriers to long-term care for stroke survivors and their family caregivers experiencing care in their community?

I focused on understanding the implementation of the LTC policy and how this policy interacted with individuals and stakeholders in the communities. The research participants from diverse cultural backgrounds and stakeholders from multiple positions in the LTC enactment resulted in a large and complex data set, including formal interviewing transcripts and informal, but informative conservations during observations. Gathering data over a nine-month period of fieldwork afforded me a view of the participants’ lives and the LTC services
from a broad perspective constructed through multiple sources. However, relationships and contextual conditions between the policy and individuals and the policy in the situated communities could only be comprehended by deconstructing the complex data set into smaller, manageable data units for analysis, while retaining the descriptive characteristics of the ethnographic work.

3.7.2 Coding process

Initial coding

In the first step of analytical work, I undertook initial coding with 24 interview transcripts and 48 observational field notes data separately. This step was conducted whilst undertaking the fieldwork at each site; I initiated this approach to my initial analysis after I had completed the first observation notetaking and the first interview transcription. The recruitment of the urban-based indigenous people was the most challenging aspect of recruitment as I could only recruit eligible participants from three separate communities situated in different administrative regions. See sections 3.6.2 and 3.6.3 for details of data access and participant recruitment in the three fieldwork sites. Hence, the initial coding was processed according to the order of participant recruitment and data collection. I conducted the analysis in the following order: the indigenous group (four dyads) followed by the urban-based indigenous dyads in the post-disaster resettlement community (for disaster-stricken indigenous households in the plainland; two dyads), the non-indigenous group (four dyads), and the other two dyads of urban-based indigenous people in the plainland community (see Figure 3.3 for the coding flow). The analysis of the dyads of urban-based indigenous people was divided, as they were recruited at different times in different locations, due to the fact that minority groups are hard to identify in mainstream communities. The observational field notes and the interview transcripts, sourced from three fieldwork contexts, were coded separately within their own group. However, they were mutually impacted.
Data from the succeeding groups spurred me on to question the primary data and develop thoughts to contrast and compare among dyads and across groups.

**Figure 3.3 Coding flow of participants**

I coded the data line-by-line and incident-to-incident, depending on the nature of the raw data (Charmaz, 2006) or based on the comprehensibility of the paragraphs. Coding the data line-by-line was conducive to familiarising myself with the narrative data and provided me a quick overview of it with respect to similarities and differences among individual participants, and direct data collection in the succeeding fieldwork (Saldana, 2015). The initial coding technique helped me grasp nuances in the data derived from the participants’ standpoints, as I stayed at the field sites and was contextually immersed in the circumstances in which the activities, statements, and the ideas occurred. The initial coding process was open to all possible directions to guide me in shaping subsequent interview questions and remaining flexible for different observational lenses over the course of data collection (Charmaz, 2006). Coding in this step was performed in Mandarin to preserve the original meaning and cultural value hinted at in the discourses. Subsequently, the initial
codes and their contents were translated into English for further analysis. An example of the coding process is presented in Appendix F to demonstrate how I managed the analytical work between the Mandarin and English versions of transcripts and codes. In the initial coding phase, more than 170 codes were developed as labels for describing the data.

Descriptive coding
Once the data were familiarised and labelled by initial coding, the next step was to identify the category from the coded content, while preserving the nature of thick description from each ethnic group (Coffey, 2018). The descriptive coding involved integrating the observational field notes and interview transcripts. It is a foundational step for comprehending data in the context, as it is essential to interpret the symbolic meaning of the situated environment, that is the fieldwork sites of the social worlds (Hammersley and Atkinson, 2007; Berger, 2016). In this stage, I managed my data using NVivo 12 as it helped to archive and retrieve data in one operating interface (see Figure 3.4). I created a codebook (a section of it is exemplified in Appendix G) demonstrating the development of the descriptive codes and categories. The descriptive codebook changed overtime, reflecting the ongoing analysis, ensuring that the definition and meaning of codes and categories were the same and to make the coding process transparent to others e.g. supervisors. I usually analysed the codes by raising questions such as what drove this situation, what action did they take, where and in which context did this happen? These general questions helped me to iteratively reflect on the methodological focus and place value on the empirically informed description of the situation as well as social actors to construct an analytical insight into the daily lives of individuals engaging with the LTC system.
Stepwise coding system

Observational data

From the data set of observational notes, contents from the observational field notes labelled with the initial codes were extracted from the main body of the original field notes and reassembled together in a new document with my narratives and descriptive summary which reminded my thoughts about the data. To illustrate this process in my analysis (see Appendix H), I developed a file of my observations that elaborated on ‘Indigenous people’s decision about post-disaster and post-stroke resettlement’ from which my analytical thinking about people-place relationship emerged. Ten emerging categories (listed in Table 3.5 below) were organised in ten separate files constructed from 48 observational notes for further analysis.
In the data set of interview transcripts, I carried out the coding and analysis using the following steps: (1) data coded in dyad; (2) data coded in each group; (3) codebook composed for analysing dyads and groups across contexts; and (4) codebook containing my coding track was applied as references for developing descriptive categories. The codebook helped summarise and maintain an overview of my rich data within clearly delimited units without losing the informative nature of the ethnographic field notes. When I re-visited the data and traced the trajectory of data analysis, the codebook served as a point of reference that documented and justified the creation of new codes and merging correlated codes. Following the codebook, I made a consistent coding decision when I analysed data from the different contexts to achieve across-context dependability. For the interview transcripts, 21 descriptive codes, extracted from 170 initial codes, were clustered into seven descriptive categories: (1) Individual’s post-stroke recovery trajectory, (2) Family caregiving system, (3) Place attachment, (4) Multiple systems of care resources, (5) Role and functions of LTC services, (6) Transitioning factors, and (7) Environmental properties. Table 3.5 below lists the seven descriptive categories.

Analysis of observational and interview data sets

I found that the categories emerging from the two data sets were mostly analogous and compatible with their counterparts. In the data set of observation notes, category six, ‘Coordination and distinction’, and category seven, ‘Feeling bad about troubling people as in demands for additional support’, were found analogous to category six, ‘Transitioning factors’, in the data set of interview transcripts. These categories covered the data relevant to situations that facilitate or impede post-stroke recovery. Moreover, in the data set of observation notes, category eight, ‘Environmental landscape and characteristics’, category nine, ‘Indigenous people’s decision about post-disaster and post-stroke resettlement’ and category ten, ‘Hard to reach urban-
based indigenous population’, were comparable with the category of ‘Environmental properties’ in the interview transcripts data set. It was mutually informed to category three, ‘place attachment’ and ‘people-place relationship’, so that social actor’s relationship with the environment stood out from these categories. The commonality and comparability between the data sets enabled me to integrate ten observational categories with the seven categories from the interview as categories emerging from across both the observational notes and interview transcripts data sets (see Table 3.5).

Table 3.5 Descriptive categories from datasets of interview transcripts and observational field notes

<table>
<thead>
<tr>
<th>Descriptive categories</th>
<th>Data Set Interview transcripts</th>
<th>Data Set Observational notes</th>
<th>Descriptive categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Individual’s post-stroke recovery trajectory</td>
<td>New pattern of life</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Family caregiving system</td>
<td>Family obligation</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Place attachment</td>
<td>People-place relationship</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Multiple systems of care resources</td>
<td>Regional disparity of system organisation</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>Role function of the LTC services</td>
<td>Flexible operation of the LTC services</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>Transitioning factors (coordination or tension)</td>
<td>Coordination and distinction</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Feeling bad about troubling people, in demands for additional support</td>
<td>7</td>
</tr>
<tr>
<td>7</td>
<td>Environmental properties</td>
<td>Environmental landscape and characteristics</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Indigenous people’s decision about post-disaster and post-stroke resettlement</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hard to reach urban-based indigenous population</td>
<td>10</td>
</tr>
</tbody>
</table>
Triangulation

I conducted triangulation across data sources, collection methods, and iterative-inductive analysis among different field work contexts. As a strategy for establishing credibility, narrative data sourced from multiple perspectives such as the stroke survivors, family and care providers increased the depth of interpretation (Morse, 2015) regarding the (inter)action of LTC service providing and receiving. Two datasets gathered through observation and interview were mutually explanatory and collaboratively generated common categories by identifying overlapping or irregular codes (Creswell and Miller, 2000). The data sourced from different correspondents through different methods did not always afford me an equivalent abundance of value. In certain circumstances, observational notes and interview transcripts contributed to providing different analytical dimensions to illustrate the category. I equally valued the formal and informal narratives and closely reflected on the data contents, focusing on the details of the descriptions that supported me in mapping out and reasoning the fieldwork and real-life contexts. The credibility of the field notes data was ensured as I relied on multiple correspondents elaborating several incidences in different scenarios, rather than a single incidence at a point in time.

3.7.3 Emergence of phenomenon

Code Mapping

As Coffey (2018, p. 80) stated, “data analysis in qualitative research should be methodical but feasible, imaginative as well as rigorous”. A technique of code mapping that integrates textual and visual methods (Saldana, 2015) was conducted manually to obtain a view on data saturation and help me detect any trends. Figure 3.5 illustrates the emergence of post-stroke recovery trajectory as I clustered the research participants’ self-perceived life status and arrayed the initial codes and descriptive codes in sequence to bring meaning and coherence to data (Anfara, 2008). The dyads of stroke survivors and family caregivers were the storytellers of their post-stroke lives. I depicted the post-
stroke life based on their narratives regarding living with illnesses and interacting with healthcare services. Each stroke survivor experienced his/her own trajectory and had a position that corresponded to their immediate situation. I therefore attempted to know the stage at which the individual participants were situated in their life trajectory which I diagrammatically presented. I extracted the interview excerpts that narrated the immediate status of life and positioned the stroke survivors in the corresponding stage of their post-stroke recovery trajectory. Appendix I provides the participant excerpts as references corresponding to their position in the post-stroke recovery trajectory. After linking the participants with their trajectory, a phenomenon of varied distribution relevant to socio-contextual trend emerged. Figure 3.6 shows the preliminary findings of varied recovery developments along with uneven sociodemographic tendency/distribution. The phenomena potentially implied the role socio-context played in determining the post-stroke life and engagement process of the LTC system.

**Figure 3.5 Diagram of themes and nodes from analysis**
Throughout analysis it transpired that people from the same socio-context were more likely to have similar opportunities in the environment that enabled them to transition to recovery. In this sense, context played a notable role in the post-stroke recovery and interacting with the LTC system in the environments. It brought me back to the descriptive codes from the first coding cycle, of which seven descriptive categories emerged from the datasets of interview transcripts and observational documents that shared similar descriptions and were compatible with their counterparts. However, the appearance of the context dimension helped to identify the significance of three descriptive categories, category eight, nine and ten, from the data set of observation, which characterised the natural and social environments.

The three descriptive categories were integrated as environmental properties in the first cycle; however, in the transitioning stage, they became significant factors that are explanatory to compare and contrast the findings across the three fieldwork sites. It was a transitioning step to link the descriptive codes with the narrative speakers which iteratively cycled me back to the initial steps.
of my analytic efforts to reorganise my data with the corresponding participants and the distinct fieldwork sites/context, before taking me a step forward on with the ethnographic analysis.

**Reflexive turn during ethnographic analysis**

Visualising codes and linking it with the participants not only enabled me to gain a wider perspective of the ethnographic aspects of the data, participants and the context, but also gave me a stage for reflexivity. My reflexive diary and analytical memo showed the gap between my understanding about culture and its real instantiation in the LTC system engagement. As my coding methods followed the methodological consideration to explore human experiences from different cultural and ethnic backgrounds, I endeavoured to find the content relevant to the cultural aspect. The following paragraphs provide an example of memos reflecting my transformed perspective of culture and context, based on my reflexive diary and analytical memo writing.

*An example of memo- What makes culture as culture?*

I found that my practice of an ethnographic gaze is something that can be a challenge in fieldwork experiences. Attempting to familiarise with the site in the indigenous region (the first site I attended as an ethnographer), such as landscape, facilities, and residential environments caused me to miss seeing things that were of ethnographic importance. My preconceptions have fluctuated after accessing the indigenous region. When I accessed the indigenous region, I realised that the traditional practice of healthcare seems next to nothing compared to advanced healthcare practice and that the National Health Insurance (NHI) had been widely implemented. Knowledge about herbal medicine might be mentioned but is not in current use in real life. I doubted the existence of shared traditional and cultural meanings among the subgroups, considering that the sociocultural-interpretive purpose might not be salient. Additionally, my initial gaze was shaped by the problematic presupposition of perceiving the disadvantaged accessibility of LTC
services in the indigenous region, which could be a problematic comparison between my own familiar native environment and that of the indigenous region I am studying. After a month of being shown around the region – having this domain described by the service users, residential care attendants, and LTC supervisors in terms of facility constructions, source of services, responsible units of the healthcare, and overcoming strategies – I began to ‘see’ the site differently. The discussion of the disadvantages was not raised as salient to my presupposition. People at the scene did not perceive and describe in the same fashion. They provided me with different ways of seeing instead. Although my consideration of the disadvantaged was not wiped out, it was revived after the relative medium disadvantage of this site, the indigenous region in the mountain, being displayed compared to other ethnographic settings, the better accessibility for non-indigenous and weaker accessibility for the urban-based indigenous population in the non-indigenous region. During data collection and data analysis, culture neither made its appearance as traditional practice and herbal knowledge about illness care, nor as common value that determines acceptance or perception when the ethnic populations interacted with the healthcare system in their life. Instead, culture became visible when people from different contexts, featured in natural geography, institutional and socio-structural properties, experienced inequitable access to the LTC system that led to variances in the practice and perceptions of the LTC services.

I realised that it is my preconceived ideas around the culture, and actually, I took a very narrow viewpoint of this. Corresponding to Wolcott (1990, p. 50), “there is no ethnography until culture makes an entry”. Focused ethnography can usually help reveal cultural meanings, shared experiences, tacit facts, and regularity hinted within such contexts (Knoblauch, 2005; Cruz and Higginbottom, 2013; Madden, 2017). Therefore, either culture or context is an abstract concept based on my observations of behaviours, phenomena, principles of action, and organisation which could be attributed to the group
members I studied in this context of dealing with that (Goodenough, 1976). However, culture might imply some tacit facts, knowledge, or phenomena to exist behind regularity or commonality. It was these contextual features which seem dissimilar or different that makes a culture-forming process or that presents as a culture – the culture I thought of before does not exist in the community in the same manner I presumed. This does not decry the occurrence of events. It just demonstrates differently from the ethnographer’s expectation and seems to emerge in a comparative or relative manner. In this sense, context is a substrate of culture (Northoff, 2013; Savard and Mizoguchi, 2019). This reflexive awareness was subsequently reflected as a strategic process in abductive reasoning that made context a marker of difference to identify the stakeholders involved and the aspects present and absent in the stroke survivors and their family’s recovery trajectory in the context of them dealing with the situation.

3.7.4 Abductive reasoning

The next step in my analytical process was to apply abduction to explain empirical data using theoretical concepts (Fletcher, 2017). Considering the phenomenon that emerged from coding, mapping and reflexive practice, I made an inference that contextual factors played a decisive role in determining the post-stroke recovery trajectory and engagement with the healthcare resources. In this ethnographic study, abductive reasoning was adopted to deliberate and double-check these inferences between empirical data and theories. I engaged with the biographical disruption (Bury, 1982), status passage theory (Glaser and Strauss, 2011) and framework of the structuration theory (Giddens, 1984) in the abductive process to interrogate my analytical thinking and imaginative conjectures. I initially considered applying Bandura’s (1986) social-cognitive theory to explain the relationship between social environment and a person’s cognition. However, Bandura’s theory focuses on immediate context and personal agency and puts less emphasis on defining a structure (Bandura, 2001). Instead, Giddens’ theory contextualises social
practices across space and time by viewing action and social structure as linked by their inseparable relations. Giddens provides a more explicit role definition that describes human actors as elements for producing the social structure through social interaction, such as reproducing values and norms (Giddens, 1984). The core concepts I adopted from the structuration theory included time-space-power as constitutive elements, macro-meso-micro sociology, and duality of structure and agency.

In research, abduction is a process that starts with empirical data in a particular field of study, identifies phenomena of interest, and explores the emerging phenomena along with broader concepts and theories (Timmermans and Tavory, 2012; Coffey, 2018). To strengthen my inference, I conducted abductive reasoning using the following steps: (1) conceptualisation of post-stroke recovery trajectory, (2) reconfiguration of the descriptive category, (3) negotiation between the etic and emic perspectives, (4) interpretation of outlier cases. These steps were interdependent and mutually informed. Therefore, I carried out these steps recursively as I felt it necessary to address and revisit a particular procedure. I carried out the abductive reasoning by de-contextualising the empirical data from the original field, abstracting to comprehend different perspectives, and recontextualising the emerging phenomenon by a theory-abducted context.

**Conceptualisation of post-stroke recovery trajectory**

The first process of abductive reasoning took place after the post-stroke recovery trajectory emerged. Earlier in the data analysis, I considered the concept of patient-centred care and transition theory (Meleis et al., 2000). However, I rejected them because they were inadequate for explaining the data theoretically. Patient-centred care is a holistic concept, containing core elements that show the interactions between patients and professionals during each encounter (Stewart, 2001; Kitson et al., 2013). Transition theory views the life transition from a nurse’s viewpoint, which is limited to the post-stroke trajectory derived from the individual’s first author biographical narratives.
Biographical disruption (Bury, 1982) seemed fitting for understanding the loss of self-identity occurring in the stroke survivors, and so I applied biographical disruption as a theoretical concept, which enabled me to explain the post-stroke life. However, this concept had its limitations in terms of understanding the complexity of biographical continuation. Consequently, status passage theory (Glaser and Strauss, 2011) and biographical disruption (Bury, 1982) were both utilised to help me understand my data and delineate and explicate the post-stroke life trajectory (see Figure 3.5). Subsequently, the phenomenon of varied distribution along the trajectory emerged, featured in the socio-contextual trend.

**Reconfiguration of the descriptive category**

I created a code matrix and code maps manually to trigger innovative thinking and capture the prompted ideas. The abductive reasoning process involved reconfiguring the descriptive codes and categories derived from data sets of observation and interview transcripts in a matrix (see Appendix J). During the process of code matrixing, I extracted the environmental properties as the principal analytical guide to compare and contrast the absence and existence of LTC in terms of facility and service in the communities. Moreover, as context refers to the settings and boundaries in which the action or process occurs (Saldana, 2015), I de-contextualised the data from the original field and re-contextualised it in a three-dimensional structure framed by the axes of time, space, and power. Thereafter, I reconfigured the descriptive categories in the three-dimensional structure. I configured the category 'Individual's post-stroke recovery trajectory' on the axis of time as it represented a lived form of time. The category 'Place attachment' was configured on the axis of space as it presented as a lived form of space. The categories of 'Environmental properties', 'Multiple systems of care resources', 'Family caregiving systems', 'Transitioning factors', and 'Role function of the LTC services' were placed on the axis of power. My reasoning for this is because Giddens (1984) indicates that power is generated from social relations which occur across time and space. Figure 3.7 illustrates the three-dimensional social structure with applied
concepts from the structuration theory (Giddens, 1984). On the power axis, the hierarchal interplay among the categories prompted me to layer the axis with macro, meso, and micro aspects. In this step, I revisited the three fieldwork sites’ data and explained the interpretation of the LTC system implementation from a conceptual and theoretical perspective informed by theories.

Figure 3.7 Concept map of time-space-power and macro-meso-micro, adapted from Giddens (1984)

**Negotiation between the etic and emic perspectives**

Next, I attempted to make sense of relation and interaction in the social structure abducted with the theoretical concepts of time-space-power and macro-meso-micro. These concepts provided a backdrop for understanding the empirical data through abstraction and distancing. The theoretical concepts were instantiated with empirical data and thus became pragmatic and sensible. When the descriptive categories were conceptualised in the social structure, links and hierarchical relations among the stakeholders, the system, and the environment became visible to me. New concepts emerged carrying variant (alternative) properties and dimensions according to interrelations between data and concepts across social levels. I consequently
recategorised them, according to the properties and dimension, into context, condition, interaction, and consequence (see Table 3.6 below).

In these processes, the abstraction procedure refers to a higher logical level, displaying a kind of classification or pattern with wider capacity to explain emerging phenomena (Lindgren et al., 2020). I abstracted the narratives and reorganised them into boxes of concepts. In this study, levels of abstraction increased as codes were compared and grouped into descriptive categories and conceptual categories along the analytical process. The more time I spent analysing the data, the higher the abstraction level and the greater the distance from the original text. In this sense, the empirical data were abstracted up by distancing from the textual/ literal meaning. Furthermore, theoretical concepts were concreted down by verifying close to tangible facts. The semantic distance between the emic perspective derived from empirical data and the etic perspective informed by theories was allowed to negotiate through abductive reasoning (Timmermans and Tavory, 2012). Instead of tangling the loss of immediacy or relegating rich data, abstraction and distancing made focal points or taken-for-granted factors stand out. My understanding of the social relations was enriched and this refined my inferences of emerging phenomena.
Table 3.6 Summary of the analytical process
This table provides a summary of the coding process, showing a link from the development of the seven descriptive categories in the first stage (heading number 1.1 to 1.7) to the 12 conceptual categories (heading number 2.1 to 2.12) in the second stage and to the theming-up stage.

<table>
<thead>
<tr>
<th>Analysis stage</th>
<th>Coding</th>
<th>Transitioning</th>
<th>Abductive reasoning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strategy</td>
<td>Initial coding, descriptive coding</td>
<td>Code mapping</td>
<td>De-contextualisation, Abstraction, Re-contextualisation (matrixing and mapping)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Descriptive categories</th>
<th>Phenomenon illustration</th>
<th>Conceptual categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Environmental properties</td>
<td>• Varied distribution among social contexts • Environmental properties matter</td>
<td>2.1 Macro context for policy implementation 2.4 Accessibility: unequitable access to LTC 2.7 Barrier to accessibility 2.10 Integrated LTC system</td>
</tr>
<tr>
<td>1.2 Multiple systems of care resources</td>
<td>2.2 Meso context for system organisation 2.5 Situated LTC system: availability, sustainability and affordability 2.8 Tension coordination 2.11 Culture of adapted LTC practice</td>
<td></td>
</tr>
<tr>
<td>1.3 Family caregiving system</td>
<td>2.3 Micro context for adapted service practice 2.6 Appropriateness: adapted service practice &amp; individual's needs 2.9 Facilitator of accessibility &amp; appropriateness 2.12 Individual's biographical continuation</td>
<td></td>
</tr>
<tr>
<td>1.4 Transitioning factors: coordination and tension</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.5 Role function of LTC services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.6 Individual's post-stroke recovery trajectory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.7 Place attachment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interpretation of outliers

As the indigenous, non-indigenous and urban-based indigenous contexts were framed by the same social structure, phenomena and findings emerging between or across the contexts were easier to examine in the realm of existing theories. However, as evident in Figure 3.6, some participants developed differently on the recovery trajectory, as outliers, from the group members in the same context. The outliers refer to people who did not follow the trend with other group members. To understand the varied distribution in the same group, I constantly checked and compared every participant. I observed every participant within their individual situation and in the contextual situation to determine the causes underlying the similarity and irregularity. Following that, I explicated the outliers by searching for alternative concepts. I used another core concept, duality of structure, of the structuration theory to search for mechanisms that constrained or enabled social interaction across individual’s life, family, the LTC system, and the social context. The key questions I interrogated during the inference are as follows: ‘What agency has existed for the feasibility of the phenomenon?’; ‘What agency has been absent for making the infeasibility the phenomenon?’, and ‘How did the agency occur?’ Being compatible with the concept, duality of structure and agency, I contextualised the mutually influenced relationship between the structure of LTC implementation and individual action of service delivery (human agency) through constant comparison among individual participants. In this step, new concepts enabled me to comprehend the individual trajectory, engagement with LTC system, system with the situated context by identifying underlying agency of coordination between individual and collective, individual and system, and identity and place. I then verified the new concept across the fieldwork sites to double-check with individual participants one-by-one to understand their common and uncommon experiences with other members.

To summarise, I primarily elaborated on the process of applying appropriate theories to revisit phenomena in a theory-informed context, negotiate the etic and emic views, and interpret deviant cases by seeking alternative casing for
abstraction. This abductive process strengthened my analysis from my initial inferences, allowing me to conclude that context was crucial in determining the post-stroke recovery trajectory and the LTC engagement. Additionally, this abductive process strengthened my interpretation and refined the theoretical construct of social relation with refined concepts. I capture the social relation between each individual and the LTC system with the concepts of individual-collective, individual-system, identity and place. These concepts interacting along the time-space strands illustrated the biographical continuation of the post-stroke recovery trajectory.

3.8 Quality of the study

So far, I have elaborated on the methodological concerns, analytical process and reflexivity practices of the study. I will now consider the rigour of this research and explain how I developed the trustworthiness of the study, based on the four criteria of dependability, confirmability, credibility and transferability (Lincoln and Guba, 1985). I applied six strategies, adapted from Lincoln and Guba (1985) and Morse (2015), to ensure that the research and analytical processes were trustworthy: (1) prolonged engagement; (2) a stepwise coding system; (3) triangulation; (4) peer debriefing; (5) reflexive awareness of researcher bias; and (6) thick description. These strategies were incorporated to achieve the relevant criteria and maintain the rigour of the study.

Credibility is a criterion that can assess the extent to which findings are believable from the perspective of the research participants in qualitative research (Lincoln and Guba, 1985). It entails the questions of whether the findings authentically reflect what the participants reveal and what the study intends to find out (Maher et al., 2018). My prolonged engagement in the field enabled rapport-building that helped me obtain thick and credible data, which has been explained as part of the data collection process (see section 3.6).
Dependability refers to the degree to which a study can be repeated and variations understood (Shenton, 2004). It implies the extent to which research will produce similar or consistent findings (Lincoln and Guba, 1985). My detailed explanation of the methods in this chapter, my ethics and access strategies along with my stepwise coding procedure, in collaboration with observation and interview data, all ensure a dependable coding process. The supplementary and mutual standpoints of my participants, identified by mutually clarified data triangulation, ensured that I had credible and dependable perspectives to view data (see section 3.7.2). Moreover, I needed to prevent one perspective from being more representative than the other, as the vulnerable minority groups featured in this research are susceptible to being silenced and disempowered within society. To ensure no participant’s position was neglected, I provided equal representation of the participants’ descriptions and analysed common and deviant cases in order to take into account factors that may have affected the findings (see Appendix I).

Confirmability concerns neutrality, i.e. the extent to which the interpretations are grounded in research inquiry and not subject to the researcher’s bias (Lincoln and Guba, 1985). However, an ethnographer has no neutrality or objectivity. I was an active co-participant in the fieldwork. My existence was essentially an engagement in the social actor’s life, and my value informed the research project, as elaborated in the research reflections and literature. Therefore, the reflexive practices applied through recording my role in the fieldnotes and presenting my reflexivity in the personal diary served as a reminder of my active participation and also reminded me to avoid research biases. The neutral viewpoint from my PhD supervisors, as peer debriefers, and my reflexive practice kept me aware of potential researcher bias, which enabled me to maintain confirmability.

Transferability is the extent to which the findings of qualitative research can be applicable and sensible in other situations or settings (Lincoln and Guba, 1985; Speziale et al., 2011). It can be achieved through de-contextualisation and
abstraction of emerging concepts and theory, followed by re-contextualisation to other settings (Morse, 2015). The abductive reasoning process (presented in section 3.7) that negotiated the emic and etic perspectives in light of my changing insider and outsider positions affirmed/verified that the analytical steps were based on research inquiry in order to ensure the confirmability, credibility and dependability of findings.

3.9 Ethical issues and considerations

Signposting

I felt a deep obligation to ensure the ethics of the study, as I was recruiting minority and vulnerable groups and built a close relationship with the research participants that developed through my ethnographic fieldwork. First, I considered the question of “how can I make use of the trust relationship with the research participants but not exploit it?” as one of the primary ethical issues in the study. I explained my set of principles in my applications for ethical approval, as well as the strategies I was using and the decisions I was making to prevent unethical practices in the actual research. Secondly, I reflected on the question “to what extent can a pre-fixed ethical protocol supervise and support an ethnographic study?” This is another ethical issue, as socio-cultural and political factors affect the negotiation of ethics. I justified my attempts to find a balance between the requirements of the Research Ethics Committee (hereafter REC) and the fundamental connotations of qualitative research, and also extended it to the real-life implementation of this focused ethnographic study.

3.9.1 How can I make use of the trust relationship with the research participants but not exploit it?

This project aimed to gain an in-depth understanding of the LTC field based upon relationships of trust with the research participants. Some of the participants were stroke survivors and/or indigenous people considered to be
relatively vulnerable within mainstream society. The project not only involved vulnerable populations but also took place in residential environments that are not open to the public. The most frequently raised ethical concerns in the literature resources include codes and consent, privacy, confidentiality and anonymity, trust, and the risk of harm (Hammersley and Traianou, 2012; O'Reilly, 2012; Atkinson, 2015; Ryen, 2016; Madden, 2017), as well as the accountability of informed consent (Murphy and Dingwall, 2007; Dingwall, 2008). Therefore, I brought these concerns together and outlined my ethical considerations as: (1) ongoing consent and continuous supplementation; (2) potential risk assessment; and (3) confidentiality in handling of data. I believe that these ethical considerations evolved from the trust relationship and were an integral aspect of my research in terms of carrying out an ethical ethnography.

3.9.2 Ongoing consent and continuous supplementation

Consent means that research participants are well-informed regarding the researcher’s purpose for undertaking a study, the processes and potential hazards involved in the study, what will happen to any material collected, and the rights they possess in deciding to take part or withdraw from the research at any time without giving reasons (Murphy and Dingwall, 2007; O'Reilly, 2012; Madden, 2017). To ensure that every essential detail is made clear to participants, codes and consent refer in particular to informed consent, which usually requires the targeted population to sign informed consent forms (Ryen, 2016).

Preparation and implementation of the informed consent form

I prepared the consent form in both Mandarin and the indigenous language (see Appendix D). Both versions were scrutinised by a township administrator who is fluent in the native language, then subsequently submitted for ethical approval. This project recruited adults aged 20 or above who were deemed competent to give consent. The participants and I each kept one signed copy
of the informed consent form. Since the indigenous language is most prevalent in the indigenous community in the dialectical tongue, the literalised format can only be understood by a professional interpreter and not by most of the community members. As a result, I also enlisted a qualified interpreter who could read to the indigenous participants when necessary. However, during my fieldwork, none of the participants required the interpreter, as all of them were able to read the Mandarin version of the consent form.

Eligible candidates were provided with easily understandable information about the research project so that they could make voluntary choices about whether or not to participate. I was responsible for clearly informing the participants of the potential positive and negative consequences relating to their involvement in the study (Lipson et al., 1995). Additionally, the consent form specified what I intended to do with the narrative expression and the results of the study. The research participants understood that their experiences would be given to and read by other people in an anonymous form, where the reader would not be able to distinguish the identity of the storyteller. Appendix C shows the information leaflet I presented to the research participants. I addressed further doubts and knowledge discrepancies among individuals by supplementing them with the required information, and enough time was provided for them to consider whether or not to participate in the research before they were asked for formal consent. In this sense, I made every effort possible to empower individuals to be able to make a knowledgeable decision about their participation in the study (O'Reilly, 2012; Iphofen, 2013). I continued to explain and provide extra information about this research project, and also reminded them that their consent was continually negotiable. Their right to withdraw from the study was communicated to them concretely instead of only being mentioned vaguely.

**Ongoing status of consent**

The accountability and appropriateness of an informed consent form in ethnographic research is widely challenged, as it enforces a pre-fixed consent
form, usually with a ticked-off format as “done” or as a symbol of agreement. It primarily considers the individual participant, but fails to take general practical and political perspectives into consideration (Murphy and Dingwall, 2007; Atkinson, 2015). Before the observations, I acquired the LTC providers' formal consent via an informed consent form and subsequently requested that they inform and seek verbal consent from their clients, the dyads of stroke survivors and family caregivers. Stroke survivors and their family caregivers' formal consent for the semi-structured interviews was sought after a few more instances of observation contact and before the individual interviews took place. The initial stage of informing them was carried out by different LTC service providers and sometimes involved assistance from the LTC service supervisors; in this regard, I could not ascertain the extent to which the dyads had understood the research process before giving permission for an unknown researcher to visit their home. It was hard to ascertain whether the research participants or even the LTC providers fully understood the purpose and process of the study, despite my having engaged with the LTC service managers to gain access and seek permission for observation. The reasons why they agreed to my involvement in their daily care services lay in other extrinsic factors such as introductions by gatekeepers, service supervisors and LTC providers. Individuals rendered their consent due to the trust they placed in me or their LTC providers, rather than an essential understanding of my research.

Distinct from the typical discrete episodic intervention of clinical trials or biomedical experimentation (Murphy and Dingwall, 2007), the contract between myself and my research participants definitely rested on pre-contractual bases of mutual trust, which were negotiated and renegotiated over time during the ethnographic fieldwork (Alder and Alder, 2000). The observational sessions of my research project involved participants with different roles in the LTC field. Each LTC service observation included the engagement of multiple participants rather than a series of individual participations that took place in a linear way. Due to the nature of ethnography,
access was tentative and consent was conditional (Murphy and Dingwall, 2007). I believe that consent is never a one-off procedure that can be immediately completed at the moment of research explanation or signature acquisition; instead, it is ongoing throughout the whole process of data collection. The benefit of the ethnographic approach was that it enabled me to position myself more centrally and closer to the research field and participants than most other forms of research; however, it also required a more significant personal commitment to the field and participants. Therefore, I seized every opportunity and occasion to explain and clarify my study, and continued to supplement, through verbal explanation, the information that was impossible to specify at the outset of contact. I attempted to keep the consent in an iterative condition.

3.9.3 Potential risks to participants and researchers

Given the fact that the research participants were likely to provide consent due to friendship and trust rather than their understanding of the study, I undoubtedly had more control over the data collection process, and so it was important not to overlook the potential risks that might have brought harm to the research participants. Trust, one of the three classic concerns, refers to “the relationship between the researcher and the participants, and to the researcher’s responsibility not to spoil the field” (Ryen, 2016, p. 33). In this regard, in order to obtain knowledge and establish rapport, I made attempts to minimise social distance with the research participants so that they would be willing to convey their experiences of LTC services utilisation. However, I might also have intruded into their personal zone of privacy, as Stake and Jegatheesan (2008) point out.

Emotional distress

Considering that human subjects were being directly studied and vulnerable and disabled populations were involved, I had to ensure that the research participants became no more vulnerable than in their ordinary lives as a result
of participation in this research. With regard to physical and psychological state, the onset of a stroke results in the considerable pressure of adjusting to an altered lifestyle for stroke survivors and their family caregivers (Cott et al., 2007; Nasr et al., 2016). While I continued to ask questions, I realised that their distress and suffering, which was not often displayed, might break out at points. Some psychological consequences, such as emotional distress and a sense of anxiety, might have resulted from participants being encouraged to express their experience and divulge personal details regarding stress and uncertainties. As a result, I left no stone unturned in terms of minimising the negative influence on the subjects; I ensured that the interview questions were carefully phrased, and probed with sensitivity. In addition, the participants were informed that if they experienced any emotional discomfort that they were unable to alleviate, they could terminate the interview and I would refer them on to other healthcare professionals.

**Pause, turn and ethical decisions**

I excluded one potential dyad from recruitment because the family caregiver had a diagnosed bipolar disorder. However, I did not preclude this dyad when I first learnt of this condition. I met the stroke survivor at an LTC neighbourhood station, when a residential care attendant was accompanying him to community activities. The survivor was 85 years old and had suffered a stroke ten years previously. The stroke survivor very passionately consented to taking part in the research during our first meeting, and invited me to visit his home. I asked him and the residential care attendant to inform the family caregiver prior to my visit. As soon as it was confirmed that the wife had been informed, I turned up at the dyad’s house after accompanying him to his activity at the LTC station that day. I could tell that the family caregiver was very cautious during my visit. She invited me to sit down, but remained standing herself while chatting with me; everyone was sitting down, including her husband, while she was standing! The situation remained the same during my second visit. She invited me to have some fruit, answered every greeting and chatted. The stroke survivor explained, "It is her personality; she always behaves like that"
and welcomes you to visit us often”, when I asked him about this situation. However, I eventually decided to exclude the dyad as I knew that the family caregiver was not able to get out of bed and had experienced difficulties eating with chopsticks two months previously, as a result of her recurring symptoms of bipolar disorder. The stroke survivor explained, “She became stable now. Two months ago, my daughter flew back from the US to look after her and supervised her to comply with the medication. As a result, she could retain a stable condition”. However, I decided to exclude this dyad from further observation and interview, feeling that my presence in her private space could possibly break down her current stability. An exercise of retrospection such as an interview might also trigger her emotions by forcing her to look back at past experiences that might have stimulated her disorder in the first place.

Given the choice to prioritise either research commitment or protecting the participant from harm, I decided to remove myself from their private space; as Stake and Jegatheesan (2008, p. 2) articulate, “privacy is not defined only by the content of disclosure, but also in terms of audiences and circumstances involved”. Even though her disease was irrelevant to any sphere that my research would cover, my involvement in her daily living could become an intrusion into her private, intimate stable state, or breach her sense of privacy. I had no intention of worsening her health condition, especially as it had already been arduously retained. Moreover, I also considered that if the fragile family caregiver encountered negative consequences, the information about mental health consultation, attached on the informed consent form, would not be supportive enough to assist this dyad. It is difficult to predict the complexities and uncertainties of real-life fieldwork holistically at the outset of research preparation. As a result, ethics approval and informed consent does not guarantee that a researcher will be well-prepared.

3.9.4 Confidentiality and the handling of data

In this ethnography, upholding confidentiality also implied a commitment to my trust relationship with the research participants and the gatekeepers. Since
discourse from the research participants might refer to significant others, I was obliged to ensure that what I heard or saw would go no further (or not be attributed to anyone who could be identified) (O'Reilly, 2012). In helping the research participants to understand what they were consenting to, and collecting their consent later on, I was responsible for explaining what and how data would be managed and used, and how the findings would be reported and published. To maintain confidentiality and anonymity, the transcripts of narrative data were stored on a password-controlled computer and all paper data were preserved in a locked cabinet in a locked room. The details of the data management process have been explained in section 3.6.6. Confidentiality is generally essential for protecting one’s privacy as well as protecting against harm (O'Reilly, 2012). I cannot become a sounding board for other healthcare providers in the research setting. Therefore, I will not reveal any perceptions or complaints from the LTC service recipients, in order to safeguard the privacy of the individual, uphold their rights and ensure that their benefit from the services is not hampered. In addition, this research project aimed to explore the experiences of the dyads of stroke patients and family caregivers. Therefore, I will not reveal a participant’s conversation to another family member unless he/she asked me to convey their thoughts to other people.

3.9.5 To what extent can a pre-fixed ethical protocol supervise and support an ethnographic study?

Presumed ethical considerations and some interludes explained above show that ethnographic approaches are subject to the same ethical codes as other approaches, but some circumstances that required ethical consideration in this particular ethnographic fieldwork nevertheless emerged by themselves. When the ethical issues emerged, dealing with them case-by-case or giving situational responses, as raised respectively by Atkinson (2015) and Ryen (2016), required the integrity of carrying out ethical considerations and providing ethical decisions that were weighed with respect to the commitments
of ethnographic fieldwork and participants’ rights. A few pragmatic issues I encountered led me to agree on the rightness (accountability and righteousness) of applying a pre-fixed ethical protocol informed by a positivist epistemological stance in the supervision of qualitative research (Murphy and Dingwall, 2007; Hammersley and Traianou, 2012; Atkinson, 2015; Ryen, 2016). In the upcoming paragraphs, I will articulate the circumstances I encountered in the course of ethical approval application and my attempts to balance my commitments to ethical ethnography.

The fulfilment of ethical considerations in this ethnography was scattered with dilemmas, and I could not easily render answers to clear-cut presumed questions. One of the REC institutions required me to attach the interviewing questions. This requirement from the supervising institution actually conflicted with my research design; I planned to generate interviewing questions from what I saw in the course of non-participant observation. In this sense, the actual implementation of the ethnography was jeopardised, echoing the assertion that the fulfilment of the qualitative approach is subject to ethical applications (Dingwall, 2008; Atkinson, 2015; Ryen, 2016). In the ethnographic approach, predicting every possible condition, analytical outcome or even unanticipated finding of the analysis appears awkward to me. I tried to explain this to the supervisors of the ethics application, but they asked me to include a list that would help them understand the focus of my research further. In order to gain formal access to the research field, as well as fulfil one of the requirements from a gatekeeper, I had no choice but to compromise and provide a list of hypothetical interviewing questions to the ethics committee.

‘Whose field?’ and ‘whose ethics?’

As I articulated in the access-gaining and ethics applications discussed in section 3.6.2, the cooperation between the REC committee and CIP seemed to weaken the autonomy and authority in terms of dealing with indigenous affairs. The purview of the specialised ethics-supervisory department in the CIP was set out by an administrative regulation, “Consultation for acquiring
indigenous consent and regulations for agreed commercial interests and its applications”, based on the “Human Subjects Research Act” (Laws and Regulations Database, 2017). This purview mainly required the township or local government department to establish a consultancy meeting, which would involve key persons from tribes in order to conduct agreement rights. It was a process by which critical persons from tribes would gather in order to enable me to conduct research involving indigenous people by obtaining collective consent.

Seeking such collective consent under the supervision of administrative staff and tribal leaders was rational with respect to my ethnographic research, which enabled me to build incredibly close relationships with research participants and placed me in a central/participatory role in their lives. As my access to the community was essentially a participatory action, I became sensitive to whatever I saw and heard, and began to observe people in the field. Therefore, this consent process made sense to me, as a collective and well-rounded supervision of my research. However, to a certain degree, it was peculiar; the collective process was crippled, because it was still highly reliant on an authoritative unit, a formal REC, and could not function smoothly by itself. This situation evidenced the fact that indigenous affairs were inextricably attached to mainstream society, as well as the implementation of the ongoing LTC system. Providing LTC services with cultural awareness and sensitivity was advocated widely, but the real conditions resulting from their inherent inadequacy impeded this possibility, and the structure of the mainstream mechanisms fundamentally limited the services’ availability.

Perhaps this deadlocked consequence could be attributed to the half-developed regulation, which was only promulgated in 2017 (Laws and Regulations Database, 2017); its development and preparation still require improvement. However, it is warranted to conduct an in-depth discussion and an evaluation of the structure and hierarchy of research ethics and power issues, as they are usually intertwined. As the ethics became crippling when it
came to bureaucratic barriers or administrative incapability, I inevitably thought, ‘whose field?’, ‘whose ethics?’ It is believed that collective consent is significant to the indigenous population, and so the CIP cooperated with and enabled the REC institutions to evaluate the characteristics of the research project for them. However, the ethics issues turned out to be forsaken due to administrative incapability. In this instance, the indigenous-specialised process seems to have been a by-product rather than an integral part of the ethics approval.

Furthermore, I also consider it to be a flaw that non-foolproof regulations are applied to divide research into two types: human-body-related and non-human-body-related research. As stated by (Bauman, 1993, p. 10), "the foolproof – universal and unshakeably founded – ethical code will never be found". Prefixed and structured field roles are the main targets of most protocols and research governance (Hammersley and Traianou, 2012). I consider that protocol should also refer to proper conduct, since a particular group of people, institutions and committees are authorised and empowered to take control and scrutinise the integrity of the ethics.

**Balancing the commitments to ethical ethnography**

Ethnography can be among the most ethical forms of research, as it conveys adequate respect for social actors (Atkinson, 2015). Compared with the regulation usually predicated upon a positivist stance, ethnographic study lays its predication on a set of commitments and values that render it much more sensitive to the interests of participation. In this regard, Atkinson (2015, p. 183) addresses three issues that need to be considered: "(1) giving adequate analytic attention to muted, marginal or subaltern social categories; (2) ensuring that the rhetoric of publications does justice to the reported actions and actors; (3) ensuring that research promotes the interests of social justice.” As this study essentially intended to understand the experiences of care users from different ethnic groups, the research lenses targeted a population situated in disadvantaged circumstances in the context of the social and healthcare
structure. To ensure their voices would not be muted and would be equally represented, I carried out a series of reflexive practices, from research design to data analysis, in order to prevent research biases. To minimise the risk of participants becoming more vulnerable through participation in this study, I respected the autonomy of the indigenous people. I contacted the relevant authorities, including the gatekeepers and ethics-accountable institution, to strengthen the ethical considerations of the research. Research ethics itself is a socially constituted and situated field (Ryen, 2004). Although the ethnographic commitment conflicts with the philosophical base of the hard, pre-fixed ethics protocol, I made maximum effort to comply with the ethics application process, consulted with the relevant units to negotiate access, and provided situational responses in order to reconcile and make less harmful decisions.

3.10 Limitations

Reflecting on the context-specific nature of this ethnographic work, I have identified the main limitations relating to the study process, methods of access and study sample. The first limitation is that I was the main research instrument of data collection and analysis. I am also an inexperienced researcher who was conducting a study by myself for the first time. This lack of experience influenced the extent of my sensitivity to clues and my tendency to delve into the core focus. It may also have led to a too subjective and shallow view, considering the underlying disadvantages. In order to minimise potential researcher bias, various forms of triangulation were applied; I sourced from different perspectives with different collection methods, and validated between themes and theories. Moreover, my regular supervision meetings also helped me to minimise potential biases and supplement shortcomings.

The second limitation is related to the pathways in accessing the field. I entered the indigenous region through formal contact with the local government sector, while I approached the urban-based and non-indigenous
participants through connections in service provider organisations. Both methods were carried out through the supervisory sectors, and the research participants might have felt pressure from authorities to participate in this study, which probably made their expressions shallow in terms of reflecting the actual situation. It is conceivable that the participants gave tailored answers that highlighted the positive and downplayed the negative aspects. Having an awareness of this possibility, I adopted a prolonged engagement in order to establish a reciprocal relationship with the participants and maximise the chance of ascertaining their authentic perspective. Furthermore, I carried out persistent observations in order to validate multiple data sources and comprehend them in terms of the real scene, as detailed in section 4.7.1.

The third limitation relates to the sample. Due to the difficulties in accessing and recruiting adequate numbers of indigenous people, I only managed to sample LTC users who were stroke survivors receiving services in the residential setting. My study did not capture the life trajectory of care users who had other long-term conditions and opted for different patterns in terms of interacting with the LTC system. Moreover, I only interviewed care users; conversations with the frontline workforce were only collected informally. Hence, stakeholder positioning at different levels of the LTC system was not covered by this study. Although the illness trajectory for other users may be dissimilar, this study does provide a detailed explanation of LTC service engagement by discussing the social relationship among individual, system, collective and place. Thus, it can facilitate an understanding of the individual situation with regard to seeking resources from the healthcare system in different contexts, facilitating and constraining factors, and conceptualising the context/situation.

Finally, my research aimed to explore the operation and utilisation of LTC services from the perspective of service users. The best efforts were made to enrol care users from different ethnicities and from three geographic and sociocultural backgrounds. This ethnographic study could be challenged as
context-specific and involving relatively small-scale populations, compared to the complex population of the nation, which comprises 16 tribes of indigenous and Han Chinese people, among others. However, “qualitative researchers argued that findings of qualitative study aim to generalise to theory rather than generalise to a wide context or populations” (Bryman, 2016, p. 391). I have applied the ethnographic qualitative methodology in order to contextualise the way a nationwide policy was implemented regionally in the urban context and on the contextual scale of the indigenous tribes. This study has managed to develop the conceptual implications regarding “integrated individual needs in a healthcare system” in structuration theory. The concepts are grounded in empirical data, but conceptualised in structuration theory, which works at a higher abstraction level than the concepts. The theorised insights embedded in the sociological framework do have the potential to make the overarching findings transferable and extend them to other areas in further studies. Therefore, the concepts could be extended beyond a given context and tested or applied in other studies in practice, through the thick description elaborated in the analytical process (see section 4.6).

3.11 Summary of the chapter

This chapter has justified the rationale for a focused ethnographic approach as the methodology of choice for this study. Following the connotations of social constructionism, “Individual’s biographical continuation”, “Integrated LTC system”, and “Culture of adapted LTC practice” were identified as the principal conceptual categories in the central theme: the LTC system situated in a three-level context. Additionally, the abductive process strengthened my interpretation and refined the theoretical construct of social relations with refined concepts. I have captured the social relation between each individual and the LTC system with the concepts of individual-collective, individual-system, identity and place. These concepts, interacting along the time-space strands, illustrate the biographical continuation of the post-stroke recovery trajectory. The reflexivity, ethical considerations, quality and limitations of this study have been considered in order to demonstrate the trustworthiness and
transferability of the research. In Chapters four and five, the main findings of my analysis will be elaborated upon with evidence from the raw data. Each category and themes will also be discussed, along with the literature.
Chapter 4: Status passages in the post-stroke recovery trajectory

4.1 Introduction

This study aims to explore the experience of utilising the long-term care (LTC) service from the perspectives of stroke survivors and their family caregivers in the Taiwanese community. Given that the Taiwanese community consists of diverse populations including indigenous and non-indigenous people, insufficient attention has been paid to the specific healthcare needs of people residing in different contexts. My study aims to shed light on this under-researched area.

In this chapter, I contextualise findings as derived from my inductive-abductive analysis in a three-dimensional structure, constituted by post-stroke recovery trajectory, place attachment, and power of coordination. A post-stroke recovery trajectory represents a lived form of time. Thus, each dyad of stroke survivor and family caregiver has their own trajectory, reflecting distinct coping strategies, interactions with the healthcare services, and status passaging over time. Place represents a lived form of space available for or being used by the participants as meanings are attached to a particular spatial setting. Power becomes visible, as it shifts between social actors when individuals attempt to coordinate lived time with lived space or to coordinate care needs in a family with healthcare systems within the social structure.

These three dimensions chime with the propositions of Structuration Theory introduced by Giddens (1984), indicating that the social world is embedded in the spans of time-space, and that social contexts are closely bound up with the social relations and power structure generated in it. The social relations that occurred in the social structure enabled status transition in the post-stroke recovery trajectory, which is inspired by the concept of biographical disruption coined by Bury (1982) and resonant with the Status Passage Theory developed by Glaser and Strauss (2011). These theoretical perspectives have
underpinned this study’s narrative that people’s dynamic interaction in the social structure is a construction process of the life course. These theoretical perspectives, extended from the literature, were adopted in the abductive analysis phase and strengthened the findings presented in the context. Section 2.7 elaborated on the rationale for drawing on these theoretical underpinnings. Section 3.7.4 explained the adoption of theories in abductive reasoning.

As family dynamics play a crucial role in a life transition of individuals living with long-term health conditions (Kaakinen et al., 2015; Shajan and Snell, 2019), it would make the post-stroke recovery trajectory more intelligible and tangible if the family caregiving context in Taiwan were presented. In this chapter, I first explain the family caregiving system by applying Giddens’ (1984) concept of the duality of structure and agency. Second, I depict the post-stroke life transition as a recovery trajectory that reflects on the needs and expectations of the dyads by aligning with the concept of biographical disruption (Bury, 1982) and status passage theory (Glaser and Strauss, 2011). I go on to analyse the engagement of the LTC system along the recovery trajectory in order to address the first research question:

- How does the current long-term care policy meet the needs and expectations of stroke survivors and family caregivers experiencing LTC from different ethnic or cultural backgrounds?

Following this, in Chapter 5, I continue to show the engagement of the LTC system in arguing for the post-stroke recovery trajectory by looking at articulations of time, space and power, wherein the macro environment for policy implementation, the meso context for system organisation and the micro context for adapted practice join together to address the second research question:

- What are the facilitators of and barriers to long-term care for stroke survivors and their family caregivers experiencing care in their community?
4.2 Context of Taiwanese family caregiving and intergenerational relations in the community

Post-stroke life often occurs in a family caregiving system resulting from the agency of intergenerational relations in families and societies. As Giddens (1984) has argued, structure and agency demonstrates an interwoven and mutually influenced conjunction between social properties and human actions. The structural properties in the family caregiving system could be conceptualised as the illness type (Newby, 1996), the impact of the on-going recovery phase for individuals, and the role of individuals in the family and society (Rolland, 1987; Moore et al., 1993). The structural rules, meanwhile, involve cultural norms and social phenomena related to familial obligation. The interplay among these components forms part of the family caregiving system in Taiwanese society.

4.2.1 Filial piety enables the agency of intergenerational support

In the context of Taiwanese society, the family caregiving system reflects familial obligation across generations, which stems from the cultural norm of filial piety. Under the broad construct of familism, filial piety as a moral concept or virtue refers to children’s ability to show care and respect to their parents, which has helped form the family caregiving system for generations in the Taiwanese community (Hsu and Shyu, 2003; Hsu, 2007; Chen, 2008; Chen et al., 2016) as well as in some other Asian countries (Lai, 2010; Ng et al., 2016; Zhang, 2016; Peng, 2018). Filial piety has been passed on as a principle of mutual familial support and caring obligation in the intergenerational context of the Taiwanese family caregiving system. A reciprocal relationship means that adult children, as caregivers, can support their parents and satisfy their daily needs as an expression of their gratitude towards their parents for bringing them up (Finch et al., 2003; Chen et al., 2016), especially during their old age when they are ageing and dependent on the care provided by others. The data excerpts that will follow show how cultural beliefs and filial piety influenced adult children in taking on the responsibility of being caretakers for their
parents. Table 4.1 outlines the codes and pseudonyms of the stroke survivors and family caregivers; I will explain the findings using their narrative excerpts.

**Table 4.1 Codes and pseudonyms of the research participants**

*‘S’ refers to stroke survivor and ‘F’ refers to family caregiver*

<table>
<thead>
<tr>
<th>Mountain-based indigenous group</th>
<th>Urban-based indigenous group</th>
<th>Non-indigenous group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>Pseudonym</td>
<td>Code</td>
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<tr>
<td>--------</td>
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</tr>
<tr>
<td>A1S</td>
<td>Andrew</td>
<td>U1S</td>
</tr>
<tr>
<td>A1F</td>
<td>Georgia</td>
<td>U1F</td>
</tr>
<tr>
<td>A2S</td>
<td>Bridget</td>
<td>U2S</td>
</tr>
<tr>
<td>A2F</td>
<td>Deborah</td>
<td>U2F</td>
</tr>
<tr>
<td>A3S</td>
<td>Yuri</td>
<td>U3S</td>
</tr>
<tr>
<td>A3F</td>
<td>Molly</td>
<td>U3F</td>
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<tr>
<td>A4S</td>
<td>Novia</td>
<td>U4S</td>
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<tr>
<td>A4F</td>
<td>Beryl</td>
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</tbody>
</table>

The stroke survivors and their family caregivers co-experienced the life transitions, as family support is the preferable resource for people living with health issues. The default obligation of caregiving in families was formed by the linkages across familial generations. Data from family caregivers residing in three-generation households in the non-indigenous region showed how they perceived the family care across generations based on filial piety. For example, in one family, the family caregiver, Louis, revealed that the stroke survivor, Leonard, was not seen as a responsible father in the family. He neither fulfilled his expected obligation as a father nor showed loyalty to the family during the son’s childhood. However, the son, now the family caregiver, still regarded it as his obligation to support his father in his old age. Louis expressed how filial piety had driven him to fulfil the family caregiving responsibility:
“People are all gaining age, turning old… I also need my son to look after me when I turn old, just like what we say in Mandarin, the filial piety. […] What happened before resulted in the present. It might not be right to say that, but I think he has got his karma, the stroke attack… and then, I should look after you (him), it is what I need to do (as a son). Although he is capricious and irritable because he is sick, but I think it is still ok, still acceptable.” (Louis, non-indigenous family caregiver, son)

Louis attributed his father's illness to karma, indicating that ‘what happened before resulted in the present.’ However, it did not conflict with his obligation as a son, which is relevant to the concept of filial piety, as is his expectation that his son will care for him in turn when he becomes old. Despite his father not following the intergenerational obligation to take care of his own children, Louis still felt that he was responsible for caring for his father, under the moral concept or cultural virtue of filial piety.

4.2.2 Familial belief: interlinked between stroke survivors and family caregivers

In addition to filial piety, which relates to the family caregiving relationship between parents and children in particular, in this study the individual lives of the stroke survivors and family caregivers also involved the societal expectation constituted by familism. Familism refers to a commitment, affection, reciprocity and responsibility to put family needs ahead of individual development (Sayegh and Knight, 2011; Campos et al., 2014). In this study, the belief in familism is displayed not only in kinships between parents and children but also between siblings, spouses and cohabitants; they may form a nuclear family, three-generation co-residence family, extended family or cohabitant relationship. The dyads believed that family support was at the forefront of resources for the stroke survivors.
One dyad, Driscoll and Delia, expressed their preference of being looked after by their family, perceiving family-provided care to be more dedicated. Delia stated:

“She (the residential care attendant) is not our child and she is not dedicated that much. […] Our children would do it with all their heart.” (Delia, non-indigenous family caregiver, wife)

Driscoll’s expression echoed his wife’s opinion. As a stroke survivor, he also felt more comfortable in voicing his care demands to his own family. He stated:

“I would prefer to be cared for by one of us.* […] (Because) I could speak out more immediately and freely to my own children.” (Driscoll, non-indigenous stroke survivor).

*[NOTE]: In the dialect, a mixture of Mandarin and Taiwanese, “one of us” indicates a person from one’s own family, an insider or an acquaintance.

4.2.3 Family caregiving system in the indigenous population

I found no difference in the family caregiving system between the indigenous and non-indigenous populations. The excerpts below show that the responsibility for providing mutual support to family members was also present among indigenous families. The relationship of caretaker and dependent member in the indigenous households included not only parent-children relationships but also siblings, spouses and cohabitant relationships. Deborah, who had been a care worker in hospitals before caring for her parent, perceived that taking the attitude of treating patients like family was essential to providing good care. She said:

“Like me, my way of looking after the patient is letting nature take its course. Anyway, everyone I’ve taken care of is all my family and needs to be treated carefully, and that’s it. If you don’t do this way, positioning the mind right, you might treat them badly.” (Deborah, indigenous family caregiver, daughter)
Other respondents from the urban-based indigenous group echoed the significance of family responsibility in supporting care-dependent members in the household. Prima and Bob respectively stated:

“My attitude is that I am the elder sister and I certainly have to look after her since our parents passed away.” (Prima, urban-based indigenous family caregiver, elder sister)

“Our children are all married and have their own family. They come back only in the Lunar New Year holiday, so I take the role.” (Bob, urban-based indigenous family caregiver, husband)

Maxwell, who was in a cohabiting relationship, considered himself responsible for caregiving even though he found it burdensome and exhausting. He felt guilty and angry with himself for thinking about giving up on his partner. He described his dilemma thus:

“She cannot fetch or hold anything, also [there is] changing diapers, and so on. Moreover, I need to prepare for her wherever we go. However, I am also in this situation (referring to his own reliance on a walker as a carer). Certainly, I am obliged to do that but I am grossly tired. However, it’s not right to give up on her.” (Maxwell, urban-based indigenous family caregiver, cohabitant)

In this study, a variety of familial relationships were involved in care provision, including siblings, spouses, adult children and cohabitants. Everyone who had taken on a family caregiving role convey a solid obligation to support their family member during illness. In addition, the family remained the crucial support for both the indigenous and non-indigenous people living with long-term health conditions.
4.2.4 How are intergenerational relations in society and families intertwined?

The research participants’ perceptions of care were considerably intertwined with familial notions including filial piety and belief in the concept of family. In addition to preferring family members as caretakers, the core values of familial caring profoundly shaped care users’ expectations of care and services received outside the family. The extracts above show that the family was considered a crucial resource and also the most preferable and reliable support when people were ill. However, the family caregivers in my study also showed that the structure and function of mutual familial support have been changed by changing social phenomena, which is an embodiment of the increasing number of care-dependent people and the decreasing number of people who can provide care in the household (Dykstra and Komter, 2012; Karpinska et al., 2016). Increasingly, women are entering paid work, as it is an economic necessity for families. The responsibility of being an earner in today’s society makes them less available for caregiving at home. The capacity of the family caregiving system has decreased accordingly (Hsu and Shyu, 2003; Gans and Silverstein, 2006; Lee, 2007; Bennett et al., 2019). This situation caused Clara to feel anxious about leaving her stroke survivor husband alone at home. Clara explained her worry thus:

“What if he falls… when he stays home while I go out, because I deliver the newspapers in the morning, what should we do if he falls at home without being noticed? No one is home. The children have to go out for work and earn money after all.” (Clara, non-indigenous family caregiver, wife)

Clara continued to share her opinions about the way societal transformation has constrained the capability of intergenerational support in the families. As she described:

“The contemporary children (the adult children generation) are all very busy, (they) need to work, take care of their own families. They probably could only take care of themselves so we can’t say that they are not filial.” (Clara, non-indigenous family caregiver, wife)
The excerpts demonstrate that the associated generational transformations in society have weakened the default obligation of mutual generational support in families, including the family caregiving system, which has played a significant part in Taiwanese society. This reflects a tension between society and family over competing human resources.

**4.2.5 Structure and agency of the family caregiving system**

**Figure 4.1 Family caregiving system in the Taiwanese context, applying Giddens’ (1984) structure and agency duality model**

Family caregivers take on multiple responsibilities for care in the family and work in society. Generational relations in societies and families are constrained and have enabled the capacity of the family caregiver system in Taiwan, which can be conceptualised through the duality of structure and agency (Giddens, 1984). In terms of the structure and agency of the family caregiving system in Taiwan (see Figure 4.1 above), the generational relations in families, formed by familial belief and filial piety, enable the agency of intergenerational support. On the other hand, the generational relations in society, embodied as social...
transformation, constrain the capability of modern-day family caregiving, since a primary caretaker often cannot afford to provide care within the family and take on a paid job in society at the same time (Finch et al., 2003; Dykstra and Komter, 2012). This fact conforms to the division of intergenerational relations into societal and familial aspects (Bennett et al., 2019). From the familial perspective, the types of generational relation in this research included parents-children, adult children-young children, grandparents-grandchildren, and sisterhood. However, “Generation is a wider window of time than precisely the same year of birth” (Bennett et al., 2019, p. 4). Mannheim (1970) describes the social phenomenon of a generation as a particular kind of identity which contains an age group and is related to location. It represents an inventory of experiences absorbed from environments and generated within social and historical intercourse. From the perspective of society, a generation is identified as a group of people sharing a collective identity and belonging within a location. In the societal aspect, the transformation of the household structure as a consequence of the growing older generation and the declining number of children in each family, along with women devoting themselves to the labour force, weakens the caregiving capacity in the familial aspect.

The generational relations in society and families necessitate that family caregivers distribute their time, energy and capabilities in order to find a trade-off among their multiple responsibilities. This kind of multi-tasking is more common among female caregivers, who are more likely to be the primary caretaker in families that need care (Gallicchio et al., 2002; Alpass et al., 2017; Mehta and Leng, 2017; Yan et al., 2019). Their role in society constrains their capability to respond fully to the care needs of the stroke survivors in their families (Doty et al., 1998). The transformation of social phenomena has weakened family caregivers’ capabilities to continue providing dedicated care to post-stroke family members when the caregiving timeline expands into a long-term arrangement. Filial piety and socio-structural transformation undergo an intersection, where a different form of relationship is required. In this regard, stroke survivors and family caregivers inevitably come to a
transition and alter the caregiving pattern by seeking support from the healthcare system. It is at this moment that the LTC system is often brought into the family caregiving system. The alteration process will be discussed in section 4.3.4.

4.3 The post-stroke recovery trajectory

I have explored post-stroke life by understanding the individual’s embodiment of biophysical and psychosocial states. The research participants’ self-perceived life statuses, as derived from the data analysis, have enabled me to delineate the post-stroke recovery trajectory. Figure 4.2 below shows a diagram of one of the descriptive categories from the data analysis, the individual’s post-stroke recovery trajectory and sub-ordinated codes from empirical data. The figure shows how I have been able to examine the timeline after a stroke occurrence; this has been helpful in analysing the features that characterise post-stroke life.

Figure 4.2 Diagram of themes and codes from analysis
In Figure 4.2, the first column displays seven broader codes representing the status of the stroke survivors and their family caregivers in post-stroke life. These statuses are formed by the subordinated codes elicited from the research participants' narratives, which are attached in the corresponding row below each status. The codes from the dyads’ post-stroke experiences consisted of the way they felt, the way they lived their life, the way they responded to each stage, and the meanings and expectations that had been rendered at the moment of every stage. These statuses transitioned as they were fuelled by expectations and positive behaviours and could also reverse by unsuccessful practices. Through perceptions, expectations and practices, I was able to depict the post-stroke life as an ongoing and dynamic trajectory that involves four mindsets and three passages, viz.: (1) a sense of loss; (2) acceptance passage; (3) a sense of interdependence; (4) alteration passage; (5) a sense of independence; (6) identification passage; and (7) wellbeing state. This trajectory transitions from one mindset status to the next under the momentum statuses (Glaser and Strauss, 2011), i.e. the passages of acceptance, alteration and identification.

Mindsets are psychological statuses held by individuals that reflect their perceptions of their physical (lived body) and social identity on the trajectory (see Figure 4.3 below). The loss of physical control and social role brought about by illness can lead to loss of self (Charmaz, 1983; Ellis-Hill and Horn, 2000), which echoes the concept of biographical disruption introduced by Bury (1982) and marks the start of the trajectory. The stroke survivors had lost parts of their body control exerted by their pre-stroke body and were attempting to reshape and re-identify what had emerged post stroke. While loss of self reflects biographical disruption, the regaining of self sets off the process of biographical continuation (Becker, 1993; Cott et al., 2007). Meanwhile, momentum statuses are transitioning passages driven by the purposive actions and behaviours (Glaser and Strauss, 2011) of the stroke survivors when they sensed the loss or obtainment of body and identity.
These statuses have been charted in a sequence (see Figure 4.3), but do not always proceed in the same sequential order. When the stroke survivors and their family caregivers discussed their post-stroke life, they mentioned not only the physiological changes but also their perspectives of psychological and sociological needs as they established self-identity and relationships between themselves and their environments (Wolfenden and Grace, 2012). Moreover, the status passages occur under actions directed by socio-psychological needs and socio-structural transformation in the context of family caregiving. Thus, the experiences of the dyads helped me understand their post-stroke lives in a trajectory that was characterised by: (1) ongoing and dynamic movements; (2) interlinked co-experience; and (3) mutual influence on each other. The mindset status proceeded and/or reversed along the trajectory, while the dyads attempted to transform expectations and consciousness into actions.
Figure 4.3 Analytical forming process of the post-stroke recovery trajectory

Category
1. sense of loss & worry
   1.1 physical incapability
   1.2 distressed about role transformation
2. acceptance passage
   2.1 hope to return to normal life
   2.2 rehabilitation are important
3. sense of interdependence
   3.1 time was combined with family caregiver
   3.2 life was combined with family caregiver
4. alteration passage
   4.1 expect the stroke survivors can be more independent
   4.2 expectation for a new relationship
5. sense of independence
   5.1 being independent of overcoming challenges
   5.2 me time to do my matters
6. identification passage
   6.1 applying self-efficacy
   6.2 establishing self-identity
7. Well-being state
   7.1 think positively
   7.2 feeling good
4.3.1 A sense of loss and worry

The phase of biographical disruption, featuring and occurring within the hospital facility, starts from the stroke onset, when patients experience a sense of loss and family caregivers experience a sense of worry. The sense of loss comes from the realisation that the stroke survivor cannot continue life as they did before the stroke due to their physical incapability (Burton, 2000; Wolfenden and Grace, 2012). The sense of loss involves a psychological reflection on the loss of body control that is part of the self, as well as a somatic sense about the body (Bury, 1982; Kelly and Field, 1996). As Driscoll described:

“I could no longer do everything. I lost my freedom. I cannot get in, not able to walk inside (the room). I need other people to support [me] by my arm, or I will fall down.” (Driscoll, non-indigenous stroke survivor)

Stroke occurrence led to spiralling consequences in the stroke survivors’ lives. They could not sense their ‘self’ when they attempted to interact with people and display their role functions in everyday life. Stroke survivors talked about the frustration of realising their physical incapability, the role transformation in their household, and the embarrassment of socialising. Abilities that they had used to build their self and define their identity were no longer available to them. Andrew felt that his role as one of the breadwinners in the household was disturbed by the stroke occurrence:

“Sometimes, sometimes I felt unwell in my mind… (in terms of) the daily living condition of myself. Certainly, there are barriers in my life. I couldn’t work and couldn’t make money.” (Andrew, indigenous stroke survivor)

The lack of a sense of control over the body led to a crumbling away of the former image of self and identity, as an equally valued new form was not developed concurrently (Charmaz, 1983). The discrepancy of self-image resulting from bodily limits also affected relationships and resulted in role transformation in social circumstances, which gave rise to a sense of loss for the stroke survivors. Hank described this sense of loss, reflecting on his loss
of body control and social identity when he met up with a group of people he had known before the stroke; he perceived a stark contrast between his healthy old friends and his own inconvenience. He said:

“They (his friends) were good to me before. Now when we went out and got together, it became the way that they were all well. I saw them walking (well), but I couldn’t. I was inconvenient and, thus, felt sorry for them.” (Hank, urban-based indigenous stroke survivor)

At the stage of loss and worry, the stroke survivors were still hopeful of resuming their pre-stroke life and family relationships. They tried to overcome bodily limits on their own without burdening their family, which highlighted their expectation that they would maintain the same status as before the biographical disruption. Molly explained how, several times during the night, her mother-in-law fell over but did not notify the family or ask for help:

“She has fallen down twice according to my memory… (it happened) at midnight. We were annoyed that she never called us (for assistance). She might have fallen down more than twice. I came to know when I heard the clatter of chair movements in her room. I was woken by that sound. I opened the room and saw her making attempts to get up by grasping the arm of the chair, but she couldn’t. The chair fell and she kept getting dragged. She tried to stand up but couldn’t make it.” (Molly, indigenous family caregiver, daughter-in-law)

The stroke survivors made efforts to resume physical ability as the pre-stroke status; however, these aspirations were not easy to meet. Tension between the dyads in terms of deciding how they would carry on with their lives indicated different ways of recognising the shattered wholeness of body, self and identity in the domestic context. Although the stroke survivors expected to maintain their previous lives and continue to perform their roles, their family caregivers expressed worry over the accidents that had happened and might happen again because of the survivor's physical predicament. Julian tried to fit his role into the family and support their daily living in ways of which he was temporarily capable, whereas his father was more concerned about his safety than with needing assistance. Consequently, the father did not compliment him for the
assistance he gave, and that disappointed Julian. He described his father’s reaction when he tried to share the tasks of the morning routine:

“For instance, there is a convenience store close to my house. My father is usually busy in the morning with domestic chores like boiling water, driving the children to school, and buying the newspaper. So that, once I thought… I thought that I could walk, so I went out. I walked to purchase a newspaper for my father and returned all by myself. After being able to complete the task by myself, I felt good at that moment. But, instead, I was… when I came back… he (my father) didn’t encourage me, instead, he… he blamed me, ‘What if you fall when you walk alone?’ I felt uncomfortable for not being encouraged but scolded instead.” (Julian, non-indigenous stroke survivor)

When the dyads experienced the disruptive event, they defined the way that the disturbance of the stroke would affect their present hopes and future expectations of full recovery and being independent enough not to inconvenience family. According to their narratives, the loss of body control, self and identity marked a biographical disruption (Bury, 1982). The different ways that the dyads assessed that the physical limitation signified their individual paces as they moved through the different status passages in an effort to redefine their self-identity after the stroke.

4.3.2 Acceptance passage

While the acute symptoms stabilised, the dyads recognised the deficit of physical ability and residual functional limitation following the disruptive event. The survivors and their family caregivers explained in the interviews that their expectations at this stage were to recover quickly and live a normal life, with high hopes of a full recovery. However, this expectation changed over time, and they realised that a full recovery might not be possible. Consequently, they focused on reshaping a renewed life in the later stages of the trajectory. To fulfil their expectations, the dyads therefore took action by attaching great significance to exercise and conceptualised their acceptance through the action of attending the rehabilitation scheme. This practical action became the
focus of their post-stroke life, which demonstrated their acknowledgment that it was probably a permanent change, but also enabled them to build their expectations of living a renewed life. Therefore, the temporality of acceptance became a momentum enabling them to implement expectations into strategic practice, constituting a passage from the previous temporality of biographical disruption to the next temporality of seeking continuity in post-stroke life. Transition between the temporality of sense of loss and the acceptance passage was driven by individuals' intention towards recovery and thus their engagement with rehabilitation, as well as the facilitation of their treatment regime in the healthcare system, which fell under the post-acute care (PAC) programme. The passage of acceptance was undergone through the co-effects of individual and systematic forces, which determined the success and the transition time.

**Individual-level passage**

Glaser and Strauss (2011, p. 77) state that “no matter how scheduled and prescribed the passage, acceptance as process leads the passage and agent to be ever alert to emerging changes that may modify its direction and temporality”. Consistent with Glaser and Strauss (2011), my findings show that acceptance formed a momentum for the dyads to move along the trajectory and a link helping them to seek continuity in post-stroke life between their past and future self-identity (Rolland, 1987). Several stroke survivors recognised the significance of exercise in their daily living as a strategy for retrieving body sensation. Novia said:

> “Well… it’s been a bit better. I need to exercise because I got sick… Sitting still there was doing nothing good.” (Novia, indigenous stroke survivor)

Andrew also attached importance to exercising and felt as though he was investing in the healthcare services by supporting his body’s recovery. He recounted:
“These two parts of care services (vital signs check-up) can be added up to the timeslot of exercise, because exercise is the most important. [...] My expectation is to recover sooner, to recover soon.” (Andrew, indigenous stroke survivor)

Julian explained what he had expected in terms of discharge planning:

“Just returning home, returning to normal life would help recover sooner since that would mean doing things by oneself. Otherwise, people would become too dependent and not able to improve if they usually ask for help from people.” (Julian, non-indigenous stroke survivor)

Their active participation in rehabilitation was driven by body image and the desire to recover quickly and return to a normal life. This agency was motivated by individuals’ expectations and influenced their behaviours in terms of actively engaging in exercise with the support of a rehabilitation programme from the healthcare system. The coordination of individual expectation and healthcare resources enabled the passage of status transition.

**Systematic level passage: engagement with PAC programme**

In addition to the dyads’ desire to return to normal life, which motivated the practice of rehabilitation, the post-acute care (PAC) programme, an in-patient rehabilitation programme, also shaped the process of acceptance on a systematic level. Concurrent with the expectation of returning to normal life, this programme played an important role at this stage by directing the passage and forming a context for post-stroke knowledgeability development.

The PAC programme gives stroke survivors the opportunity to receive acute treatments and intense in-patient rehabilitation schemes by aligning hospitals together. Due to the limited length of hospitalisation (maximum 28 days) under the regulation of National Health Insurance (NHI), patients need to transfer to other hospitals if they do not have critical reasons for extended hospitalisation in the same hospital. The PAC programme operates a scheme for stroke survivors to undergo long-term in-patient rehabilitation in their prime time (the
first six months) for physical recovery. The eligibility criteria requires stroke survivors to be: (1) within a month of the onset; (2) in a stabilised medical condition; and (3) possessing rehabilitation potential according to the assessment of the medical team. If the criteria are met, the stroke survivors will be referred to the programme by the physicians. It operates in three-week blocks; the therapist re-evaluates the eligibility of the stroke survivors for extension or conclusion of the scheme once every three weeks. Each patient can spend a maximum of 12 weeks in a particular hospital. Therefore, patients transfer to another hospital after three months of hospitalisation and take turns attending the hospitals participating in the PAC programme.

The PAC programme enabled the patients to have more extended hospitalisation to accommodate their long-term intensive rehabilitation needs within regulation limits. During the rehabilitation process, the stroke survivors would still require assistance in their daily living. However, the PAC programme mainly focused on providing the venue and health professionals for accepting rehabilitation. The health professionals in the hospital would only be available to provide health care (such as rehabilitation instruction or medication administration), while the social care in daily assistance relies on the family. Therefore, the family caregivers are required to be involved in the PAC programme to support daily living.

Glaser and Strauss (2011, p. 57) elaborate that the “shape of a status passage is determined by combining its direction and temporality”. They go on to argue that “a principle theoretical problem to consider in regard to shaping the passage consists in its control: who is in control and who is vying for control” (Glaser and Strauss, 2011, p. 58). On the structural level, stroke survivors tend to be seamlessly directed to a PAC programme, so the passagee and correlated agents follow the structured intensive rehabilitation scheme after the stroke survivors have gone through the crisis phase and are stabilising in order to transition to a chronic phase along the illness timeline. The PAC programme structurally builds a passage with a prescribed direction for the
stroke survivors and family caregivers while they are in the temporal stage of disruption.

It nudges the passage from disruptive temporality to acceptance by carrying out treatment and providing a context where the dyads can receive information from other participants and internalise the illness and the changes that they have experienced. The PAC rehabilitation scheme in Taiwan is evidenced to be beneficial to functional improvement and supportive of patients’ return to their home (Lai et al., 2017; Chien et al., 2020). The dyads’ statements further revealed the benefits of PAC rehabilitation in terms of enabling the survivors to understand their physical incapability, accept the changes in their social roles, and proceed to the next mindset status along the illness trajectory. The shaping of a passage continues when the balance of control between agent and passagee can be maintained (Glaser and Strauss, 2011). The PAC programme demonstrates the mutually influenced characteristics between human agency and the healthcare structure. Agency exerted on the individual level between care provider and care recipient, as well as system organisation, can transition stroke survivors from receiving acute care in a crisis phase to post-acute care in a chronic stage, and prepare them for future community life after discharge. The PAC programme shapes time and space, coordinating the recovery time of the individual patient and their rehabilitation time in the system. In addition, it creates time-space for survivors to adapt to their sense of loss and to realise that some of their hopes about returning to their pre-stroke life state are unrealistic, as some physical changes are unconquerable and some roles in social relations cannot be maintained (Carod-Artal et al., 2005; Brodaty et al., 2007; Kitzmüller et al., 2012).

The acceptance of chronic illness can be understood as an embodied practice of adjusting hopes and expectations to a new reality, which here refers to carrying on through life with a changed body. In this sense, each dyad entered a new life after the stroke. Clara explained how her post-stroke expectation for
the stroke survivor had transformed from full recovery to adaptation, through a passage of full acceptance:

“At the period of hospitalisation, (I) had seen people who utilise the Rehabus and the carer. (I decided that) I absolutely gave him no chance to stay home gloomily. I also worried he would become dull-witted, therefore, he definitely would have had to go for rehabilitation even if it has been in the midnight no matter how. [...] I don’t really have any requirements for him, just seeking not to degenerate. That would be all right. I mainly meant to let him go there and see the crowd, make some friends while everybody knows each other.” (Clara, non-indigenous family caregiver, wife)

Drawing on the experiences that Clara observed during the hospitalisation, she started to map out her post-stroke care plan by learning from other stroke survivors and other patients. This highlights that rehabilitation and/or the medical healthcare environment is a social environment where patients and families can learn from each other, and even provide peer support. Clara further explained:

“People there kept discussing plenty of information... such as how [a] particular carer applies the care, how they assist and compare mutually. ... I knew this (the LTC services) already. At that time (when we stayed in hospitals), I thought that I must apply for the services with the Rehabus shuttling back and forth, definitely apply it, apply for him to go to rehabilitation.” Clara (non-indigenous family caregiver, wife)

This also shows that, under the PAC programme, stroke survivors and their families from the non-indigenous region usually stay in hospital for more than a year in order to receive long-term, intensive in-patient rehabilitation; as a result, this period could be regarded as a sound and proper time for introducing/engaging with LTC services. Because of their regular, repeated access to LTC service providers, families are able to establish an in-depth understanding of the LTC service from what they observe and what they are told by other peer groups.
Difficulties with acceptance of transition

The success of transition and the length of time spent attending the PAC programme depended on the dyads’ decisions, the health professionals’ legitimacy and the communication between them. I found that inadequate communication led to poor cooperation between the stroke survivors and therapists, which often caused the stroke survivors to drop out of rehabilitation. Another reason was the distance between the healthcare facility and the caregiver’s place of work; one urban-based indigenous stroke survivor left the programme and was discharged home earlier than scheduled, as their family caregiver had to return to work.

*Inadequate communication between the care provider and care recipient*

Andrew, a stroke survivor in the indigenous region, left the hospital without the physician’s consent because he felt that the post-stroke care plan was not suitable for him, as it did not fulfil his expectation of rehabilitation. He felt that the health professionals could have been more cooperative and communicative with him, and he was dissatisfied with the timeline that the therapist had set out. In this case, the stroke survivor’s expectation and the healthcare professionals’ care scheme did not match well enough to support the passage of acceptance. Andrew recounted his experience of hospitalisation:

“They implemented the treatment and care in light of their thoughts without communicating with the patients; [this] has brought plenty of problems. I felt it is important to enhance the exercise about the joints after the stroke to enable… to recover its mobility. I told them at that moment, however they didn’t cooperate with me; therefore, I didn’t feel ideal to be there, and thus I ran away. […] (The therapist) said that ‘at the earliest, you might be able to recover in three months.’ But, I was not happy about that so that I ran away.” (Andrew, indigenous stroke survivor)
**Distance between livelihood and healthcare facility leading to early discharge**

As explained previously, the family caregivers needed to participate in the PAC programme because the hospital settings mainly provide treatment and healthcare venues for rehabilitation, but do not have sufficient human resources for daily living and social care. However, the hospitals involved in the PAC programme were primarily located in the urban plains, far from the residence of the indigenous households in the remote mountain area. In this respect, the location of residence also influenced the chance of receiving long-term in-patient rehabilitation. The indigenous dyads residing in the post-disaster resettlement community or a relatively rural region were less likely to spend a whole year transferring between hospitals. As they needed to get back to their livelihood, the family caregivers could not accompany and support survivors with the in-patient rehabilitation. Ella explained her decision to discharge earlier than the rehabilitation schedule:

“Yeah, I felt that I was about to get well soon after staying in the hospital in the plain land and carrying out rehabilitation for two to three weeks. … I got the feeling. I might have been able to walk now if I had kept rehabilitation exercise. …I could talk very soon. I could pronounce clearer; they also included acupuncture in the rehabilitation scheme. But my husband must [go] to work or we didn’t have money for hospitalisation; and then, I went back and stayed home and my husband was out for work.” (Ella, urban-based indigenous stroke survivor)

The passage of acceptance was able to proceed more smoothly under the PAC rehabilitation scheme, a regularised format that demonstrates the structure and agency of the status passage. The PAC programme demonstrates the mutually influenced characteristics between human agency and the healthcare structure. Agency exerted on the individual level between care provider and care recipient, as well as system organisation, can transition stroke survivors from receiving acute care in a crisis phase to post-acute care in a chronic stage and prepare them for future community life after discharge. However, the agency exertion was influenced by socioeconomic and sociocultural factors. This shows that livelihood reliance and financial concern
decreased the possibility of continued rehabilitation, even though the stroke survivors perceived a physical improvement.

4.3.3 A sense of interdependence

A sense of interdependence reflects the proceedings of a co-experienced life, reflecting the combined time and overlapping life between the dyad members. The interdependence between the stroke survivors and their family caregivers was formed by the sociocultural norm of mutual support in families, which could be interpreted as a commitment stemming from filial piety. This commitment made family teamwork temporarily more significant than individuals’ developmental tasks. After acknowledging and accepting the stroke occurrence, the stroke survivors experienced a phase wherein they required significant support in order to counterbalance their lack of physical ability and supplement their deficit in social roles. I found that the sense of dependency mainly lay with the family caregiver, owing to their close relationship with the stroke survivor, which had been bonded by familial commitment and intergenerational relations (Finch et al., 2003; Campos et al., 2014; Ng et al., 2016). The relationship of interdependence is bonded by an intense need for support that is sought from within the family, drawing members and resources together (Combrinck-Graham, 1985; Moore et al., 1993) to cope with the unexpected disruption caused by stroke.

The nature of interdependence, by the definition of Status Passage Theory (Glaser and Strauss, 2011, p. 70) is “an important condition which affects the passagée’s and agent’s balance of control over a passage. A primary question is whether either can go on without the other in the passage.” Consistent with Glaser and Strauss (2011), the dyads’ mutual interdependence stood out in circumstances where they were temporarily separated from each other, when they were not visible to each other or did not sense their co-presence in the same time-space zone. The mindset of interdependence was psychologically embodied as stroke survivors’ insecurity and family caregivers’ concern. Prima
described the embodied practices of bonded life when either she or her dependent sister went on at will while apart from the other:

“I had to help her for everything she needed before having the residential care attendant. I couldn’t leave, I couldn’t deal with the household chores, couldn’t be away and go on errands. For example, I couldn’t go out to pay the bills… because I couldn’t be away for too long because she would phone me once I was away and ask, where are you?” (Prima, indigenous family caregiver, elder sister)

The stroke survivors felt insecure when the family caregivers needed to separate from them temporarily in order to go to work. The family caregivers, meanwhile, worried when they were not able to stay with the dependent stroke survivors. At the beginning of the caregiving period, neither the stroke survivors nor the family caregivers could go on with their daily living at will and at ease apart from the other. Ivy worried about leaving her father alone at home. She said:

“In the past, no one was home because we were all at work. I just went home to have a look for a while during the lunch break and then back to work in the afternoon. I helped him shower, prepared the lunch box, chatted a bit and I was off to work. The tiredness is from worrying what would happen while my father was at home.” (Ivy, indigenous family caregiver, daughter)

It appears that the interdependence was concretely visualised in the overlapping stretch of time and space accessible by the dyads. The family caregivers disclosed that their time was fixed due to their caregiving work, as the stroke survivors were highly dependent either on physical or psychological support. The family caregivers seldom had their own time or flexibility. Maxwell stated:

“It wasn’t really about the difficulties. It’s just… sometimes it’s annoyed. I felt annoyed sometimes. Wherever I want to go, it seems not ok; and I was nagged even leaving [for] an hour for taking a stroll. Because I have to care for her from morning, afternoon and to evening.” (Maxwell, indigenous family caregiver, cohabitant)
In the biophysiological aspect, the sense of interdependence was generated as the family caregivers compensated for the changed body while the stroke survivors experienced the divergent body-self (Timothy et al., 2016). In the familial development aspect, Combrinck-Graham (1985) family life spiral model represents the life cycles of individuals in the family and their relationships with members of other generations. The model illustrates the density of a family system through centripetal and centrifugal forces. Centripetal forces bring members together and show intense bonding and cohesion in the family, while centrifugal forces lead to loosened intrafamilial ties, which demonstrate family disengagement (Combrinck-Graham, 1985; Moore et al., 1993).

This paragraph gives an example of the way centripetal force becomes more prominent than centrifugal force when a family experiences a disease onset. In the post-stroke trajectory, the occurrence of disease and the assistance required by stroke survivors become centripetal forces that pull family members together cohesively. In this study, nearly two-thirds of dyads (seven out of the 12 in total) lived in a three-generation co-residence household. Owing to the fact that stroke often happens in late adulthood, a considerable number of stroke survivors (nine out of the 12) belonged to the eldest generation in the household. I take the adult children within the middle generation as examples in the families of Driscoll/Delia and Novia/Beryl.

Delia described a scenario where her daughter took leave from her family; she recounted:

“She asked for leave from her husband and mother-in-law and came back to care for him (the stroke survivor) for six months. She left her children to her husband and mother-in-law. [...] She was an illustrator, and she could work at home. But eventually, she had to quit because she was too busy to keep up with the deadlines.” (Delia, non-indigenous family caregiver, wife)
Beryl recounted a scenario where she, her brother-in-law and her sister-in-law had gathered together to work out the best caregiving arrangement for their mother, Novia. Beryl said:

“Because she (my sister-in-law) took on the care most of the time, yeah, she took the most caregiving work. And then... because she was also caring for her children, and was not able to look after her mother at the same time later on. Therefore, my brother-in-law asked me whether I could look after her and I said, ‘Yes, I can.’ Then we picked her up from Gunisoyogk and brought her over here.” (Beryl, indigenous family caregiver, daughter-in-law)

During the acceptance process, the families demonstrated an oscillation from a relative centrifugal state to a more centripetal state and shifted the orientation of family resources toward the stroke survivors. This was because they had parted from the original family and had formed a newly developed family, which positioned them in a centrifugal state in terms of the original family. Moreover, the care resources of the middle generation had previously been focused on looking after young children; the older generation had also supported the middle generation by providing childcare, as the young couple of the middle generation had both devoted themselves to the labour market in order to maintain financial stability in the household.

However, the occurrence of stroke drew most families back into a more centripetal mode within their original family, as the individual's post-stroke care needs became a joint issues for the collective family members. In other words, the so-called illness life structure, developed by families in order to accommodate each phase in the illness life cycle, is characterised by each time phase’s inherent centripetal and centrifugal nature (Rolland, 1987). At this point, the centripetal forces not only make the interpersonal boundaries within the family more diffuse in order to enhance cooperation (Combrinck-Graham, 1985; Rolland, 1987), but also weave the lives of the stroke survivor and family caregiver together and shape a co-experienced post-stroke trajectory.
4.3.4 Alteration passage

Having described above how individual and family life adjusted and interwove in order to cope with the temporal crisis, I will now move on to discussing how this sense of interdependence inevitably came to a transition, moving from the current temporality to the next stage, which is a sense of independence. This transition is driven by the avoidance of interdependence and desire for independence due to the family caregivers’ busy, multitasking engagement with family and work. As explained in section 4.2.5, the capacity of the family caregiving system has weakened as the caretakers, usually women, have faced additional multiple responsibilities for paid work and family caregiving. The stroke onset forms a centripetal force that pulls a family together and integrates energy and resources in order to prioritise care demands for the stroke survivor (Combrinck-Graham, 1985). When acute conditions and complications have been stabilised, it implies that the factors leading to the temporal circumstances of ‘out-of-phase’ in the developmental model of the family system (Combrinck-Graham, 1985; Rolland, 1987) have been solved; therefore, the family life can start to get back on track. Family caregivers have to respond to multiple status passages in their lives (Glaser and Strauss, 2011), both internally in the family cycle and externally from social change.

Expecting that stroke survivors will be more independent

This section looks at the properties that shape the status passage of alteration, which transitions the co-experienced post-stroke trajectory from a sense of interdependence to a sense of independence. As the generational relations in society resulted in multi-tasking caregiving roles for the families, the stroke survivors and family caregivers inevitably went through a process of altering their close interdependency to a relatively loosened relationship. Beryl encountered a moment where she needed to respond to financial responsibility needs in the household. She recounted the conversation she had with the stroke survivor:
“I told her, ‘I want to start working because I feel my husband works hard for earning money by himself. Kids are growing up and expenditure is growing too.’ Then she (Novia) said, ‘Huh… I have to be alone at home. Then I want to go back to live with my daughter.’ I said, ‘But she has to work too. It wouldn’t be better, could only be worse. You will be yourself at home as well, and you’re going nowhere.’ Then she said, ‘All right, then I shall stay at home by myself.”’ (Beryl, indigenous family caregiver, daughter-in-law)

Once the stroke survivors’ condition stabilised, the centripetal mode gradually transformed to centrifugal and moved outward to other responsibilities in the family and jobs in society. The dyads would enter a transitional stage where they adjusted their life to cope with an expected new relationship.

**Expectation of a new relationship**

Expectation of a new relationship between the dyads was also a motivation for status transition. The family caregivers anticipated that the stroke survivors would become independent and capable of partially looking after themselves. Julian recalled:

“She (my wife) usually expects I can be independent, do things by myself if I’m getting to recover… (If I) become more independent, and then not bother other people for assistance, that would be okay.” (Julian, non-indigenous stroke survivor)

The stroke survivors also perceived that the family caregivers adapted their daily time arrangements in light of their needs. The survivors sensed the load of the family caregivers, feared being an inconvenience to their families and worried about inconveniencing their lives. Bridget explained that she dared not express her care demands due to her fear of burdening her family:

“Yes… cooking the meals… it fixes on her (daughter’s) schedule. It’s what I feel bad about. Because she is very busy, I dare not nag. It’s me feeling the need to be courteous. Because they keep taking care of me. I feel bad about speaking too much.” (Bridget, indigenous stroke survivor)
The family caregivers experienced multiple status passages when they had to respond to their multitasking roles. Meanwhile, the burden and load of the family caregivers was co-perceived, pushing the stroke survivors to enter an alteration passage out of the current status. During this alteration passage, the dyads juggled not only their family commitments but also their time and resources. At this stage, their expectation was to regain maximum mutual independence, in contrast to their current state of being pulled together by dependence based on care demands and caregiving. The alteration passage was shaped by complex factors owing to the multiplicity inherent in the family caregiving role and the interaction between caretakers and structural components. A social phenomenon is a product of interaction between human action and structure (Giddens, 1984; Kouroubali, 2002). Changes in the ageing of society that result from people living longer and in combination with both genders needing to be economically active have impacted the availability of female caregiving resources within families (Miller, 1981; Keene and Prokos, 2007). Therefore, the insufficiencies in the family caregiving system drive dyads to shift from interdependence to independence. Glaser and Strauss (2011) in Status Passage indicate various properties pertinent to status movement throughout the course of life, one of which is multiplicity.

“The multiplicity of passages set problems based on different kinds of relationships between them. Although some status passages may be relatively independent of each other, others may compete for time and energy, often causing considerable personal strains” (Glaser and Strauss, 2011, p. 142).

Engagement with the LTC system

As interdependence exists between dyads, the alteration passage involves trade-offs regarding priority, support and competition while they pass along the trajectory (Glaser and Strauss, 2011). Stroke survivors and family caregivers change over time and at their own pace. The stroke survivor may focus primarily on their recovery trajectory. Their family caregivers undergo multiple passages due to their various concurrent roles in the family and society. When
the stroke survivor and family caregiver are closely tied together, they feel that their time and life are combined and further confined. The dyads expect a new caregiving relationship when the family caregivers start to encounter multiple passages in their life; therefore, they seek resources from LTC systems and the community. A social relation occurs when the family caregiving system cooperates with the LTC system in time and space; in this articulation process, the individual actor’s lived time-space requires coordination with the LTC system’s organised time-space in order to enable the temporality of adjustment. Regularised resources such as the frequency and duration of services allocated to the household are relevant to the issue of whether the care resources can assist the dyads in transitioning from the stage of interdependence to the stage of independence.

Family caregivers believe that they will have time to focus on their own activities such as work, domestic chores or rest when they include LTC services in their households. Involving a care provider in the caregiving not only helps with sharing the physical workload but also alleviates the psychological strain of family caregivers. Ivy and Molly’s narratives evidence that the input of the LTC system can alleviate the burden of the family caregiving system:

“I don’t need to worry about him when I am at work. I don’t worry that something might happen when he goes to [the] toilet.” (Ivy, urban-based indigenous family caregiver, daughter)

“I was always tense, and sometimes it was quite stressful emotionally. I’m relatively relieved now thanks to the residential care attendant.” (Molly, indigenous family caregiver, daughter-in-law)

Molly further indicated that taking time to get some rest after work was a great respite for her. She recounted:

“The difference is… I perceived there is a time where I could take some rest. I felt better when I returned home because I could have my 30-minute nap. My mother-in-law has the problem of urinary incontinence but she resolutely would not wear a diaper, and resolutely refused to wear
it. As a result, I had to mop her room as well as the aisle back and forth. Now the residential care services can help with this part.” (Molly, indigenous family caregiver, daughter-in-law)

Deborah’s statement was similar to Molly’s reflection: she, as the family caregiver, was exhausted after work, so the support from the residential care attendant hugely alleviated her load. She also expressed her expectation of a longer time allowance from the LTC system:

“It does make a big difference. You can imagine… we don’t even have enough time for our work, what would it be like if there was no residential care attendant? I would have to shower her and prepare breakfast and dinner after I get back home. Having her (the residential care attendant) assist me in providing the shower is a great support. … It would be optimal if someone could physically accompany her for half a day but I was told that it wasn’t possible because the schedule was full.” (Deborah, indigenous family caregiver, daughter)

With the engagement of LTC services, family caregivers and stroke survivors experienced changes in their daily life and were able to have some separate private time. It is not uncommon for family members to have personal time under normal circumstances. Both the stroke survivors and their family members had anchored their time either in employed or self-employed jobs or social activities in the community pre-stroke. However, as the family caregivers compensated for limited ability and the stroke survivors relied on support from their family caregivers, their living time overlapped during the recovery time. In this regard, the family caregiving system interacted with the LTC system to alter the caregiving pattern. In the LTC system, each household was allocated hours for services depending on the dependency extent of the stroke survivors. Within the service allowance, the individuals discussed the content and time arrangement they expected from the LTC system with the care providers. The agency for enabling post-stroke recovery trajectory was attributed to the communication between the care recipients and care providers and the coordination between the available service time in the LTC system and the expected personal time in the family caregiving system.
Continuing the progress along the recovery trajectory, I will discuss how the healthcare system supplements the inadequate workforce in the family system and alleviates the workload of family caregivers in order to support the passage of alteration. Following this, I will show how their socio-psychological statuses arrived at the mindset of independence, moved on to the passage of identification, and achieved the state of well-being when they were able to attain a corporeal sense of themselves and regain their identity in the social world. Next, I will discuss the elements that constitute the biographical continuation in the community so as to complete the description of the meaningful post-stroke recovery trajectory.

4.3.5 A sense of independence

Self-autonomous daily living: independence in overcoming challenges

Stroke survivors gain a mindset of independence when they sense that they have more control over their body and thus more control over their lives. Compared to the properties in the interdependence stage, which reflects a co-experienced life characterised by combined time, stroke survivors in the mindset of independence perceive that they have started to autonomise their daily living. Kelly and Field (1996) explain that self is a cognitive entity that is constantly being reshaped and becomes tangible through an individual's self-presentation. Although the body and self are not always exactly the same entity, individuals commonly sense their self and present it to other people when they can mobilise their body in the way they desire (Kelly and Field, 1996). The self can be and is expressed through the body, and this is disrupted by a stroke occurrence. In other words, when stroke survivors lose the capability to control their body, they thus lose their old self, because the body and the self are dissociated at this point.
As stroke survivors recover, they gradually retrieve their body control, normalise their incapability (shifting from full recovery to adaptation), become capable of managing their body, and regain their self. They are more confident in moving their body in an expected way; as a result, they take back control from the caregivers on whom they used to rely, and enjoy a sense of independence through gaining self-autonomy in their daily life.

Julian felt that he could manage his life without depending on family assistance, and would no longer need to accommodate the family’s schedule. He recounted how he took control of his body, and how this also made time management in daily living possible for him:

“More than halfway through the recovery I could make things by myself if there was any need for it… I felt more… autonomous… that I could control things. … For example, I could take a shower by myself. I didn’t overly depend on others’ assistance. Otherwise, if I were too dependent and people were not available to assist, in that case, I would keep waiting. I was annoyed by the waiting time. … Sometimes it might be a meaningless sentence I heard someone say, perhaps, such as ‘please don’t bring me to this moment every time’. That pricked my heart.” (Julian, non-indigenous stroke survivor)

Julian explained how he overcame the challenge when taking a shower by himself:

“I took action to overcome the issue. I tried to figure out the solution. If I was unable to reach some body part (when I took a shower by myself), I just bought a long-handled brush with which I could reach it.” (Julian, non-indigenous stroke survivor)

Ella found it troublesome to keep relying on her husband’s assistance. A stroke survivor’s mindset has been transformed; they feel annoyed and uncomfortable if they need to keep accommodating their family caregivers’ timetable. In Ella’s case, she wanted to take control of her daily living when she needed something done. She wanted to be independent, which turned out to be a desire that empowered her and helped her learn some coping skills.
She described how she learnt to manage the call of nature by herself, which involved getting out of the car and back into the car again:

“During the bamboo harvesting season, my husband was very busy. If I had kept calling him (to assist me with the call of nature), he would have had to come a long way, and I also felt it was inconvenient to keep calling him. I felt that was not the way, and I thus figured out a way to resolve the issue by myself. I made all effort to figure out how I could do that by myself. I practised… I had to use my hands to pull this leg (the leg at the weaker side). (When I needed to go back to the car), I heaved this leg (the healthy leg) first. And when I sat back into the car, my other leg (the weaker leg) was straight so I had to pull it back… with my hands. When I was back into the car, then I could close the door.” (Ella, indigenous stroke survivor)

The desire to be independent motivated survivors to find ways to link their body and mind. The excerpts show how physical ability and psychological independence earn stroke survivors more time and control for themselves. Time is a social construct, a resource that social actors can manage in their life. In this sense, independent time provides stroke survivors and family caregivers with time for social life.

**Self-autonomous daily living: “me time” to do one’s own matters**

A sense of independence and being able to self-autonomise one’s life was highly valued by the stroke survivors and their family caregivers. Their consciousness directed them to pursue self-autonomy and a sense of control. Novia joined the LTC station, a community venue provided for elderly people so that they could attend regular social activity and maintain a social life. The LTC policy aims to retain elderly people at the LTC station for a long period of time. In this sense, the role of the LTC station is to ensure the safety of the elderly by reducing the period they spend alone at home and supplementing the inadequate care workforce in the family while the family members are out at work. During my observation, one of the staff at the LTC station in the indigenous region indicated that the new policy was to keep the elderly at the station until 4 p.m. (previously, they would be driven back home after lunch). The adjusted structure meant that participants would remain at the station for
a nap and one more afternoon activity, and then be driven back home. However, the staff member disclosed that the elderly were not keen on this new policy and that they preferred to take a nap at home. I also interviewed one of the elderly people, who said:

"I want to go home after I finish lunch here. I want to take a nap at home and take care of the vegetables and plants. I do gardening in the afternoon. I won’t have enough time to do my work if I am [not] back home [until] after 4 p.m."

Beryl, the family caregiver of Novia, stated the following:

“Actually, the LTC station is open until 4 p.m. but elderly people usually go home at noon because they want to have a nap at noon. They wouldn’t return to the club after having a nap at home. But officially, the gathering activity for the elderly takes place until 4 p.m.”

I further inquired if she had asked her mother-in-law why she did not want to be at the club until 4 p.m. Beryl answered, “She said that she wanted to watch TV.”

**Self-autonomous daily living of family caregivers: “me time” to carry out one’s own matters**

At present, family caregivers are able to arrange their own time if their stroke survivor can live independently. Clara said that due to the involvement of the LTC service, she was able to have independent time to focus on her work. She explained:

“The planning of long-term care from the government is very good. I can have my time; otherwise, I would be worried when I am at work… I would worry when I am delivering the newspaper whether he fell or not during these couple of hours and no one would notice if he falls over. I used to think of coming back and having a glimpse at how everything is. Now he gets a residential care attendant to accompany him when he goes to the rehabilitation appointment; I can then confidently do my own work and arrange my schedule.” (Clara, non-indigenous family caregiver, wife)

This shows that the significance of LTC resources lies in compensating for the disability of stroke survivors and their reliance on family support.
coordination of an individual’s lifetime in the residential setting with the system organisation of time-space enabled the alteration passage. In this transitional passage, the stroke survivors lived a renewed life with their new bodies. Consequently, the family caregivers could spend time separately from the stroke survivors to rest or fulfil other role tasks.

4.3.6 Identification passage

After adapting to their changing lifestyle and redefining a new body-self, stroke survivors embark on a process of identification by positioning themselves in a social life or a new identity. The sense of independence that comes from physical improvement allows stroke survivors to sense a corporeal self, acquire flexible time, obtain control over their life, and seek an extension of their lives. They transfer from viewing what they have lost and desperately endeavouring to recover to finding a new focus in their life. As Kelly and Field (1996) note, they need to find a new position for themselves by interacting with people and the surrounding setting. As a result, a post-stroke identity is established. Hence, the passage of identification is driven by applying self-efficacy and establishing self-identity through defining a sense of place. In this section, I show how the participants demonstrate self-efficacy in the following ways: (1) managing themselves and providing help to family members; (2) being self-sufficient; and (3) re-establishing social links.

Applying self-efficacy

Self-efficacy is the “belief in one’s capabilities to organise and execute effective courses of action” (Bandura, 1997, p. 3). The findings show that displaying self-efficacy fosters self-esteem, achievement and a sense of belonging for stroke survivors.
**Being capable of managing themselves and providing help to families**

Owing to their physical improvement and ability to control their changed body, the stroke survivors were able to complete tasks by themselves and provide support to the family. Julian described a sense of achievement resulting from his self-care and ability to be helpful to the family:

“I could do it myself. … For example, my wife was on the third floor, and she wanted to fetch children’s stuff on the second floor. I happened to hear that and carried the things for them. There was no handrail on the right-hand side of the staircase, only on the left-hand side. I walked upstairs and showed their stuff to them. It was the first time I tried to bring her stuff to her. I felt a sense of achievement because I was able to walk by myself and bring things to her. After that, I dared to walk upstairs all the time, even climbing the stairs. … I used to sleep on the first floor (ground floor), but now, I could return to my bedroom on the third floor (second floor).” (Julian, non-indigenous stroke survivor)

**Being self-sufficient**

Andrew described how he regained his family role as a breadwinner capable of covering his daily cost of living by running a grocery store from his house. He was even able to provide work and payment for his son when he asked for help with purchasing some stock in the plain land area. He said:

“Financially, it’s ok, about 50 points (out of 100). We (my wife and I) each cover a half of the daily living cost. But selling things is not profitable. I didn’t sell a great variety of products. I used to purchase the stock once a week before, but now it’s been several weeks since last time I purchased the stock… My son sometimes helps me and I pay him wages.” (Andrew, indigenous stroke survivor)

**Re-establishing social links**

Stroke survivors seek interaction with other social actors in places they visit regularly. At the same time, family caregivers also expect that the stroke survivor will extend their daily living area from the household to the community. They expect stroke survivors not only to adapt to their physical limitations but also become capable of finding a way to involve themselves and engage with
society, instead of being isolated. They highlighted the importance of stroke survivors having social connections in order to prevent isolation. Molly explained her concerns:

“I am afraid she will become increasingly reclusive. Frankly, I worry that she likes to stay at home day by day. I don’t like that. Besides, people degenerate quickly if they stay at home and don’t exercise. She also can participate in a number of activities at the tribal culture and health station.” (Molly, indigenous family caregiver, daughter-in-law)

Clara’s narrative showed her determination to provide social networking opportunities for her husband post-stroke:

“I felt that it was a very good choice to utilise the rehabilitation facility. He is happier after getting out, and I am rather reassured. I don’t let him stay home. It is not good for a sick person not to get around people. If you are capable of getting out, you should just go off and exercise. You feel rather happier and I feel happy as well. He is fairly cheerful and I am very cheerful too.” (Clara, non-indigenous family caregiver, wife)

The identification passage is highly connected to people’s roles and functions exerted in the social world. Social identity, grounded in the surrounding environment, is beneficial to health because humans are social animals who experience value and self-worth through social connectedness and group life (Cameron et al., 2018). This shows that the momentum to proceed from the stage of independence to the next stage on the recovery trajectory is driven by an identification passage. It is crucial for stroke survivors to re-sense and redefine their social identity by connecting their life with their places of living. These places enable them to extend their life from their home to the social infrastructures such as the rehabilitation centre, the LTC station or the tribal culture and health station where gatherings take place. Identity transitioning is initiated through interacting with people and contexts, i.e. the meaning attached to places.
Establishing self-identity through defining places

The connectedness with community members and environments seems to have helped the stroke survivors, especially those from the indigenous population, to re-identify themselves through social life.

Two indigenous participants, Yuri and Novia, used to live in the non-indigenous region in the plain land but moved back to the indigenous region in the mountain for two reasons: first, the places in the non-indigenous region did not feel like home, and second, the environment for rehabilitation and social participation was confined by the housing style of multi-storey buildings they lived in urban plains. Molly recounted the conversations that happened when Yuri, her mother-in-law, asked her children to bring her back to the mountain:

“Consequently, after six months (living in the plain land), my mother-in-law called and said, ‘Do you guys intend to tie me up here and not bring me back?’ She said, ‘I will jump from a building and kill myself if you don’t pick me up.’ My sister-in-law lives in a flat on the sixth floor.” (Molly, indigenous family caregiver, daughter-in-law)

Molly subsequently explained why her mother-in-law did not want to stay in the sister-in-law’s residence:

“She simply didn’t want to live there. She said, ‘it wasn’t my own home’. This is possibly because she couldn’t get used to the place and couldn’t go out. Going outside was a trouble since the place of residence was an apartment building.” (Molly, indigenous family caregiver, daughter-in-law)

Molly’s recollections show that the feeling of home was an indicator that Yuri used to define a place. She could not sense a home-like feeling in the new residence; therefore, the residence, a concrete entity, could not be transformed into a place that carried social meaning for her. Yuri was not the only respondent for whom home had a symbolic meaning of intimacy between a person and a spatial setting. Leonard experienced the feeling of home due to the fact that his church made his new residence feel like a place where he felt a sense of familiarity after he moved. The feeling of home was maintained because he could meet old friends at the church, which made the new place
familiar to him and supported him in interacting with the place. Due to the familiarity caused by the link with acquaintances, he could engage with the new place smoothly, even though some of the participants were not his age and they did not have much in common. Therefore, attending the church service on weekends became part of his life. Leonard perceived a sense of familiarity when he unexpectedly met old friends at the church:

“I found that there was a church near the house of my son. I knew the priest and missionary very well... and it was also near the house. [...] Some of the priests asked ‘Un!? My brother, why did you come here?’ That sense of familiarity made things completely different. Staying there made me feel just like home. There are relatively few elderly people there (compared to the previous church). They are rather younger so I couldn't chat with them well. Sometimes, missionary priests from the Taipei branch came for mission delivery services. We knew each other so that I felt happy. Therefore, I yearned to stay in this place.” (Leonard, non-indigenous stroke survivor)

These stories resonate with Rowles and Bernard’s (2012, p. 11) description of the sense of being at home, where home is seen “as an expression of our relationship with a concrete entity, a physical location, a place that becomes imbued with meaning through our habitation or dwelling within its confines.”

The difference between a house and home lies in the fact that the former, a concrete entity, is brought to life when residents live in it, imbue meaning in it, and become emotionally attached to it as a place where they feel familiarity, comfort and inclusiveness. Moreover, they feel a sense of control, ownership and identity that relates to the place. The intimacy that develops between people and their houses over time evokes the concept of home and a sense of being at home that influences how they define other places in the light of their impression of home.

For the indigenous population, the ethnicity of the population coexisting in the spatial setting influenced the way they defined the place. Linda’s place attachment was also embodied as social links with the indigenous group. Linda, who belonged to the urban-based indigenous group, described her expectation of a living environment that showed she psychologically longed to
live in an environment with familiar languages and faces surrounding her. She explained how ethnic and cultural identity influenced her way of defining a place:

“I psychologically perceived it was better to go back to the mountain. I am more familiar with the environment. I was able to hear clan members speak the indigenous language. ... I felt I was doing well in the surroundings because I could hear my own language.” (Linda, urban-based indigenous stroke survivor)

Novia, a mountain indigenous stroke survivor, explained that she gained pleasure from chatting with friends, which lightened up her post-stroke life and motivated her to attend the gatherings on a daily basis. However, the spatial setting in her previous residence in the plain land could not provide an environment full of indigenous people, which was a barrier to her social networking needs. She could not establish friendships as easily as she could have done with the indigenous population. This shows that, for a stroke survivor, it is important to be surrounded by familiar people with shared ethnic characteristics, because this facilitates the rebuilding of social links in post-stroke life.

When Novia moved back to the indigenous community in the mountain area, she did not want to attend the gatherings of the elderly at first because she had no acquaintances there. Before she experienced the joy of these gatherings, a residential care attendant accompanied her to the LTC station regularly (once a week). This shows that a social circle can motivate a stroke survivor to take part in the community outside the home and attend social events. The agency of residential care attendants in the LTC system makes social life more available to stroke survivors. The LTC workforce, as an agency, transforms unfamiliar locations into enjoyable social places, so the venues for elderly gatherings become part of social infrastructure.

As Linda defined her expectation based on the environment and Novia distinguished the neighbourhood from herself, it became clear to me that
cultural and ethnic identity was their indicator for defining a sense of place. Participants with experience of living in the non-indigenous region defined their sense of place by identifying themselves and other dwellers using ethnicity and cultural characteristics. Encompassing ethnic identity, cultural identity was associated with memorable experiences of their native land, a place they had felt attached to in the past.

4.3.7 The wellbeing state

Wellbeing is a state or living attitude in which stroke survivors are physically, psychologically and spiritually in good health and feel positive. Wellbeing is an optimal subjective sense of identity (Erikson, 1968). This mindset also applies to family caregivers because they co-experience post-stroke life with the patient. The state concretely manifests itself as positive thinking and a good feeling resulting from physical, sociological and psychological coordination.

Instantiation of wellbeing: positive thinking

Julian elaborated on his understanding of Buddhism and the way his religious beliefs and the rehabilitation process together influenced his way of thinking and brought meaning to his life. His interpretation of wellbeing was that it is a state in which body, mind and spirit are aligned and work together in synergy. Julian described what he had learnt from an occupational therapist:

“To recover, the body, mind, and spirit have to align and proceed together, which leads to a better recovery. If only the body makes the effort, while the mind and the spirit keep getting injured, the recovery seems to lack momentum/energy to keep moving forward.” (Julian, non-indigenous stroke survivor)

This was his reflection on praying to Guanyin, the Bodhisattva of Compassion (Avalokitesvara in Sanskrit):

“I told Him that ‘I hope He could bless me to recover soon’. It is an invisible power that seems to make me more confident. But it doesn’t
mean I should be overly dependent on Him… I also make effort in the rehabilitation to achieve better recovery. Body, heart, and soul need to move forward together. That makes it possible.” (Julian, non-indigenous stroke survivor)

Julian felt that belief in a supernatural power could provide moral guidance and mental support in order to enhance inner strength and allow endurance. However, he understood that this did not mean that he could hope for a miracle provided by a supernatural power. Concurrently, he had to make efforts in his rehabilitation to achieve better recovery. The individual perseverance and invisible spiritual support that energised the body, heart and soul worked together, and drove him forward on his recovery trajectory. Julian’s wife Ginger confirmed his story. She reflected that Julian’s mindset became positive and confident after re-establishing his social life at the LTC station and engaging with his religious beliefs:

“He quite enjoys attending rehabilitation at the hospital, and also feels cheerful to go to the day care (centre, the neighbourhood LTC station). What’s more, also... we attend classes, I feel he doesn't think that much negatively on the whole […] I feel it is highly correlated with taking courses at the Buddhist college or going to the day care centre.” (Ginger, non-indigenous family caregiver, wife)

Leonard achieved a state of wellbeing when his physical needs for rehabilitation and psychological needs for social life and mental support were all anchored. He found mental support in the church, where he could be mentally calm, find inner peace and develop coping skills. Leonard said that when he felt irritable, he calmed down by praying to God:

"I learned to change my way of thinking and control my temper. I didn’t get angry. I needed to change because you are (I am) a Christian who is supposed to show the image of Jesus Christ, that is to love, to tolerate, to forgive, and not be angry, so everything should be ok. … Friends at the church also render their caring and considerations. ... Everything has its own arrangement. Yes, just believe in Him. Believe. Believe. If He wants me, I will definitely be submissive to him, not oppose him; and then I will be happy. The happier I am, the more light-hearted I will be.” (Leonard, non-indigenous stroke survivor)
In addition, Leonard experienced a sense of belonging and imbued social and functional meaning in his attachment to the rehabilitation centre. He described the clients who were going through rehabilitation at the same time as classmates with shared experiences. They shared their daily experiences, as they regularly attended the rehabilitation scheme; they followed each other’s progress, exchanged information and learnt from each other. In this sense, the rehabilitation centre was no longer merely a healthcare facility; it became a social infrastructure where Leonard could re-establish his social circle and create happy memories with classmates:

“As classmates, we chat and share our experiences while everyone is doing their rehabilitation activities. We improve each other by discussion. The happiest time of my day is the hours I spend there. I always ask the teacher, ‘May I exercise for an extra half an hour there?’ He says, ‘Yes, of course you can.’” (Leonard, non-indigenous stroke survivor)

Autonomous time, actors of social exchange and approachable environments are the essential elements of the wellbeing state. For the stroke survivors, social life took place through daily activities in the LTC station or regular attendance at the rehabilitation centre. If they had only met up with social actors once or for a limited time, this social link would not have been created. Members of a social circle have to be present in the same sphere of time and space, following a regular pattern that enables frequent meetups.

4.4 Summary of this chapter

Stroke survivors’ and family caregivers’ needs and expectations comprise a post-stroke recovery trajectory conceptualised by their post-stroke life experiences. This is part of a larger analysis that aims to answer the first research question:
• How does the current long-term care policy meet the needs and expectations of stroke survivors and family caregivers experiencing LTC from different ethnic or cultural backgrounds?

The post-stroke recovery trajectory involves mindsets and a momentum passage driven by the sociological and biological factors sensed by dyads in their post-stroke life. Each mindset or momentum passage is formed and shaped by the interplay among physiological (biomedical, body, self) and psycho-social (identity, body image) properties. To answer the first research question, the LTC policy meets individual needs by establishing an essential context for biographical continuation along the recovery trajectory. The context refers to the setting of daily living interaction that the stroke survivors can physically access; in this setting, they can experience family functions and/or social roles, and become emotionally attached to a place and a group of people during their daily practices.

As Cameron et al. (2018) stated, social identification is a psychological link between the individual and a contextually meaningful group that can provide an avenue for numerous social processes and resources that promote health-related outcomes. This study has found that the connectedness of self (body), identity (social role) and place attachment (environment) determines the wellbeing and health-related outcome of dyads. In this study, the community reintegration for all groups of stroke survivors was based on self-identification within a place. Their wellbeing was connected to place attachment. Indigenous people’s identity and sense of place were less likely to be attained in the urban plains because they could not define themselves through cultural and ethnic characteristics in the urban environments. The socio-cultural characteristics in the urban area were insufficient to construct a place where the indigenous people could find a social group with whom they were familiar and to whom they felt connection and belonging. An individual’s recovery trajectory is shaped by perceptions of physical and social identity coupled with the appearance of
other social factors, which means that post-stroke life is developmental, pliable and contingent (Kelly and Field, 1996).

In this research, the dyads’ expectations and practice have highlighted the developmental possibilities of the post-stroke life trajectory. The family caregiving system shows the flexibility in the attempt to find balance and apply resources from communities. The contingent feature reflects the way the existing environment and healthcare structure enable or constrain the development of patients along the trajectory and the potential for mobilising resources from communities. In the following chapter, I first present the variation of development along the post-stroke recovery trajectory among indigenous, urban-based indigenous, and non-indigenous people living in the indigenous region and the non-indigenous region. I then present the variation and the contingency they encounter, which will allow me to evaluate the efficacy of the LTC system and other resource systems in the communities in question. Thus, I will answer the second research question:

- What are the facilitators of and barriers to long-term care for stroke survivors and their family caregivers experiencing care in their community?
Chapter 5: Contextual conditions and interactions of LTC system-in-use

5.1 Introduction

This chapter presents my findings relating to the contextual conditions and interactions of the LTC system-in-use from the research participants’ distribution along the post-stroke recovery trajectory (see Figure 5.1). Chapter 4 charted the post-stroke recovery trajectory based on the stroke survivors and family caregivers’ life experiences and their engagement with the LTC services during my fieldwork observation. As part of my analysis, I positioned the individuals along the recovery trajectory according to their personal development status. As seen in Figure 5.1, the distribution along the trajectory visually illustrates the findings from my analysis that a greater number of non-indigenous participants perceived that they had reached the wellbeing state post-stroke. The indigenous group living in their own communities were mostly positioned in the identification passage of moving towards wellbeing. In contrast, the urban-based indigenous participants had made the least progress towards recovery and were positioned at the point of either alteration in their life or having a sense of independence and heading towards the identification passage.
The post-stroke recovery trajectory progressed differently for individuals of different ethnicities and regional deviations. Furthermore, the indigenous and non-indigenous regions were characterised by ethnic, socio-cultural and environmental features that shaped the contextual conditions for LTC system implementation and individuals' life transitions. Therefore, an exploration of the way LTC and other resource systems have displayed their efficacy in the given communities can only show trustworthiness by taking the contextual factors into account when analysing the second research question:

- **What are the facilitators and barriers of long-term care for stroke survivors and their family caregivers experiencing care in their community?**

In this chapter, I will first outline my views about the macro, meso and micro context in the structure of the LTC system-in-use. Subsequently, I will describe the context of the LTC system-in-use in respect to mountainous geography for the indigenous people, urban geography for the non-indigenous people and sociocultural context for the urban-based indigenous people.
5.2 Views on macro-, meso- and micro-sociological context

In Chapter 2, I justified my theoretical perspectives that resulted in the adoption of biographical disruption theory (Bury, 1982), status passage theory (Glaser and Strauss, 2011) and structuration theory (Giddens, 1984). Drawing from these theoretical underpinnings, I will contextualise the findings in a three-dimensional structure framed by time, space and power. The post-stroke recovery trajectory illustrated each dyad’s life transition and their engagement with the LTC system. In this chapter, I will further explain the findings of the contextual conditions of the LTC system-in-use, derived from the emergent conceptual categories from data analysis (see Table 3.6, p. 130). Figure 5.2 illustrates the contextual conditions and interactions across the macro, meso and micro contexts built into the time-space-power structure.

Giddens (1984, p. 224) stated that “the problem of order in the theory is the problem of how it comes about that social systems bind time and space, incorporating and integrating presence and absence”. I will explain the determinants that influence post-stroke life and LTC service utilisation at the macro, meso and micro levels, and show that they are by no means more or less important than each other. The distinction refers to the sociological properties with regard to social actors across the strands of time and space. The determinants were analysed, and each one emerged when I observed its presence in one context, which reflected its absence in another context. The context involves demographic, geographic and sociocultural aspects.

Context is a setting that accumulates the seriality of spatiality and temporality. It presents not only the immediate but also the past time-space. The current landscape of geography and sociocultural characteristics, a presentation of history, has the appearance of a bygone time-space that forms the sociological properties of the three ethnographic fields in this study: mountain geography in the indigenous region; urban geography in the non-indigenous region; and sociocultural context for the urban-based indigenous participants. In a sense, a macro context involves an accumulation of social actions evolving across
time-space that are supra-individual and outlive the sphere of individual agency. In this regard, I classified the sociological properties as the macro context due to this context's solid and predominant existence, which is beyond the control of the individual. In contrast, the micro context is within the control of the individual, and shows their flexibility in turn-taking while confronting the constraints that act as a medium for the enablement of action (Giddens, 1984). The meso-sociological context is an intersect that demonstrates the real scene where the micro and macro contexts are articulated.

The findings demonstrated the mutually interactive and reconstructive characteristics among the macro, meso and micro contexts. In this study, the conditions and interactions of the LTC system-in-use were contextualised as the macro context for policy implementation, the meso context for system organisation and the micro context for adapted service practice. The sociological properties in the macro context are the barriers to equitable access to the LTC system. The situated LTC system-in-use in the meso context refers to the LTC system establishment in the community, reflecting tensions between environmental properties and the fulfilment of policy initiatives. The adapted LTC services in the micro context are facilitators of tension coordination in the situated LTC system, which coordinates individual needs with contextual barriers. The coordination between individuals and the system across the contexts and along the span of time-space determined the stroke survivors’ development of self-identity when they proceeded along their trajectories. In the following sections, I discuss the interplay among sociological properties, coordination barriers and practice facilitators in the given indigenous, non-indigenous and urban-based indigenous contexts based on this conceptual structure (Figure 5.2).
5.3 Mountainous geography as the macro context in the indigenous region

From the analysis of the data, it is evident that the geography of the regions where the participants resided impacted their recovery trajectory. This was due to a variety of reasons, outlined below. Consider Figure 5.1 (p. 198), which illustrates where the different participants were situated along the recovery trajectory; three stroke survivors in the non-indigenous group, Julian, Hobart and Leonard, who were all at the fourth level of service demand (see Table 1.2, p. 13), could be considered to have arrived at the wellbeing state, experiencing happiness and positive thinking while continuing with their biographical journeys. The three stroke survivors in the indigenous region, Andrew, Yuri and Novia, who were at the third level of service demand, were positioned in the identification passage, signifying that they had re-built and perceived their self-identity again, and were capable of controlling their
Those non-indigenous stroke survivors who had achieved a wellbeing state, in fact required more care than those indigenous stroke survivors. However, the indigenous people who were less reliant on LTC proceeded more slowly on the recovery trajectory. These two groups resided in the non-indigenous and indigenous regions, geographically characterised as plains for the non-indigenous participants and mountainous areas for the indigenous participants. Thus, in one aspect, the impact of socio-environment in the mountain geography appears to have been more predominant than the illness severity. These two groups, positioned in the wellbeing state and the identification passage respectively, resided in the non-indigenous and indigenous regions, geographically characterised as plains for the non-indigenous participants and mountainous areas for the indigenous participants. The disparity in recovery lay in the intrinsic geographical characteristics of the natural context, the mountainous area, which gave rise to coordination barriers in the structure. This impeded the establishment of healthcare settings, the accessibility for the care users in the indigenous community, and the maintenance and sustainability of the care services. The meso-coordination barriers were brought about by the macro-sociological property, the mountainous geography, which was experienced by the indigenous group but not encountered by the non-indigenous people. In the next few paragraphs, I present the coordination barriers in the natural geographical context by showing data exemplifying the following aspects: (1) accessibility to transportation services; (2) sustainability of outsourced resources; and (3) availability of equal quality services. Table 5.1 outlines the codes and pseudonyms of the stroke survivors and family caregivers; I will explain the findings using their narrative excerpts.
Table 5.1 Codes and pseudonyms of the research participants

*’S’ refers to stroke survivor and ‘F’ refers to family caregiver

<table>
<thead>
<tr>
<th>Mountain-based indigenous group</th>
<th>Urban-based indigenous group</th>
<th>Non-indigenous group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code Pseudonym</td>
<td>Code Pseudonym</td>
<td>Code Pseudonym</td>
</tr>
<tr>
<td>A1S Andrew</td>
<td>U1S Linda</td>
<td>N1S Julian</td>
</tr>
<tr>
<td>A1F Georgia</td>
<td>U1F Prima</td>
<td>N1F Ginger</td>
</tr>
<tr>
<td>A2S Bridget</td>
<td>U2S Ella</td>
<td>N2S Hobart</td>
</tr>
<tr>
<td>A2F Deborah</td>
<td>U2F Bob</td>
<td>N2F Clara</td>
</tr>
<tr>
<td>A3S Yuri</td>
<td>U3S Hank</td>
<td>N3S Leonard</td>
</tr>
<tr>
<td>A3F Molly</td>
<td>U3F Ivy</td>
<td>N3F Louis</td>
</tr>
<tr>
<td>A4S Novia</td>
<td>U4S Dora</td>
<td>N4S Driscoll</td>
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<tr>
<td>A4F Beryl</td>
<td>U4F Maxwell</td>
<td>N4F Delia</td>
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5.3.1 Barrier to accessible transportation services in the meso context

The concept of time and geography, introduced by Hägerstrand (1970), stresses the significance of the co-presence of human existence and associated contexts resulting from interaction. As long distance in physical space can also be regarded as long distance in time (Giddens, 1984), the conditions of this co-presence are considerably affected by the degree of time-space convergence, which is enabled by the means of transportation and communication available to the human actors (Hägerstrand, 1970).

Andrew was not satisfied with his current situation, despite having been able to exert self-efficacy and regain social identity, due to the inaccessibility of transportation to an out-patient rehabilitation centre. Based on his status as a self-sufficient grocery shop owner, I located Andrew in the status of identification passage. The unmet needs that impeded him from the wellbeing state were the frustration arising from unmet hopes for physical improvement
as a result of inaccessible transportation and rehabilitation services. In the
mountainous indigenous region, the rehabilitation centre was 19.8 miles away
from Andrew’s community. Due to the mountainous geography, the
rehabilitation transport bus, hereafter Rehabus, could only pick up the care
users at a public site, which was a police station 7.4 miles away from Andrew’s
community. Andrew discussed the challenges he faced when trying to seek
rehabilitation resources through Rehabus:

“Yes, I do (want to go for rehabilitation). But the pick-up point is at the
police station. It doesn’t come over here. The service is available every
Wednesday. [...] There is only one car (providing the service). Every
month they call me and ask, ‘Can you go?’ And I reply, ‘No car.’” (Andrew,
indigenous stroke survivor)

In Andrew’s situation, he was required to attend according to an assigned
timeslot. However, he could not physically travel to the pick-up point by himself;
thus, the distance between his home and the pick-up point, which the
transportation did not cover, constrained his opportunity to receive all-round
rehabilitation in the physio-rehabilitation centre, which was the only
rehabilitation facility in the indigenous region. Ideally, the transportation
services should have picked up the stroke survivors from their homes, which
is what I observed occurring in the non-indigenous region. As Miller (2016)
states, well-functioning services make up for physical limitations and distance,
enabling users to attend fixed-time activities and therefore achieving
accessibility. The mountainous geography, however, led to distanced health
facilities and an insufficient volume of transportation services.

A well-operated and accessible transportation service was exemplified by the
experiences of one of the dyads, Hobart and Clara. This dyad was non-
indigenous and recruited in the non-indigenous region, where pickup and drop-
off services between home and the rehabilitation facility were available to all
users. I located Hobart in the wellbeing state, as the dyad expressed their
satisfaction with their current daily life. This good feeling resulted from the
physical and socio-psychological coordination achieved when Hobart resumed
his social life and maintained his physical ability through regular rehabilitation attendance and transportation support. Clara paid compliments to the transportation services:

“The government operates long-term care with a person accompanying alongside and the Rehabus picking up and dropping off him (Hobart) at home, which is fairly good. […] I do consider that it provides good services. He waited in front of the shoe cabinet every morning. The Rehabus picked him up and brought him back every day. I felt relieved and secure." (Clara, non-indigenous family caregiver, wife).

Clara explained that she felt lighthearted, as Hobart was able to re-establish social links and enjoy social life in the rehabilitation centre due to the conduct of the transportation services. She recounted:

“He met the crowds and chatted with other people. Although I do not surely know how he has been rehabilitating, but… after all, (he has been) walking around instead of staying still at the original place. When you go outdoors; you feel happy and I feel happy." (Clara, non-indigenous family caregiver, wife)

Hobart’s optimal sense about his post-stroke life was a benefit resulting from the transportation services and the care provider, who compensated for his physical inability and the unavailability of family caregiving. Hobart’s description of attending the rehabilitation with the assistance of the care provider was resonant of Clara’s reflection. He stated:

“The grounds are uneven. For example, where we take the shuttle bus, the ground is not fairly flat. It’s easy to feel that I was nearly tripping over after a few slightly-wobbled walks. She (the residential care attendant) seized me immediately. What a quick reaction … She is always thoughtful and considering of everything. … The LTC services don't add to the burden financially and psychologically. I am fairly happy and I eat well and sleep well.” (Hobart, non-indigenous stroke survivor)

These excerpts show that transportation services should be able to link people with care settings in a timely manner, bring the care users to the time-space zone of the rehabilitation facility, and arrange timeslots that fit both the system organisation and care users in order to achieve the requirements of service
accessibility and co-existence of social interaction. An activity at a station is not feasible unless the station intersects with the prism spatially and temporally – the latter for at least as long as the minimum activity time required (Miller, 2016). Andrew and Hobart both expressed their expectations about continuous long-term rehabilitation in the communities. However, the mountainous geography in the macro environment led to an inaccessible and insufficient volume of transportation services, which consequently caused different life status developments on the post-stroke recovery trajectory.

5.3.2 Barrier to sustainable resources in the indigenous region

The geographical properties not only led to the inaccessibility of transportation services but also insufficient volume and non-sustainability of LTC services. Long distance and time consumption for care delivery in the mountainous region caused considerable challenges for both local and outsourced care providers. In the indigenous region, parts of the service resources, including the care providers, the organisers and the operational units, were outsourced from institutions based in the plains region. However, the geographical barriers led to difficulty in sustaining those external resources in the long run. Residential reablement services, provided by therapists, were more likely to conclude cases without a clear reason or transition them to other available care facilities.

Novia, positioned in the status of independence, used to receive a residential reablement service from an occupational therapist based in a rehabilitation clinic in the plains. The non-sustainability of the outsourced LTC resources was observed in the circumstance of her residential reablement services. Her family caregiver, Beryl, stated:

“I don’t know. The therapist didn’t show up afterwards. […] So, I just told her that, ‘you need to practice exercising by yourself. You cannot rely on other people all the time. Try to rely on yourself with your own efforts.’” (Beryl, non-indigenous family caregiver, daughter-in-law).
The dyad were unsure why the residential reablement service had been discontinued. They did not explicitly understand whether the service was terminated due to rehabilitation scheme completion or suspension. Although Novia and Beryl did not consider it necessary to chase it up, the communication between care providers and care recipients could have been better.

The continuity of the rehabilitation service was also limited by inadequate workforce in remoter areas due to the disadvantaged geographical conditions. Bridget, situated in the status of the alteration passage, explained that the limits of the LTC services did not meet her expectations in terms of improving her physical ability. Bridget received reablement services from the only physical therapist in the only local rehabilitation centre in the mountainous region. As the number of service users increased, the workload of the physiotherapist became heavier and less time was available for all-round services. The long distance required long travelling times from one household to the next, which shortened the service provision time available to each care user. Bridget received residential reablement services from the LTC system three times a month. The physiotherapist used to visit her house and take time to bring her to a standing position after electrotherapy. However, the physiotherapist became too busy to help Bridget to stand after taking on more clients. Bridget perceived that workload for the care provider influenced the quality of care:

“The reablement service took place for 30 minutes. He used to let me stand a while after the electrotherapy. […] He laid my feet on his feet to walk a bit. But he is busier now… having many (clients), he needs to go more places […] so he left right after the rehabilitation (referred as to the electrotherapy).” (Bridget, indigenous stroke survivor)

In contrast to Novia and Bridget, Julian was able to receive a residential reablement service six times a month for six months, as well as out-patient rehabilitation three times every week, with free Rehabus transportation for three years.
5.3.3 Barrier to sufficient volume of services in the urban plains

Structure of transportation services
There are two major transportation resources available in the community, the Rehabus and the transportation service of the LTC system. The organisational authority of the Rehabus service is the responsibility of local institutions, based on the application of a public-to-private concession arrangement. The Rehabus is a privately-managed public social welfare service in the Taiwanese community. Local governments follow the welfare policy stipulated by the central government and recruit private foundations to operate this non-profitable social welfare care service. The service fee is charged according to each local administrative unit’s regulations, and is sometimes based on the taxi charge fee. The Rehabus service in the indigenous region (the first fieldwork site) is free of charge due to the benefits granted to indigenous people. In the non-indigenous region (the second fieldwork site), the Rehabus service is free because the local government runs it as a social welfare service. However, the urban-based indigenous region (the third fieldwork site), where I recruited the final dyads, charges the users each time they take the bus. I explain the barriers of natural context by contrasting the sufficient volume of services in the plain land region with the insufficient care services in the mountainous region, as well as comparing the non-indigenous and indigenous groups.

Availability of synergetic work and dual transportation resources
As they benefit from geographical characteristics, the resources in the urban area are easier to centralise and employ (Giddens, 1984). Dual transportation resources are available and accessible to stroke survivors in the urban region. Leonard was situated in the wellbeing state, as he was able both to mobilise the transportation resources in the urban community in order to undergo rehabilitation in the hospital and to enjoy the social life re-established by routinised attendance at the rehabilitation centre. The Rehabus in Leonard’s residential region is free; he was also able to apply for transportation from the LTC system when the Rehabus was overbooked. The synergetic work of the
dual transportation services in the non-indigenous region is demonstrated by Leonard’s recollections:

“I booked the Rehubus too late; by then, it was already fully booked. I usually book at 12 a.m., a time when no one else [is] making bookings, so care is usually available. I attempted to make my first booking during the holidays when they hadn’t opened bookings yet, and by the time I remembered to book again, it was fully booked.” (Leonard, non-indigenous stroke survivor)

Leonard further explained how he managed the situation by contacting the LTC unit when he found the Rehubus was fully booked:

“As a result, I had to call the foundation (the residential care provision unit). A staff member from the foundation said, ‘I will find you a car from the LTC. It can be taken four times a month. Going and coming back counts as one time. The monthly allowance is four rounds […] What if I go to the Lynn Hospital for extra rehabilitation once a week? Then it would be enough.” (Leonard, non-indigenous stroke survivor)

When I observed his rehabilitation process, Leonard disclosed that he used his maximum allowance of the services to enable frequent rehabilitation. He enjoyed exercising and the vibe in the rehabilitation facility; the clients were like classmates because they shared information and updates about their daily life. The stroke survivors in the non-indigenous plains region were more likely to utilise resources that were available, accessible and approachable to them. This was a common phenomenon expressed by the indigenous participants, Andrew, Novia and Yuri, evidenced by their post-stroke recovery trajectory; it contrasted with the experiences of the non-indigenous participants, Julian, Hobart and Leonard.

Miller (2016) indicates that routinised activities act as anchors in the time-space surface, and other activities tend to take place in the temporal gaps between these routinised activities. Leonard’s need for physical exercise was guaranteed by the synergetic work of the dual transportation services provided by the Rehubus and the LTC system. The accessibility of routinised activities was ensured by the transportation services that supported the stroke survivors
in finding anchors in their post-stroke life. The fixed activities took place in a regular, repetitive pattern that enabled stroke survivors to find their focus in daily living, reconnect with other situated activities adjacent to the anchors, and, as a result, regain their social links. Therefore, social networking was as important as physical rehabilitation.

5.3.4 Adapted service by workforce agency in the micro context

The dyads encountered situations that required them to consult with the LTC providing units or the service providers in order to adjust their individual care needs. The data show that the agencies of open communication between service providers and recipients and flexibility of the LTC workforce were helpful for the dyads in overcoming the barriers they encountered in real-life care utilisation. In this section, I discuss how the agencies of open communication and the flexible adaption of the LTC workforce supported the dyads in their lives.

Benefiting from the flexibility of the LTC providers, Andrew was now self-sufficient and ran a grocery shop in the indigenous region with support from the residential care service. The residential care attendant assisted with the replenishment of stock, since the grocery shop was situated in Andrew’s living area. Flexible management of the residential care service not only supported him in rebuilding his family role and social identity but also alleviated the family caregiver’s workload. Andrew’s family caregiver, Georgia, described the changes in her life after receiving support from the residential attendant:

“I told her (the residential care attendant) that, ‘you just tidy up his bedroom. Don’t do other matters.’ We will rearrange it (the space) [...] Dealing with the stock is difficult because my legs hurt. I can’t make it. It was my help to replenish the stock when my legs were able. But now, I really can’t make it anymore. It’s really troublesome. It’s been thankful to [have] assistance in showering, tidying up the room, as well as replenishing the stock.” (Georgia, indigenous family caregiver, wife)
At the beginning of the residential care service period, Georgia stated that she could manage the grocery area by herself, and asked the residential care attendant to focus on assisting with showering, muscle and joint movements. However, due to pain caused by her degenerative knees, replenishing the stock was getting too demanding for Georgia to endure. Following communication, the care provider and the supervisor agreed to apply the residential care service flexibly by covering the grocery area as part of Andrew’s daily living area and assisting with replenishing the stock.

The residential care service modified their care provision content in order to fit with Andrew and Georgia’s urgent need for someone to assist with stock replenishment. The workforce of the LTC service showed a potentiality to modify and customise their service according to the dyad’s needs. Owing to the open communication and flexibility that the residential care services showed to the stroke survivors, Andrew again placed expectations on the service provider in the hope that the workforce could supplement the inaccessibility of the transportation and rehabilitation services. Andrew expressed his expectations of the residential care attendant:

“The transport is inconvenient, that’s why. What if the residential care attendant can strengthen that part of exercise… it would be … It seems to be not enough for only two movements.” (Andrew, indigenous stroke survivor)

Moreover, the agency of effective communication during service planning was significant in supporting the dyad Julian and Ginger to find a balance between self-efficacy and care reliance in order to ensure Julian’s safety in specific circumstances. The family caregivers explained that they wanted to save on the healthcare expenditure for their household; therefore, they suspended their use of a residential care attendant to accompany Julian when he underwent rehabilitation in hospitals, since he was able to manage himself when transferring between rehab rooms and setting up equipment. However, Julian expressed that attending the rehabilitation independently would be challenging for him to control his limbs in the wintertime due to stronger muscle tension.
They thus worked out their allowance of respite care (14 sessions annually) and utilised it by having the residential care attendant accompany Julian to rehabilitation in the hospital in the wintertime (from October to March). They divided the 14 sessions (six hours each session) of respite care into 28 sessions, with three hours in each session. Although Julian was capable and made efforts to live his life independently, the respite care played a supplementary role in assisting him in overcoming occasional difficulties that might impede his pursuit of self-independence and a self-autonomous life. Practically, the respite care was flexible and well-performed regarding its potential both to customise specific conditions requested by the care user and to retain its initial purpose of giving the family caregiver relaxation time and alleviating their worry about safety if they could not be with the stroke survivor. The flexible application of the respite care and cooperation with the residential care attendant was described by Ginger:

“We were allocated 14 times of respite care services. It is six-hour for each respite care. We divided it into three hours in each care provision; therefore, it turned out into 28 times of care provision and three-hour long for each day. […] Well, we discussed with Lillian (the residential care attendant). After making sure that both of our timetables were ok, we went for reference meeting at the foundation, and then the service took place as we completed the meeting.” (Ginger, non-indigenous family caregiver, wife)

With communication and adapted services, the human agency of LTC providers can alleviate family caregivers’ workload and support stroke survivors in regaining a social role and being self-sufficient. The workforce agency findings have shown a growing need for more skilful care providers to supplement the insufficient rehabilitation opportunities due to distanced facilities and insufficient transportation coverage. Flexible time arrangements and human resources distribution has made the LTC service more adaptable in terms of meeting individual needs and contextual conditions.
5.4 Urban geography as the macro context in the non-indigenous region

I naively assumed that the non-indigenous people would encounter the same constraints engendered by the mountainous geography as the indigenous people if they resided in a mountain area. From the perspective of the time-space dimension, the past leads to the present, which leads to the future. The evolvement of history and geography, which is a past form of time and space (Giddens, 1984), has led to the current demographic and geopolitical distribution between the indigenous and the non-indigenous people, and continues to reshape Taiwan’s society. Historical and geopolitical development in the Taiwanese community has resulted in indigenous people mostly residing in the mountains and non-indigenous people often living on the plains (Huang and Liu, 2016). Consequently, in this study, I recruited the indigenous participants from the mountainous area and the non-indigenous participants from the plains.

Although the barriers brought about by the mountainous geography did not affect the LTC users in the non-indigenous group, the non-indigenous participants were faced with the barriers of infrastructure brought about by urban geography. Urban geography, characterised as structural property in the non-indigenous plains, appears as infrastructure by reflecting the social reality associated with urbanisation. The phenomenon of urbanisation reflects the social change that has evolved in time-space in some parts of Taiwanese society. Therefore, I describe infrastructure as an urban, artificially built geography, as it presents a sequence of time and space (Rowles and Bernard, 2012).

The infrastructure in the urban area includes public facilities and residential architectures situated in the natural context, and are characterised as collectively owned by multiple people (Amin, 2008; Latham and Layton, 2019). Urbanisation is a process of centralisation of resources (Giddens, 1984), as a large group of people embed their life in an urban space and establish various
kinds of infrastructure. In addition to concrete architecture, infrastructure can also refer to institutional infrastructure such as administrative and legislative systems, or soft infrastructure such as healthcare systems and the medical workforce. Although there are plenty of resources available to urban residents, who benefit from the convenience of time-space convergence, urban life is denser and urban residents are more likely to encounter situations in which their lives overlap with those of other urban dwellers. This overlapping part of life is conceptualised as the interplay between the body and the environment (Hägerstrand, 1970; Miller, 2016).

With regard to concentration of resources and density of urban life, the research participants encountered coordination barriers when they communicated a collective agreement or negotiated with administrative regulations for common area modification. In the following sections, I present the coordination barriers in the urban context by displaying data that exemplifies the significance of creating a coordinated institutional and administrative system in order to catch up with the increasing need for a barrier-free environment in an ageing society.

5.4.1 Barriers to negotiating with accountable units and the public in the meso context

In contrast to the distanced facilities in the mountainous region, the density of healthcare facilities is adequate in the urban context. However, the accessibility of these facilities is constrained by existing regulations and the need to negotiate collective consent with the stakeholders. Regulations relevant to the legitimacy of existing building reconstruction have given rise to barriers for LTC users who want to modify the common area into an age-friendly environment. Gaining a collective agreement for a shared ownership infrastructure requires negotiating with the public, because other residents also have the right of possession. Achieving consensus and obtaining eligibility
for administrative access involves coordinating the personal goals of individuals and the common good of the collective, balancing the core values between the two. The barriers to coordination involve: (1) the complex administrative structure of subsidy application; (2) inconsistent regulations governing old and new buildings; and (3) inaccessibility of healthcare facilities in the populated region.

**Governmental administrative structure**

There are two administrative systems in the governmental structure accountable for subsidising age-friendly environment improvements. Louis discussed the challenges of attempting to modify a public environment according to suggestions from an LTC supervisor after a home-visiting assessment. The safety and accessibility of the residential area were considered, as he had just completed a major renovation in the house before his father moved in; thus, the handrails beside the toilet and metal pillars beneath the sink had been modified. He further intended to improve the barrier-free access and traffic flow in their residential building. However, he faced difficulties during his application for common area improvements. Louis described his communication with the LTC supervisor:

“It was the first time he/she (the LTC supervisor) came for home-visiting. Contact was made because of the suggestions for moving flow improvements in our living area, where improvements could have been made, for example, the downstairs community area. I mentioned to him/her that if it would be possible for the government to partially subsidise the construction of an accessible space, then our community could pay the rest. But he/she said it wasn’t their responsibility, and I needed to consult with other departments to see whether the application could be approved.” (Louis, non-indigenous family caregiver, son)

Louis explained that the subsidy for environment improvement from the LTC system was only available in residential areas; common areas were not included. Environment renovation in common areas and private household areas were the responsibility of different administrative departments. Modifications for private household areas were subsidised by the LTC system.
in the local government’s Health Bureau, which belonged to the jurisdiction of the Ministry of Health and Welfare (Ministry of Health and Welfare, 2020). Subsidising common area improvements in apartment buildings was the responsibility of the local government’s Housing Development Department, which was subordinated to the Construction and Planning Agency in the Ministry of the Interior, a central operation executive (Construction and Planning Agency Ministry of the Interior, 2018).

The reconstruction of an accessible facility in the public area is regularised by the ‘subsidy scheme for improving accessible facilities in existing residential buildings’. This is an administrative regulation in the construction category, first promulgated in 1997 and amended in 2018; it operates outside the LTC system (Construction and Planning Agency Ministry of the Interior, 2018). Local governments will subsidise public environment modifications following policy and local administrative projects for accelerating the establishment of accessible facilities. However, in order for Louis to become eligible to raise this application with local government, he was required to obtain agreement from two-thirds of the residents, as every resident had ownership of the common areas in his residential building.

A negotiation over common area modification in an existing building involves various operating branches in the governmental structure. The infrastructure property in urban areas is owned by and shared with the public, resulting in various units, stakeholders and regulations that are relevant and responsible for managing the affairs of architectural reconstruction. Modifying the common area of an apartment building involves not only the rights of the holistic residents but also the architectural ownership and land ownership (Construction and Planning Agency Ministry of the Interior, 2018). Moreover, public safety is another concern; as a result, modifications in a common place require further expertise and assessment regarding the construction of the building and collective agreement between the shared owners. In this regard, authority and accountability need to be delineated to administrative units with
expertise in civil engineering and construction, which are differentiated from the field containing the LTC system within the governmental administrative structure.

As Louis explained, the complex branching system of the executive administrative structure decreased the subsidy availability. Although the supervisor provided information about the units responsible for further enquiries, the complicated process of understanding the regulations, communicating with the governmental units, and negotiating with other residents hugely decreased Louis’ ability to go through the whole administrative process, especially as he was required to contact all the residents and obtain a collective consent from them.

Internal administrative structure in the community

Louis’ attempt to negotiate a collective agreement with the public was impeded by the inconsistency of normative regulations. Following enquiries regarding regulation from the responsible units, Louis was told that the scale of their apartment building was too small to fulfil the requirement for a subsidy. Louis then raised the issue in an association meeting in his apartment community. The association meeting comprised residents and played the role of an agency that could manage and coordinate public affairs. To utilise the funds available for modifying the common area, a proposal had to be raised in the association meeting and a collective agreement had to be obtained from two-thirds of the residents. Louis’ descriptions of the negotiation process are provided below:

“It wasn’t as easy to control these matters (environment modification) as we thought. The residents’ consent to make the construction is required [to be gathered] by holding a residents’ association meeting and raising this issue. With this regard, I wish the government could see the demands. After all, people grow older generally in the communities. [...] for example, our community was too small to fulfil the criteria for the subsidy; frankly, it doesn't cost much. But like I've said... the consent from other residents... residents’ consent was required for only 45,000 NTD (approx. 1,125 GBP). Also, it didn't work when I said that I could afford the payment myself, because it’s a public space (with several owners).” (Louis, non-indigenous family caregiver, son)
Louis continued to share his perceptions and experiences:

“Just as I have said, it required the residents’ consent. You couldn’t do whatever you wanted. Once one-third of the residents disagree, you cannot make the construction even if the government offers the allowance because it belongs to public assets, unless there is an authorised legislation that compulsorily demands that once the elderly population in a community achieve a certain proportion, then it is forcibly required to establish a barrier-free space. The legislation has been made and is eligible only for the new community but does not include the old communities. This could be recorded matter-of-factly.” (Louis, non-indigenous family caregiver, son)

Louis emphatically urged me to jot this down, as it constitutes a collective need of society that is impeded by inconsistent legislative and administrative systems. These difficulties troubled him tremendously; he was trying to enhance safety in the residential area, but it was in vain. According to the ‘Guidelines for architectural technique: architectural design and construction’ promulgated by the Ministry of the Interior (Laws and Regulations Database, 2019a), newly constructed buildings must be equipped with accessible facilities. The guidelines have amended clauses about design and construction details. However, the regulation does not apply to old buildings established before the introduction of the regulation; thus, Louis and Leonard were constrained in terms of finding a way through this deadlock using the administrative system, because it was out of the current administrative, authority and regulatory scope. Therefore, they next tried to negotiate with the public in the community; however, administrative legitimation remained unachievable, because they could not gather a consensus from the residents.

Louis’ statements emphasise that infrastructure needs to catch up with demand from the ageing population so that not only new buildings but also old facilities can be repurposed for future needs. Drawing on the structural and institutional barriers encountered by the care users, it can be said that the landscape in urban geography involves not only physical infrastructure but also institutional infrastructure, such as a governmental structure or a committee.
convened in an apartment building to negotiate public affairs. Cities have many resources, but this does not guarantee an old age friendly environment or that the society will be functional enough to meet the needs of the ageing population (van Hoof and Kazak, 2018). It has been shown that physical environments (facilities for mobility and social activities) and social environments (administrative and regulation infrastructures) are equally important in determining wellbeing in an ageing life. The social system needs to upgrade the existing regulations in terms of ageing architecture, in order both to keep it functionally appropriate today and to prepare for the population’s needs in the future. It is also urgent that regulation remains consistent throughout the social and administrative systems. Consistent with the research findings, Lui et al. (2009), in their review of the key properties attributed to a sustainable environment for seniors, highlight that local authorities should take a leading role in addressing broader strategies in order to integrate the participatory governance from elderly people and the collaborative governance from stakeholders across sectors (Lui et al., 2009). The integration of governance from bottom-up and top-down can support the establishment of physical and social environments in order to construct an aged-friendly environment.

5.4.2 Barriers to accessing health facilities in the populated urban areas

Similarly, healthcare settings are also public facilities shared by the whole population. When the stroke survivors attended rehabilitation in the healthcare setting, the healthcare facility was crowded, with the space shared by many clients. The workforce in the hospital setting could not pay attention to all clients at the same time, which limited the opportunity and access for stroke survivors to receive frequent rehabilitation in the rehabilitation settings.
Leonard stated that the physiotherapist required him to be accompanied by a residential care attendant when he utilised the equipment at the rehab. He recounted this safety concern pertaining to the hospital setting:

“That rehabilitation centre wouldn’t allow me to go on the treadmills. They were concerned that I might fall down if I was by myself. The teachers (referring to the therapists) there couldn’t be at my side all the time, thus, he/she didn’t arrange for me to use the treadmill. [...] It would be dangerous if no one were by my side looking after me. Dangerous! And I also feel scared. It doesn’t help my recovery and also brings trouble for them if I fall.” (Leonard, non-indigenous stroke survivor).

When accompanied by the residential care attendant, he was able to utilise the equipment he wanted. The intense care demands from the population in the urban area made the issue of workforce inadequacy more obvious. Inadequate soft infrastructure, such as insufficient medical staff to support safety in rehabilitation facilities, constitutes a barrier to accessing healthcare resources. Residential care attendants not only supplement an inadequate workforce in the rehabilitation facility but also ensure an all-round rehabilitation course.

5.4.3 Supplementary role of collaborating with available resources in the micro context

The process of communicating with two administrative systems and negotiating with the residents constrained Louis and Leonard when they applied for the resources in the community. The unavailability of common area improvements made movement in the residential building and healthcare infrastructure riskier; however, the residential care attendants resourced from the LTC system helped to overcome the hidden risks caused by a lack of accessible facilities. A data extract from the observational fieldnotes shows the agency used by the LTC workforce to alleviate tension and facilitate coordination between individual needs and the situated condition in the social systems:
Because the living environment cannot accommodate the healthcare needs of Leonard, a barrier-free public environment could not be established. In this regard, the residential care services made an adjustment and started 30 minutes earlier from 8 a.m. to around 12 p.m. so that the residential care attendant could meet up with Leonard in front of the door on the fifth floor and accompany him while going downstairs and getting on the Rehabus to assure his safety. Furthermore, the residential care attendant also assisted in the duration of rehabilitation as the stroke survivor’s opportunity to use the equipment might have been limited if he did not have a carer accompanying him. (Observational field notes of Leonard’s rehabilitation attendance on April 9, 2019)

Infrastructural barriers limited resource availability and healthcare accessibility for Leonard; however, this shows that the LTC workforce was a human agency that acted on the front line to supplement the inadequacy in the administrative and healthcare systems. In the situation faced by Leonard, the gap between the individual time and organisational time in the healthcare system could be filled by the flexible timetable of the residential care attendant. Meanwhile, the spatial barriers, including the routes from the fifth floor to the ground floor and from home to the healthcare settings, as well as the use of the treadmill at the rehabilitation centre, could also be compensated for by the care provider’s co-presence (Hägerstrand, 1970; Giddens, 1984).

Leonard, Julian and Hobart all benefited from the LTC workforce. Not only did it enable their access to healthcare, social life re-establishment and the embodiment of their well-being; due to the coordination of the LTC services (residential care service) and the NHI medical care system (rehabilitation, outpatient clinic), they were not constrained at home, but instead enjoyed a social life within rehabilitation by treating it as a class comprising themselves and other clients. They attended the rehabilitation scheme regularly, shared experiences, exchanged information and expressed concern for each other’s conditions. As Rowles and Bernard (2012, p. 20) stated, “space matters, but place matters even more because it captures the essence meaning in life”. With social meanings generated, the concrete spatiality settings transformed into places where the participants felt safe and reassured and in which their
post-stroke lives became embedded. The place attachment was derived from meaningful interactions with a collective group of people in a place where they felt a sense of belonging. The coordination of lived time-space that generated place attachment provided momentum for an identification passage, which enabled a biographical continuation along the recovery trajectory (see section 4.3.6, p. 186). Hence, it is evidenced from Figure 5.1 that the participants, Julian, Hobart and Leonard, transitioned in a more advanced way and arrived at a wellbeing state due to their good experiences from the embodiment of physical, sociological and psychological coordination.

5.5 Sociocultural and socioeconomic context as the macro context for the urban-based indigenous group

Chapter 4 (see section 4.3.6, p. 186) showed that the self-identity of the indigenous participants was mainly built on their connection with tribal groups and native lands; they tended to define a place by ethnic and cultural symbols. Their comfort with respect to a place of living was based on their close and long-standing relationships with their home, the cultural and ethnic identity that they shared with their neighbours, the functional reliance of their residential settings, and their remarkable memories of the natural environment (Pace, 2020). Yuri and Novia had temporarily lived in the plains, but had ultimately moved back to their native land as they could not re-create self-identity in the plains. Yuri had urged her children to take her back to the tribal community because she did not regard her daughter’s home in the plains as her own home. Novia distinguished herself from other urban dwellers by defining the latter as plain land people. Yuri and Novia’s experiences epitomise the vulnerability of urban life resettlement for indigenous people. Infrastructural barriers and a lack of ethnic connection with other urban dwellers made their recovery trajectory more challenging, since biographical continuation is usually achieved by retrieving the corporeal self and re-establishing identity in the community (Williams, 2000; Cott et al., 2007).
Urban life failed to provide the contextualities to enable some indigenous participants to re-create self-identity and develop a sense of attachment to the urban environments. Their psychological attachment to the tribal communities characterised by sociocultural symbols caused a detachment from the non-indigenous plains, even though they physically lived there. These situations meant that the urban-based indigenous people ended up partially detached from both their native land and their urban residence. They found it challenging to rely on their urban homes and to benefit from their social, emotional and functional attachment to both places. In this sense, their detachment between their physical place of residence and their sociocultural identities anchored to their native lands led to a dilemma and disadvantages in the macro context in terms of healthcare accessibility and post-stroke recovery.

In the following sections, I first evidence my findings with the empirical data and the distribution of the recovery trajectory in order to discuss how sociodemographic features influenced the stroke survivors’ ability to transition through the passage of identification. Second, I show how socio-cultural and socio-economic factors in the macro context distinguished the urban-based indigenous population’s place identity and place dependence, which constituted barriers to equitable access to the LTC system at the meso level. Third, I highlight the agency facilitated by the LTC workforce in forming place attachment and integrating organisation of time with human perception of time.

**5.5.1 Barriers to re-establishing identity in the community**

The vulnerability of indigenous people living in non-indigenous regions affected their recovery trajectory (see Figure 5.1), as they did not seem to recover as well as the indigenous people living in the indigenous region. In Figure 5.1, the green figures represent the indigenous participants living in the native land (the mountainous indigenous region). Of these participants, Andrew was a grocery shop owner in the indigenous region, and Novia was a participant who had returned to the native land from the plains; both had
arrived at the stage of identification. These participants re-established their identities by displaying self-efficacy among their families and in their communities. Andrew regained his family responsibilities and societal role by being self-sufficient in his grocery business. Novia reconnected with the tribal members at the LTC station and actively participated in all of their daily activities. Yuri was positioned at the stage of having a sense of independence, while Bridget was in her alteration passage post-stroke. Bridget was behind with her recovery, as her higher needs for care and rehabilitation (the sixth level of service demand) were unmet due to geographical barriers.

The yellow figures represent the urban-based indigenous participants. Out of these, two participants were at the stage of having a sense of independence, and two were at the stage of alteration. The geographical placement of the participants may have influenced their stage of recovery, as the participants who required more care developed more quickly on the recovery trajectory. Linda and Ella, who were at the fifth level of service demands, were at the stage of having a sense of independence and approaching the identification passage; they resided in the post-disaster resettlement community, which is situated in the township adjacent to the indigenous region. On the other hand, Hank and Dora, positioned in the alteration status, required the fourth level of service demand and lived in plains that were further away from their native lands.

As elaborated previously, the indigenous people’s attachment to their native lands was shaped by their sociocultural identity and the memorable life experiences associated with their native land (Anton and Lawrence, 2014; Ujang and Zakariya, 2015). An observation of the population’s experiences along the recovery trajectory reveals that none of the urban-based indigenous people had authentically arrived at the identification stage. Corresponding with Anton and Lawrence’s (2014) findings, socio-demographic predictors are correlated to the formation of place attachment, which is influenced by factors such as region of residence, length of residence and ownership of one’s home.
5.5.2 Barriers to identifying care users

The urban-based indigenous group’s attachment to their native land and detachment from their current urban residence were brought to light during their engagement with LTC services and further reflected by their administrative connection. Although these urban-based indigenous people resided in the post-disaster resettlement community, their social links were still deeply rooted in their native land. The district nurses who worked at the local clinic in the indigenous region knew the residents very well, as half of them were indigenous themselves, and were often relatives of their patients or clients. As a result, the contact and connection between the care service advocators and potential care users were close. In contrast, the urban-based indigenous people who resided in the post-disaster resettlement community in the plains did not have a close connection with their healthcare staff and local administrative units. As a result, they were not identifiable by the administrative system, which resulted in disconnection from care sources and delayed service provision. For instance, Bob revealed that Ella was only identified as an eligible LTC user by a local clinic a whole year after she had moved to the post-disaster resettlement community. He described how they had been identified by the administrative staff:

“After (being back in the community) a year, the health clinic came here. You know? Came to the community. The clinic in charge of this region told me that, ‘there is a shuttle bus comes to the community, do you want to send your wife for rehabilitation in hospital?’” (Bob, urban-based indigenous family caregiver, husband)

This disconnect with the care service providers was also experienced by Linda when she tried to have her care services transferred from the mountain region to the non-indigenous plains region. It took three months for the LTC services to accept her new residence. When Linda lived in the mountains, her second eldest sister had taken care of her and her paralysed husband. In an attempt to give this sister some time to rest, Linda applied for two weeks of respite care
in an institution. As a result of this, her regular residential care services from the LTC system were suspended. When the two weeks of respite care became due, Linda decided to accept the help of her eldest sister and moved into the post-disaster resettlement community. However, the LTC transfer process did not initiate successfully. Linda was not re-identified until the supervisor of a residential care attendant came to visit a new client in the community and met Linda inadvertently. It was only after this incident that Linda was able to reconnect to her care services. Linda recounted:

“It had been two months since I was here, I inadvertently met the supervisor and she said that 'there was a client living in our neighbourhood'. Thus, she assigned a residential care attendant to come here.” (Linda, urban-based indigenous stroke survivor)

Multifactorial interplay in transferring services

In Linda’s case, the transfer process took three months because of an uninitiated LTC transfer mechanism and the relatively unidentifiable nature of the indigenous people in the urban area’s administrative system. In sharp contrast to Linda’s delayed service transfer experience, Leonard’s was very smooth. His transfer process was complete in ten days. Leonard complimented the efficiency of the LTC transfer process between administrative units; he had moved from north to central Taiwan to live with his elder son, Louis. The LTC supervisor visited Leonard within a week of the stroke survivor moving into his son’s home. Soon after this, the dyad was created through a swift transfer process, and the residential care services were put in place within ten days. The organisational time in the LTC system synchronised with the time needed for this dyad to adapt to a new caregiving pattern, thereby enabling the smooth continuation of Leonard’s recovery trajectory following his change of residence.

The difference between the swift and delayed transfers was a multifactorial result of the invisibility of urban-based indigenous people in the administrative system and the insufficient role task coordination between healthcare
organisations. The LTC system has demonstrated its potential to coordinate the care-dependent population's living time in their living space. However, a welfare social system would need hard, soft, administrative and institutional infrastructure in order to support the policy implementation of common goal fulfilment, care organisation establishment and care service delivery in social interactions. For the urban-based indigenous participants, the detachment of place identity from their physical locations made them invisible in the administrative infrastructure, both in their native land and in their current residence. This detachment, coupled with a lack of communication, made them more vulnerable in terms of receiving benefits from LTC resources.

5.5.3 Barriers brought about by economic instability

In addition to the place identity that influences LTC service utilisation, place dependence is an expression of livelihood dependence, as affirmed by the urban-based indigenous participants' distribution along the recovery trajectory. The indigenous participants living in the post-disaster resettlement community, which is situated in the township adjacent to the indigenous region, recovered faster than those living in the general communities in the plains. Linda and Ella were able to experience a sense of independence, and attempted to regain self-identity. They were able to self-autonome their daily lives by enjoying personal time, partially independent from their family caregivers. In contrast to this, Hank and Dora, who had moved further away from the indigenous region, reached the point of alteration without being able to enjoy any personal time. They were in the process of retrieving their corporeal bodies, re-feeling themselves through rehabilitation. Meanwhile, their family caregivers were going through the alteration process of coordinating their presence in the household and at work within their limited time by seeking external support from the LTC system.

Considering the fact that Hank and Dora had started their urban lives much earlier than Linda and Ella, the factors associated with their slow progress on the recovery trajectory were more than just a feeling of familiarity or place
identity in the urban environment. This implies that socio-demographic features may have been an underlying factor dominating the disparities. Dora and Hank’s accounts, provided below, show that economic concerns influenced their experiences and perceptions of using healthcare services.

Dora explained how economic instability had constrained her chances of utilising healthcare services. She had a hard time making ends meet; undoubtedly her financial constraints also disrupted her chances of obtaining continued healthcare services. She explained that the petrol expenditure for transportation between her home and the rehabilitation centre, as well as the co-payment fee of 50 NTD (approx. 1 GBP) for each rehabilitation visit, meant that she had decided not to attend rehabilitation as frequently as was scheduled. Instead, she usually opted to attend the LTC station, and enjoyed the free lunch there. Dora said:

“I usually go there (rehabilitation centre) for exercising in the early morning. Maxwell worried about money, no money for filling up the car, so (we) didn’t go to rehabilitation. Also, (we are) worried about requiring paying 50 NTD (approx. 1 GBP each time). … Maxwell (her family caregiver) said that ‘it's about) filling up the car. I didn't give him the expense of petrol for going to the rehabilitation.’ Because mine (money) is for rent, each of us pays half of the rent. I have no money for petrol either. How to say… it's too exhausted.” (Dora, urban-based indigenous stroke survivor)

Hank explained that his financial constraints had further influenced the way he valued the LTC services. When I asked Hank what had changed after the residential attendant came to assist him, he answered:

“Change is only fruits. No other thing has been changed. … The influence is I can have a better mood (for having the fruits). I emotionally felt more comfortable, no other influences. It’s just… I felt that my wishes… my wishes have been fulfilled.” (Hank, urban-based indigenous stroke survivor)

Economic instability limited the extent to which the LTC system could support these participants in carrying on with their post-stroke life in the urban context. The power of social determinants dominantly affected the stroke survivor’s
development along the recovery trajectory. Dora felt stressed about the co-payment, thus she did not attend the rehabilitation as frequently as was scheduled. Hank valued the social care and relief support more than the main content of the residential care services. These accounts highlight the inconsistent goals between individual care users and collective healthcare in the LTC system. The inconsistency between individuality and collectivity has led to a gap between the individual and the system. This was a barrier to equal access to healthcare and a reason for individuals’ slow progress along the recovery trajectory.

**Economic instability brought about by place dependence**

Economic instability was encountered by the two urban-based indigenous participants residing far from their native lands, and influenced their utilisation of the healthcare services. One of the factors that led to the relatively disadvantaged socioeconomic status of the urban-based indigenous group was place dependence. First, being away from the places where indigenous people earned their livelihoods directly affected their work opportunities and income. Second, they became aware that their identity and disadvantaged situation were not the focus of policymaking and welfare entitlement in the administrative system in the plains. In the next few paragraphs, I will discuss these reasons in detail, along with supporting excerpts from the indigenous and urban-based indigenous respondents.

Indigenous people’s source of livelihood is strongly attached to their native land. Andrew and Georgia said that they had fought against the government in order to settle in their native land instead of the plains. They explained why they preferred to stay in the mountainous region rather than move to the plain land area:

“No specific reason, just want to stay here, stay in the mountainous area. We even fought for having this land to be our houses with [the] Council of Agriculture.” (Andrew, indigenous stroke survivor)
“The weather is cool in the mountains, our livelihood is also based on the mountainous area, [I] find no reason to resettle in the plain area. […] I am running BBQ and growing veggies here. If I have extra harvesting then I will sell it.” (Georgia, indigenous family caregiver, wife)

Andrew and Georgia were not the only indigenous participants whose livelihoods were dependent on the mountains. Bob, the family caregiver of Ella, chose to resettle in the plains because of educational concerns. He felt that it would be more convenient for their grandchildren to attend school in the plains when they grew up. However, the family still travelled between the mountains and plain land in order to collect seasonal harvests, which were their main means of livelihood. Ella described their working pattern as part-time workers collecting harvested products before the stroke onset. She said:

“It’s certainly different. I could earn lots of money by collecting tea leaves with my husband before I suffered the stroke. We could earn three to four thousand dollars a day (75 to 100 GBP).” (Ella, urban-based stroke survivor)

Place dependence was embodied in the urban-based indigenous people’s livelihood dependence on their native land. This livelihood dependence was associated with economic stability, which was an essential factor in determining whether healthcare services were affordable to them and whether they had an equal chance of accessing healthcare choices.

**Economic instability brought about by not being entitled to welfare, in contrast to the situation in the native land**

The accounts given above conform to the proposition that the indigenous population’s place attachment stems from their place identity and place dependence. As a result, the pursuit of a coordinated life trajectory in living space for the urban-based indigenous participants was constrained by their detachment from their physical location and attachment to their psychologically-desired place of residence. The indigenous population are
regarded as a minority and a disadvantaged group in the Taiwanese community (Huang and Liu, 2016; Wang and Wang, 2019). To level the uneven geopolitical and historical development and safeguard indigenous rights, the legislative body amended the ‘Regulations on Development and Management of the Lands Reserved for Indigenous People’ in 2019, which ruled that only indigenous people could own land in the indigenous region (Laws and Regulations Database, 2019b). The indigenous region refers to the native land that the indigenous population have inhabited for a long time. Ownership of land in the indigenous region is reserved for indigenous people. For example, if non-indigenous people want to make use of indigenous land, they need to rent it from indigenous people.

Titling land rights might be an effective way for states to address socio-economic development for indigenous populations (Jordan et al., 2020; OECD, 2020). Taiwan is not the only state that has applied this method in order to secure negotiation bases for land utilisation and leasing planning for indigenous people. Canadian and Australian experiences have also revealed a positive correlation between land rights and indigenous people’s opportunities for economic development (Anderson et al., 2006). Indigenous people are more likely to gain wealth from their native land due to the natural resources, intrinsic economic value and socio-political resources for directing their path and making their choices (Slowey, 2008). In this regard, as far as I was aware, four dyads from the indigenous group held lands in the indigenous region, and their families made use of the land in order to produce agricultural products, run bed-and-breakfast hostels or run tribal restaurants. Prima, an urban-based indigenous family caregiver, also owned land in the indigenous region. However, as her caregiving role required her to travel frequently between the mountains and plains, she had to postpone her plan for growing crops and vegetables on her land. The participants from the mountainous indigenous group and urban-based indigenous group living adjacent to the indigenous region appeared to be more affluent than the other two urban-based indigenous participants, Hank and Dora, who resided further away and
had been detached from their native lands for longer than Linda and Ella. Hank and Dora were not eligible for tenure security and not entitled to land possession.

Moreover, indigenous community developments vary in terms of land rights regime, resources/welfare regime, proximity to a service centre, and population size (OECD, 2020). This study also showed a gap in economic status associated with the opportunity and welfare embedded in the native land. In the indigenous region, anyone (irrespective of whether they are indigenous or non-indigenous) who visits the local clinic will be exempt from the co-payment fee of 150 NTD (approx. 4 GBP). This policy was introduced in order to encourage indigenous people to seek medical and healthcare services as and when required, without having to worry about monetary issues. In sharp contrast, Dora had to make a self-payment of 50 NTD every time she visited the rehabilitation centre, even though it was financially difficult for her to do so. The urban-based indigenous people could not benefit from the advantages and rights that were extended to indigenous people in the indigenous region, such as land ownership and the exemption from the clinic registration fee.

Described metaphorically, the native land can be regarded as fertile land; it contains abundant resources and social links, and a policy has been promulgated for indigenous people to leverage the fundamental disadvantages of being a minority group in Taiwanese society. However, when they leave the fertile land in which their life chances are rooted (Slowey, 2008), their quality of life and equity of life chances start deteriorating, and they cease to enjoy the advantages offered to the indigenous population. At this point, urban-based indigenous people face stratification of life experiences due to their disconnection from native land and the fact that they are hidden within their current location. Urbanised indigenous people’s social identity has changed and become distinguished from that of indigenous people in the mountains, as they no longer share common experiences in the same social circumstances (Mannheim, 1970). In the meantime, they can neither create
collective experiences with urban dwellers in the same generation nor find symbols of cultural features to identify themselves within the administrative system in the urban location (Cameron et al., 2018). Thus, it is the separation from their native land in the first instance that limits urban-based indigenous people’s chances to experience a coordinated life trajectory within plain land communities. As a result, the urban-based indigenous participants in my study were the most disadvantaged group among the minority population.

5.5.4 Workforce agency enacted in information and resource linking in the micro context

The flexibility of the LTC workforce has helped urban-based indigenous people to overcome the socio-cultural barriers resulting from the inconsistency of their cultural identities in the physical environment. Care providers also act as a social link for stroke survivors.

Linda’s case illustrates this point well. When the residential care services onboarded her after three months of suspension, she was initially worried about the capability of the new care provider. But when she met her new care provider, she recognised on first sight that the care provider was an indigenous person, and acknowledged that she found the care provider to be capable of holding her up. This confidence stemmed from her impression that indigenous people naturally have good physical strength. Linda’s emotional transformation proves that, irrespective of the tribe to which the residential care attendants belonged, simply having an indigenous cultural identity was helpful in building rapport and trust. Linda described her mindset transformation from worried to relieved after realising that the new care provider was also an indigenous person:

“I worried whether she can hold me up because I am tall and heavy. I worried that she was not strong enough or perhaps very petite. But when the supervisor introduced her, I saw that she is an indigenous person. Thus, I was relieved in my mind, because the indigenous people are all
with good strength. Later on, I heard that she has worked (as a care provider) for ten years and then I felt far more relieved because she is experienced and professional.” (Linda, urban-based indigenous stroke survivor)

When Linda’s time slot for residential care services increased from one hour to two hours, the care recipient and care provider had more time to work together. The LTC provider was able to bring Linda to the LTC station, accompany her during activity participation, and then take her back home when the service time was over. Benefiting from this coordination between the individual and the system organisation of time by the workforce agency, Linda rebuilt her social life in the post-disaster resettlement community. She experienced an increased sense of attachment to this new community, as she started interacting with acquaintances who had the same cultural identity as her and shared social milieu on a daily basis. Linda recounted:

“The care provider asked me ‘where do you want to go?’ I said, ‘let’s go to the LTC station.’ Thereby, she brought me there… I felt fairly good because there were people (with whom) I (was) acquainted. I felt embarrassed in the beginning because it seemed to be a venue for the elderly. But they encouraged me to join them. Plenty of activities were arranged, such as exercising, watching the videos, dancing and playing games.” (Linda, urban-based indigenous stroke survivor)

Moreover, the family caregiver also benefited from the coordination of the individual and the organisation’s time. While Linda took part in community activities at the LTC station, her family caregiver, Prima, was able to take some time to take care of her personal work, independent of Linda. She explained:

“She got two hours now, and it used to be one hour. Now I could do my own things in this two-hour timeslot. For example, I received an urgent document that required me sorting it out (at the administrative sector) in the mountain, so I utilised these two hours back to manage it. But it wasn’t possible before, because of limited time.” (Prima, urban-based indigenous family caregiver, eldest sister)

Due to their structural disadvantages, the urban-based indigenous participants appeared to be more likely to disengage from the administrative system and
the healthcare system as well as from the information provided by them. The LTC service providers worked on the frontline and showed a potentiality to fill this information gap and facilitate communication flow. When the economic situation in Hank’s household was strained, his residential care attendant asked the welfare team in the LTC system to grant Hank a free crutch and provide him with respite care when she had to go on holiday. Ivy said that she was informed of the subsidy information by the residential care attendant:

“For example, a couple of days before, his walking stick was broken. We primarily thought of going to the store (pharmacy) opposite to the hospital where they sell wheelchairs (and medical assistive device). But the lady assisting in showering told us that ‘you don't need to buy at a store, I can help you to apply.’ Because my father is a stroke survivor and we are utilising the LTC services, we can have a new crutch for free as a result.” (Ivy, urban-based family caregiver, daughter)

LTC service providers act as an agency that supports resource integration and brings resources to the right place at the right time. Working at the frontline allows care providers to obtain first-hand information about the care needs of stroke survivors. They help the care receivers to apply for and make use of LTC resources, thereby linking supplies to demands. They have a significant potential to facilitate the power of the LTC system, which is a resource container that needs its power drivers, i.e. the LTC workforce agency, to enhance its efficacy.

5.6 Summary of this chapter

Considering that life experiences take place in and as a consequence of a relationship (Aasbø et al., 2016), the research findings provide an understanding of the complex life experiences inherent in transitioning over time in context, which is the fundamental and paramount step in this ethnographic study. The participants' distribution along the recovery trajectory shows that their sociodemographic backgrounds influenced their individual life transitions, as contextual factors predominantly influenced their access to LTC
resources. The situated LTC system implemented in the community reflects
the contextual barriers of environmental properties and the adaptability of
human agency. The position of the infrastructure and stakeholders related to
the LTC system implementation has been identified within the structure. This
helps to conceptualise the interrelatedness of individual care users and the
LTC system, and further explains how their interactions influence the post-
stroke recovery.
Chapter 6: Navigating the integrated LTC system in a conceptual model

6.1 Introduction

This study found that an effective long-term care (LTC) system, implemented on a set of three-context levels, responds to all of stroke survivors and family caregivers’ needs by coordinating contextual conditions in order to enable the biographical continuation of the individual's post-stroke recovery trajectory. The set of three-context levels of Taiwan’s LTC were structured by: the predominant macro context for policy implementation; the meso context, where tension and coordination occurred; and the flexible service adaptation in the micro context. The research findings stemmed from the aim to explore and describe the experiences, perceptions and beliefs pertaining to LTC services from the perspectives of indigenous, urban-based indigenous and non-indigenous populations in Taiwan. They answered the following main research questions:

- *How does the current long-term care policy meet the needs and expectations of stroke survivors and family caregivers experiencing LTC from different ethnic or cultural backgrounds?*
- *What are the facilitators of and barriers to long-term care for stroke survivors and their family caregivers experiencing care in their community?*

This chapter proposes to make sense of the findings in chapter four and five and elaborates on the contributions of this focused ethnographic study. My ethnographic fieldwork was conducted from August 2018 to April 2019 in three administrative regions in Taiwan, and involved indigenous, non-indigenous and urban-based indigenous stroke survivors and their family caregivers.
Participants were recruited through a combination of purposive and convenience sampling. Data were collected through non-participatory observation of LTC service delivery and individual interviews with 12 dyads of stroke survivors and their family caregivers (four dyads from each fieldwork site). Data analysis included 48 observational field notes and 24 interview transcripts from 24 research participants. Involving minority and hard-to-reach populations in Taiwanese society was key to the ambitions of this study, but posed many challenges. The process of obtaining ethics approval, gaining access to the indigenous context, and finally recruiting eligible urban-based indigenous people for the study required considerable sensitivity and commitment to the research. Addressing these issues involved protracted processes and several delays. Section 3.6 and 3.9 have detailed the process of gaining access and the ethics issues.

Chapter 4 illustrated the stroke survivors and family caregivers' life transitions and biographical continuations within the post-stroke recovery trajectory in order to examine how the LTC policy was meeting the dyads' biophysiological needs and psychosocial expectations. Biographical disruption (Bury, 1982) was identified as valuable in understanding the loss of self-identity in post-stroke life; however, it limits understanding of the complexity of biographical continuation. As a consequence, along with biographical disruption (Bury, 1982), status passage theory (Glaser and Strauss, 2011) was also utilised which helped me understand my data and to delineate and explicate the post-stroke recovery trajectory (see Chapter 4). In Chapter 5, I illustrated the predominance of the macro context, the agency role of micro context, and their resultant constraining and facilitating of actions coordinated at the meso context in order to explain the LTC system in Taiwan. The concepts of macro-meso-micro, time-space-power, and duality of structure and agency were adopted from structuration theory (Giddens, 1984) in order to theorise the data and strengthen the explanation (see Chapter 5).
This study has identified the social contingencies that integrate individuals’ post-stroke biographical continuation and engagement with the LTC system within a social structure. In this chapter, I have structured the discussion using a conceptual model (see Figure 6.1), which is an outcome of this study that navigates the integrated LTC system through the set of three-context levels. The conceptual model is built on the emergent conceptual categories from the data analysis (see Table 3.6, p. 130). It shows how knowledge of life transition and the interrelatedness of social actors have been influenced by social structure, and explains why a national universal LTC policy does not always look the same in different communities. I will elucidate this model through three main dimensions. First, I identify ‘biographical continuation’ within the post-stroke recovery trajectory. Second, I contextualise the social interactions of the individual-collective, individual-system and identity-place concepts, which form the status passages for the biographical continuation along the post-stroke recovery trajectory. Third, I identify the positions, role tasks and interplay among the social actors and social systems in the macro-meso-micro structure.
6.2 Navigating the integrated LTC system with a conceptual model

Figure 6.1 Conceptual model of the integrated LTC system

This study contributed to the unpacking of the complexity of post-stroke recovery and LTC engagement from the perspectives of the stroke survivors and the family caregivers while also considering different contexts. I delineated post-stroke life involving the LTC service into the contexts of time, space and power, as these components constituted situations and gave meaning to co-presence and situatedness of interaction (Giddens, 1984; Glaser and Strauss, 2011). In the conceptual model of the integrated LTC system (Figure 6.1), the time axis was interpreted as the post-stroke recovery trajectory. The stroke survivor’s individual biographical continuation was built into their social interactions and power relations with the LTC system and environment. Individuals’ engagement with the LTC system and social activities occurred on the surface, framed by time and space axes. When an individual interacts with
the LTC system in the social context, the coordination of individual-system, individual-collective and identity-place concepts forms the passages that support status transitions in post-stroke life. The stakeholders involved in the LTC implementation were positioned on the power axis, layered from top to bottom as the macro context of LTC policy implementation, the meso context of LTC system organisation, and the micro context of LTC service practice. Structure and agency occurred across different contextual levels.

The three-context structure is discussed using the dimensions of: the macro context as the predominant barrier for accessibility; the meso context, reflecting the tension and coordination within the situated LTC system; and the workforce agency of adapted services exerted in the micro context, which facilitate the balance between individual needs and situated conditions. The role function and interaction amongst the social actors and social system were illustrated with arrows to guide the relations and causalities. Informed by the categories generated from the data analysis, I started navigating the conceptual model from the point of individuals’ embodiment of biographical continuation on life trajectory. Subsequently, I conceptualised the social interactions between individual, system, collective population and spatial setting, and contextualised the constraints and agency across macro, meso and micro in the context of LTC policy fulfilment.

6.3 Identifying ‘biographical continuation’ in the post-stroke recovery trajectory

This study captured the complexity of post-stroke life from the perspectives of stroke survivors and their family caregivers with different sociocultural backgrounds. Each dyad’s individual experiences formed a post-stroke recovery trajectory that reflected their life status as it transitioned. They experienced the sense of loss when they realised the level of the disability, divergent body-self (Timothy et al., 2016) and shifted power in the existing
familial relationship (Anderson et al., 2017) caused by this disruptive event (Bury, 1982). Their acceptance grew as they attended a rehabilitative scheme which was geared to post-stroke recovery (Williams, 2000; Glaser and Strauss, 2011; Wolfenden and Grace, 2012). The sense of interdependence reflects the co-experienced life transitions within the dyads living with long-term conditions (Moore et al., 1993; Campos et al., 2014). It is an embodiment of ‘biographical we’ under the family caregiving relationship (Aasbø et al., 2016).

Owing to the tension between the family caregiving system and other competing needs placed on human resources by the household and the social structure (Hantrais et al., 2020), the dyads were faced with a process of continuing their life trajectory in a way that was partially independent from each other. The dyads sought biographical continuation by transitioning through the alteration passage with the support of the LTC system and community resources. Fuelled by external resources, the dyads experienced a sense of independence, as they were able to exert self-autonomy in their private time (Kelly and Field, 1996; Cott et al., 2007). They proceeded through their identification passage as the stroke survivors re-identified themselves in the communities where they were located, and eventually arrived at the well-being state when they perceived an optimal subjective sense of self-identity (Haslam et al., 2008; Anderson et al., 2013).

In contrast, the unsuccessful referrals for the intense scheme of in-patient rehabilitation and long-term rehabilitation resources for function maintenance and psychosocial rehabilitation impacted the resumption of self-identity (Wolfenden and Grace, 2012). In my analysis, the post-stroke recovery trajectory evidenced that the biographical disruption (Bury, 1982) was a consequence of the stroke occurrence but not maintained as the disruptive status all the time. Instead, it transitioned the biographical continuation while self-identity could be re-established in social contingencies that facilitated the biographical flow across time and space (Faircloth et al., 2004).
Biographical continuation did not look the same for everyone. It comes in many forms determined by social interactions in multiple situations involving many agents and agencies; each situatedness has its own set of contingent features (Giddens, 1984; Glaser and Strauss, 2011). For the participants in this study, biographical continuation was accomplished by attaining goals that were shared between the stroke survivors and the family caregivers, consensus between the individual and the collective, coordination between human perception and systemic organisation of time-space, and the convergence of identity and place. This study (see Chapter 4) identified the social contingencies in enabling the biographical continuation suggesting initiating from an individual perspective, extending to the social context, and the convergence of the biophysical and psychosocial embodiments to understand the life transition of living with a disability.

6.4 Capturing the complexity of biographical continuation engaging with the LTC system

Given the self-embodied elements of the post-stroke recovery trajectory, the contextuality and situatedness of engaging with the LTC system were constructed through the concepts of individual-collective, individual-system and identity-place, interacting on the surface of time-space convergence. This study has contributed to unpacking the complexity of the situated contexts and activities in the family caregiving system and the LTC system. I have grounded the interpretation of life status passage from the individuals' perspectives and then placed these concepts into the social interaction context in order to explore how contextual factors shaped the contingency of self-identity re-establishment. Therefore, in this section, I elaborate on the understanding of interrelatedness among these concepts.
6.4.1 Concept 1: Individual-collective relationship

The post-stroke recovery trajectory involved not only physical improvements but also psychological satisfaction with one’s life status and social participation, which brought a sense of wellbeing to the daily lives of the stroke survivors and their family caregivers. Recovery status arose from the complex interplay between the individual and the collective. The collective, as identified in this study, could involve families (households), communities (contexts) and other contextually meaningful groups (Anderson et al., 2013; Cameron et al., 2018). The family caregiving system was formed through the agency of intergenerational members providing support, stemming from filial piety and familial obligation (Ng et al., 2016; Hantrais et al., 2020) and often heavily relying on women (Alpass et al., 2017). Three-quarters of family caregivers in this study were women, which implies that the family caregiving system in Taiwan, to a considerable extent, involves female caregiving. The belief in familism refers to the commitment to reciprocate family needs as part of individual development (Lai, 2010; Sayegh and Knight, 2011; Campos et al., 2014) in order to form a centripetal force (Combrinck-Graham, 1985). In this case, it drew two individuals, the stroke survivor and the family caregiver, together as a dyad. The dyad collectively encountered the biographical disruption, experienced the loss of physical self and socio-psychological identity, realised the impracticability of returning to the old life, found a balance between interdependent and independent relationships, and shared collective goals to build a new normal life and regain self-identity. A detailed exploration of the post-stroke recovery trajectory has been elaborated in Chapter 4.

Arah (2009, p. 236), in his exploration of the relationship between individual and population health, defined collective as “a definable group of people who share or are motivated by at least one common interest or work together to achieve a common objective. Collective may give an objectionable sense of an aggregation, yet it has a powerful way of reminding us that every society or collective is made up of individuals who are bound in a rich tapestry”. Resonating with Arah’s (2009) proposition, ‘collective’ in this study is also
viewed as a definable and contextually meaningful group who interact with the LTC system in a shared situated context (Mannheim, 1970; Cameron et al., 2018). The situated context is framed by time-space boundaries around interaction strips, involving the co-presence of actors with shared values and motives to achieve common goals (Giddens, 1984). Therefore, the concept of individual-collective indicates that neither the individual nor the collective in the LTC system is identifiable or definable without informative contextualisation within the other (Arah, 2009).

The status passage theory, which informed the transitions of the post-stroke recovery trajectory, indicates that it is not possible to neglect the reality that “solo passage take place side-by-side with the collective passage” (Glaser and Strauss, 2011, p. 123). In addition to the passage along the post-stroke recovery trajectory, stroke survivors and family caregivers encounter other passages, which compete for time and energy when many of them are articulated. The reliance on women’s caregiving was affected by the fact that more women now undertake paid work for the financial stability of their households, which resonates with the literature (Alpass et al., 2017; Mehta and Leng, 2017). In the Taiwanese context, the agency of generational relations coexists in families and in society. Hence, the alteration passage was unavoidable for the dyads, as the caregiver was required to meet other social responsibilities in the family as well as wider society commitments with limited time and energy. A tension emerges when intergenerational relations affect the individual’s societal role or when other responsibilities in the family constrain the caregiver’s caregiving capacity. The structure and agency of the family caregiving system were elaborated on in depth in section 4.2.5, and illustrated in Figure 4.1 (p. 157), by applying Giddens’ (1984) structure and agency duality model.

The tension between family and society has resulted from demographic change and economic pressures (Dykstra and Komter, 2012; Karpinska et al., 2016; Hantrais et al., 2020). The growing care demands from the older
generation reflect the shrinking caregiving availability of the younger generation, especially when the female caregivers become breadwinners. It affected the alteration passage for the dyads, who sought a new caregiving relationship through the involvement of the LTC system in order to support the insufficient family caregiving availability. At this point, the relationship between individual and collective no longer remains within the family but extends to the wider population, the cohort and society. Taiwanese society also shows an instantiation of the individual-collective when undergoing a status passage following social structural transformation. It is a collective issue that every actor of the cohort has to face, as a generation is identified as a population sharing a collective identity and belonging (Mannheim, 1970; Esler, 1984). Section 4.2.4 elaborated on the intertwined intergenerational relations in society and families. As Clara stated:

“Nowadays, people give birth to fewer children. If there are fewer children or they are all busy, long-term care can take the place of this part, supplement this part. In current society, taking care of elderly families is a huge burden to children, financially, psychologically or both. Hospitalisation costs money day after day, such a great burden.” (Clara, non-indigenous family caregiver, wife)

The LTC workforce was brought into the family caregiving system to resolve the weakening of caregiving capacity among families and to respond to the collective demands of the cohort. The input of the LTC workforce can be understood as devoting time and energy to the household so that the family caregiver can remain accountable to their multi-tasking role and continue along the multiple passages in their life.

6.4.2 Concept 2: Individual-system relationship in time-space

The second concept that helps to conceptualise the complexity of ongoing engagements with healthcare systems, the National Health Insurance (NHI) and the LTC system, when undergoing post-stroke recovery, is the individual-system relationship in time and space. As stated in Chapter 4, time and space
are constituent elements of the social structure (Giddens, 1984). They are also the building blocks for comprehending culture (Helman, 2005; Palitsky et al., 2016) and understanding the social world and actors’ positions within it. Therefore, the social interaction between care users and healthcare systems can also be understood by dissecting the interrelatedness of time-space as it connects to individuals and systems. Kannampallil et al. (2011) defined complexity as the interrelatedness of the components of a system, with the components of complex systems manifesting as properties or features of the systems. In this study, the coordination of the individual’s perception of time-space and the system’s organisation of time-space exerts influence on the efficacy of healthcare systems; this is, accordingly, reflected in stroke survivors’ quality of recovery. The extent to which healthcare services can fit or accommodate the changing needs of the dyads over time, and support them in overcoming barriers in spatial settings, plays an important role in the development of the post-stroke recovery trajectory.

According to the National Health Insurance database (Chiou, 2018), 51.72 per cent of stroke survivors remain disabled six months after the stroke. Of the discharged patients, 92.9 per cent are discharged to home. The stroke survivors and their families anticipated the in-patient rehabilitation and out-patient rehabilitation transitioning on the care continuum from hospitals to the communities. The continued rehabilitation was evidenced to facilitate physical and psychological recovery (Vincent et al., 2010; Teasell et al., 2012). This study showed that a successful passage of transition to acceptance could be attributed to engagement with the post-acute care (PAC) programme, which seamlessly directs stroke survivors to an intensive in-patient rehabilitation scheme in order to make optimal use of their prime time for physical recovery, which is the first six months after stroke onset. The PAC programme can be broken down into: (1) the stroke survivor’s individual perception of recovery time; (2) the system’s organisation of time-space for in-patient rehabilitation; and (3) adaptive time-space, which allows survivors to realise that the incapacitation from the stroke is irreversible and to recognise that their
expectation of a full recovery is often unrealistic. Section 4.3.2 (p. 165) explained the PAC programme and showed how it contributed to overcoming the hospitalisation limitation regulated by the NHI system and enabling the status passage of acceptance.

Dyads are given the opportunity not only for intense rehabilitation but also for realising an authentic post-stroke life by learning from other members in the PAC programme. The experiences and information gained from these other members grants the dyads decision time-space to consider post-stroke life arrangement before returning to their communities. Therefore, the time-space coordination between the individual and the system are also involved in creating time and space for adaptation and decision-making through the interplay of the PAC programme. The interrelatedness among components in the individual and the system manifests as indivisible, emergent, nonlinear behaviour, and self-organisation (Gatzweiler et al., 2017; Gkiouleka et al., 2018). In addition to capturing the complexity of the interactions between individuals and systems, breaking down the components of complex individual-system relationships can also identify unpredictable consequences and contextualise healthcare services’ engagement in post-stroke life. Understanding such non-linear or unexpected situations is beneficial to reducing blind spots and uncertainty (Gkiouleka et al., 2018).

However, not every research participant’s time with the PAC programme went smoothly. The status passage formed by time-space coordination was constrained by inadequate communication between the care provider and care recipient, as well as the distance between livelihood and rehabilitation facility, which led to early discharge (see Section 4.3.2, p. 165). This inadequate communication resulted from unmet inconsistencies in values, goals and trust between the individual perception and the healthcare system. Consequently, it constrained the function and exertion of the rehabilitation scheme. Additionally, power components emerged in the form of the individual’s decision, the care professional’s legitimacy, social determinants, and the
consequences of dropping out of the PAC programme. In the case of indigenous people, who were economically reliant on the indigenous region, the family caregivers would not be able to spend a whole year accompanying the stroke survivors to in-patient rehabilitation, as it would mean giving up their livelihood. Therefore, the benefit of the passage of time-space coordination between the individual and the system was removed by an unmet consensus and predominant socioeconomic factors.

6.4.3 Concept 3: Identity-place relationship

The third concept that drove the post-stroke recovery trajectory was the relationship between identity and place, i.e. space. The stroke survivors rebuilt their identity by interacting with social groups and attaching themselves within the situated context. This was a process in which the individuals identified themselves by defining their surrounding environments. The spatial settings became part of their life. The sense of place emerged naturally, as they defined spatiality not only through the landscape but also through the reflection of their memorable experiences; this sense was influenced by people and infrastructure coexisting in the same place at a given moment. As Ryden (1993) explained, a place is not simply a position or coordinates in space; it is imbued with meanings granted by the people who live in it. A sense of place is the meaning attached to a spatial setting (Jorgensen and Stedman, 2001) and extends from the cognitive, affective and interactive processes carried out by a person or group (Canter, 1992; Rowles and Bernard, 2012).

In this study, people connecting their identities with place was displayed through three types of attachment: functional attachment; emotional attachment; and social attachment. Functional attachment refers to the purpose and instrumental meaning that people grant to spatial settings. Emotional attachment involves memories from within and about familiar places. Finally, social attachment is an instantiation of ethnic and cultural identity. The mixed interplay among these identified forms of attachment influenced the
identity-place relationship of the stroke survivors in varying ways and was found to be relevant to sociodemographic characteristics.

For example, home is a common symbol applied in order to define a place, because people have a close, intimate and long-standing relationship with it (Rowles and Bernard, 2012), which makes home more identifiable; it has clearer boundaries than a neighbourhood or other locations (Anton and Lawrence, 2014). Home, as a symbol, can be applied to conceptualise a sense of place for non-indigenous people or for those living in urban areas, but might not be fully sufficient to represent indigenous people’s relationship with their community or land. In the indigenous context, the bond between people and place is different from that in non-indigenous communities, which is likely correlated with genealogical ties and economic relationships (Anton and Lawrence, 2014). Novia identified herself differently from other dwellers by applying an ethnic identity that made social life in the plain land environment difficult for her:

“I didn’t know anyone there. I had no acquaintance, yeah… I didn’t know them… they were all plain land people.” (Novia, indigenous stroke survivor)

Comparing her current residence with her previous residence in the plain land, Novia was satisfied with her social life within a group of people who had a shared identity. She discussed how this transformation had occurred after she re-established her social life within the tribal community:

“I had some friends to talk to here but didn’t have any there (the residence in the plain land). … (I am) just feeling good. I am in a good mood because I went to the elders’ club. We did art, craft and exercise. I like it, there are some people, some friends to chat with. … I didn’t like it in the beginning because I wasn’t familiar with them. Now, I always walk there by myself. I walk there and come back several times.” (Novia, indigenous stroke survivor)

Section 4.3.6 (p. 186) elaborated the details about self-identity re-establishment through defining places. The identity-place relationship is built
through embedding self-identity in a situated space upon which the social actors imbue meanings (Ujang and Zakariya, 2015). This identity–place relationship also influenced the dyads' interactions with the LTC system. As illustrated, the interaction between individual and system occurs non-linearly and with unintended consequences. The bond between identity and place also benefits from coordination between individual perception and a system’s organisation of time-space convergence. For example, the fact that the stroke survivors regained a social link with other members at the healthcare facility showcases an unexpected outcome in terms of the inherent function of the rehabilitation.

The essential meaning of social life is connections between people and places that allow people to perceive comfort and a feeling of welcoming and belonging through linking their memorable experiences (Mannheim, 1970; Jorgensen and Stedman, 2001). This constitutes their attachment to home, native land, cultural landscape and socio-ethnic identity (Rowles and Bernard, 2012; Pace, 2020). However, the relationship between place and identity caused tension for the urban-based indigenous people, as their attachment to their native land consequently led to a detachment from the administrative system in their current residence. The urban-based indigenous people were socio-culturally and socioeconomically dependant on their native land (Slowey, 2008). Therefore, they moved between mountain and plain land frequently. This frequent change in location often made them relatively unidentifiable or put them out of reach of the administrative system in the urban area. As a result, their engagement with the LTC system did not go smoothly through the coordinated time-space between the individual and the system, which meant that they were less likely to accomplish their development along the recovery trajectory. For example, a sharp contrast in transferring services (see Section 5.5.2, p. 225) could be seen between Linda (an urban-based indigenous stroke survivor) and Leonard (a non-indigenous stroke survivor). In contrast to the ten-day transferring process for Leonard, it took two months for Linda to
continue with LTC services after relocating to her new residence in the plain land.

6.5 Structuration of an integrated LTC system

This study contributed to revealing that the coordinations of individual-system, individual-collective and identity-place are the social contingencies that integrate people’s need for life transition and situated LTC system. Following the discussion of the individual’s life status passage and social interactions, this section discusses the positionality and interactive flow of individuals, the collective population, the LTC system and spatial environments in the social structure. Giddens’ structuration theory (1984) addresses the duality between structure and agency by identifying the interactive process of constraining and enabling forces that shape its existence. Social structures and (human) agency are recursively linked and mutually developed due to their co-presence. Structuration is an ongoing process characterised by the properties of the social structure and system created by social interactions among actors (Giddens, 1984). Therefore, the exploration of these processes by dissecting and reconstructing is conducive to clarifying the complexity of social interaction and extracting meaningful interplay at the right level of description (Goldenfeld and Kadanoff, 1999; Kannampallil et al., 2011).

The temporal, spatial and power relational considerations between the individual and the system allow comprehension of the utilisation of care services in the micro-user context, the organisation of care services in the meso-coordination context, and the establishment of the healthcare system in the macro-sociological context. This section mainly emphasises the irreducible environmental and institutional tensions in the macro context, recognises the coordination effect in the meso context, and acknowledges the LTC workforce agency of adapted practice in the micro context.
6.5.1 Macro context for LTC policy implementation

In the healthcare literature, the macro level is considered the highest level related to policymaking in terms of organising health issues and representing collective interests at the overall population level (Krawczyk et al., 2019; Vaagan et al., 2021). This study has found that the macro context for the LTC policy implementation is an aggregation of persistent and pertinent policy framing based on the contingencies of environmental conditions and sociocultural and economic context. Properties in the macro context condense the collective social actions evolving across time and space that are beyond the reach of individual organisations or actors (Giddens, 1984; Smith et al., 2019).

The establishment and efficacy of the LTC policy in this study has developed differently in different local regions, based on the respective macro-environmental properties of mountainous geography in the indigenous context, urban infrastructure geography in the non-indigenous context and socioculture-economics in the urban-indigenous context (see Chapter 5). The macro context has influenced the establishment of the healthcare facility, workforce equipment and institutional infrastructures. It further shaped the LTC system’s different capacities to respond to the need to exert self-efficacy and reconstruct self-identity in different communities.

The macro contextual properties are irreducible and decisive to social system establishment. The tension between political ideology and environmental barriers has caused unequal access to LTC resources, which has predominately led to social inequalities between people from different backgrounds (Rogers et al., 2015; Vaagan et al., 2021). This study has found that the LTC policy is positioned as welfare from the institutional perspective, which determines equal accessibility through tax-funded and standardised service schemes regulated by the central government (Ministry of Health and Welfare, 2016; Chen et al., 2020; Yeh, 2020). In general, the positive outcomes have been recognised by the research participants, as the policy enrols a wide
population with long-term health conditions, and supplements the inadequate capacity of the family caregiving system resulting from the multiple responsibilities between household and society as more women embark on paid work. However, its efficacy in enabling transitions during post-stroke recovery trajectory varies among the indigenous, non-indigenous and urban-based indigenous populations. Therefore, from the institutional perspective, the enactment of the LTC policy should not aim to achieve equal healthcare access; instead, it needs to address healthcare equity in order to consider the needs of individuals, the collective population and the environmental properties of the situated community and thus establish an accessible, available and appropriate LTC system (Rogers et al., 2015).

6.5.2 Meso context for LTC system organisation

The meso level refers to local organisation arrangement or healthcare regulations (Rogers et al., 2015; Vaagan et al., 2021) that coordinate the organisational aspects of regulating health in a specific population and community (Krawczyk et al., 2019). In this study, the meso context of LTC system organisation is the interface of the policy implementation and service provision in the established facilities, including hard, soft and administrative infrastructures.

Intersection of policy and practice reflects power among social actors, which provides crucial information about the situated LTC system-in-use in the communities (Gkiouleka et al., 2018). Moreover, the intersection also gives prominence to the social relations among individuals, systems, identity and place. Tension in the macro context has led to a regional disparity in LTC system organisation at the meso level. Tensions at the meso level occur when working in infrastructure-underdeveloped and resource-constrained health systems coping with increasing care demands (Krawczyk et al., 2019). Potentially sensitive, unidentifiable concerns have been revealed under the accumulated effects of multiple disadvantages (Gkiouleka et al., 2018; Krawczyk et al., 2019). Urban-based indigenous people, as a population, have
marginalised the indigenous clan members, detached from the native land to which their substance of living and sense of identity was attached, and also detached psychologically from their current residence in the plain land (Pace, 2020). The multifactorial interplay caused barriers and benefits in the meso context. The interplay of accumulated sociological factors has made urban-based indigenous people more vulnerable and invisible in the administrative system in the meso context. In the meantime, they have found it more challenging to rebuild their self-identity and perceive place attachment post-stroke by defining their surroundings (Anton and Lawrence, 2014; McClinchey, 2016). However, this population can also resume their self-identity by defining shared cultural or ethnic characteristics between themselves and the indigenous LTC providers surrounding them, which will generate psychological comfort. Therefore, the role of the care provider brings unintended benefits and value in addition to the service content, as cultural awareness is enlightened during LTC service operation (Hou and Kuo, 2019; Tseung et al., 2020).

Viewing the LTC system implementation at the meso level can identify the adverse effect of multiple inequalities and the positive effects of the operation of the adapted services. Therefore, it reflects the LTC needs of the collective population in the situated place, which is an important way to rebalance and redefine services (Rogers et al., 2015). It can track changes in care service utilisation over time in order to determine the relationship between policy vision and real-life practices. The improved outcomes reflected at the meso level could inform administrative reference infrastructure development, resource distribution, and policymaking authority in the macro context.

6.5.3 Micro context for LTC service practice

Micro-sociology refers to individual behaviours in day-to-day practice (Giddens, 1984; Smith et al., 2019). The micro-operation level is characterised by human action that takes place in day-to-day practice, adapted to an individual situation.
In this study, the micro context refers to the adaptation of LTC service practice to the situated condition and individual needs.

The dominance and subversion of the environmental properties at the macro level stand in contrast to the flexibly operated human resources at the micro level. An overarching benefit of the workforce agency in this study was the flexibility and adaptation of service delivery to individual needs or to assisting with problem-solving. The LTC workforce also reflected particular patterns of agency exertion in different local regions (Groves et al., 2011; Krawczyk et al., 2019). The LTC providers showed an effective and innovative adaptation of care practice, as they understood the needs of the LTC users (Smith et al., 2019). In the non-indigenous context, the LTC workforce agency served in a supplementary role, collaborating with other resources available in the community and accommodating when other services fell short, such as when there was insufficient workforce in the rehabilitative setting. In the urban-based indigenous context, care users attached more importance to the unintentional outcomes of the services operating below the expected level of legitimacy. This reflects the fact that urban-based indigenous people are the most vulnerable group and partly evidenced in the way their specific needs are under-researched or invisible in their negotiations around the LTC system. As for the indigenous context, the available care providers were expected to be more skilful and professional, as there were limited resources available in the mountainous region. Therefore, the care recipients anticipated that the care providers would be trained with extra skills such as rehabilitative movement, which would make up for the limitations of outsourced healthcare professionals.

The LTC implementation was constrained by the macro environment and facilitated by the agency of LTC providers. The workforce agency redefined the appropriate service delivery that structures an integrated LTC system responding to personal needs, providing appropriate services, and optimising the LTC system in a situated context. The LTC providers’ position was ideal for boosting communication between care-providing units and care-receiving
households due to their proximity to care users (Suter et al., 2009). The flexible time arrangement and the adaptable delivery pattern were the power that can initiate interaction and make changes in the integrated LTC system (Giddens, 1984; Lamsal, 2012). This flexibility and communication for individual care needs were grounded on the care providers’ knowledgeability, the service organisations' reflexivity (Groves et al., 2011), and the consistent goals across levels (Bodolica et al., 2016).

Investigating the complexity of post-stroke life and engagement with the care system has provided an understanding of the processes by which the LTC system-in-use is operated and undergoes structuration. However, the innovative practice at the micro level is primarily governed by regulatory and legislative authorities at the meso and macro levels (Smith et al., 2019). The implementation and real-life practices of the LTC system involved cross-levelled constraining and facilitating interactions. It is recommended that the consistency of collective goals be enhanced vertically on the macro-, meso-, and micro-sociological levels. The functionality of human resources and the organisation at the same horizontal levels should be flexible in order to enhance their capacity to alleviate tension and adapt services and thus meet individual needs and the particular situation of the context (Suter et al., 2009; Stewart et al., 2013). Learning from structural constraints and human agency, a fulfilment of integrated LTC system requires a collaborative and mutually developed policy advocacy and service implementation across the macro, meso and micro contexts.

6.6 Summary of this chapter

The research findings resonate with the literature (Cott et al., 2007; Balakrishnan et al., 2017; Vaagan et al., 2021), which highlighted the life transition for individuals with long-term health conditions and the tension when they engaged with healthcare. This study has emphasised the importance of taking an individual’s perspective as a starting point to understand the care
needs and the challenges they encounter when utilising the LTC system. Consistent with the vast literature on post-stroke life, transition in this study involved the biophysical body, psychosocial identity, relationship, and care continuum. Strategies for passages to support life transition require systematic consideration of timing, spatial setting, power of social actors, and cultural awareness. The essential aim is to achieve coordination among the concepts of individual-collective, individual-system and identity-place along time-space strands. It is also important to expand this consideration to the contextual structure in order to understand power relations, become aware of the irreducible environmental and institutional tensions in the macro context, recognise the coordination effect in the meso context, and acknowledge the LTC workforce agency of adapted practice in the micro context. The LTC system operated within the social structure. LTC services were impeded by the macro-institutional and environmental structure and regulated by the meso-organisational infrastructure from top to bottom. The adapted care services that integrated individuals’ perspective of needs with contextual limitation informed the essential contingency of effective services to legislation and policy-making from bottom to top.
Chapter 7: Conclusion

7.1 Introduction

The significance of the LTC system in shaping the status passages for stroke survivors and family caregivers’ transitions from biographical disruption to biographical continuation has been illustrated in this study. The structure and agency of the LTC system have also been explicated. In this chapter, I convey the understanding I have gained from this study in more practical ways in order to deliver the implications of the study and the recommendations for LTC policy, future research and human resources enforcement.

The LTC policy in Taiwan aims to address long-term health issues and actualise ‘actively ageing’ in place under a community-based LTC system (Ministry of Health and Welfare, 2016; Yeh, 2020). It is expected that it will support care recipients and their families living with long-term conditions; however, in order for it to be functional, there is a necessity for family caregiving support. Without family support, the LTC system would crumble. The post-stroke recovery trajectory derived from the stroke survivors’ life transitions illustrates the transitional statuses from loss and worry, through interdependence and independence, to the wellbeing state under the passages of acceptance, alteration and identification. Nevertheless, the rates and stages at which stroke survivors moved on the trajectory varied. The factors facilitating or impeding this were the coordination between the individual’s needs, standardised care in time-space, and identification of a sense of place. This is why some survivors recovered better than others at different points in time and in different spatial settings.

On the whole, there were not many differences in post-stroke care needs between the participants from the indigenous and non-indigenous groups. However, the nature of socio-environments influenced the LTC system
organisation, which created differences. The key point is that the socio-environmental factors of urbanisation issues could actually inhibit LTC access for urbanised indigenous people, who seem to be lost in the LTC system. The volume of the LTC system was relatively sufficient in the urban area. However, the urbanised indigenous people encountered challenges in accessing services and seem to have been invisible within the urban communities; this was reflected in their slower development on the recovery trajectory. In contrast to the indigenous people in the mountainous native land, who were the mainstream population in their community and were entitled to indigenous-focused policy and welfare, the urbanised indigenous people constituted a minority within the urban plains community (Huang and Liu, 2016; Wang and Wang, 2019). They could not benefit from the welfare targeted towards their indigenous identity, and instead became invisible in the urban plains, making them more vulnerable in terms of healthcare access (Wang and Wang, 2019). The flexibility of the LTC workforce could facilitate information and resource linkages in order to overcome these socio-environmental constraints.

This study has contributed to contextualising the post-stroke recovery and the LTC engagement with the conceptual model by drawing on the structuration theory (Giddens, 1984), biographical disruption (Bury, 1982) and status passage theory (Glaser and Strauss, 2011). The study illustrates the individuality and differences through which people and families can be better supported and shows the real world through its raw data. This model gives meaning to the copresence and interactions of individual biographical continuation and systemised care in time, space and power. It describes the positional practices of LTC across the policy implementation, system organisation and service delivery levels. The extent to which healthcare resources respond to individual needs in the socio-environment where they are embedded shapes the status passage and impacts the efficacy of their recovery trajectory. The model has extended social theory in a practical way that contributes to identifying the essence of social interactions and valuing the
potential of LTC workforce agency between individuals and the LTC context within the social structure.

7.2 Implications

This study has shown that LTC policy can operate effectively by collaborating with the family caregiving system and is thus largely supportive of families facing long-term health issues. Nevertheless, it could also be improved by addressing socio-environmental barriers, calibrating the goals from universal coverage in order to address healthcare equity, and flexibly tailoring the service delivery to meet individuals’ needs irrespective of their geographical location. This study has highlighted an effective and responsive LTC policy that supports an individual’s life transition by coordinating the social interactions of individual-collective, individual-system and identity-place within a three-context structure. The coordination occurs in the contingencies where an individual’s perception of time-space works well with the system organisation of time-space, the personal goal in daily life matches with the collective population’s goals, and a sense of self is built in the situated place (Giddens, 1984; Kohli and Meyer, 1986). The implications of the integrated model are an awareness of the nature and irreducible predominance of socio-environmental features and institutional ideology in the macro context, a recognition of the accumulated tension and coordinated effects at the meso level, and an appreciation of the innovative and facilitative practice of the LTC workforce agency at the micro level. Institutional and socio-environmental properties influence the LTC system from top to bottom, but the workforce agency produces the service delivery tailored to community conditions at the grassroots.

Given the structuration of the integrated LTC system, which uncovers the mutual reinforcing interaction amongst the macro, meso and micro contexts, I consider that LTC implementation would benefit from an interactional process under policy reform and infrastructure incorporation with human workforce
enforcement (Giddens, 1984; Bodolica et al., 2016). The policy reform could clarify the collective goals from top to bottom within the set of three-context levels. The incorporation between infrastructure and human agency at the meso and micro levels would further inform policy reform from the bottom up. Resonating with Bodolica et al. (2016), improvement of top-down normative consistency with bottom-up functional empowerment is linked to greater emphasis on the contexts of policy implementation, system organisation and service practices. Following the relevant sections, I extend the implications brought by the integrated LTC system conceptual model and present recommendations for LTC policy structure, service organisation, workforce enforcement and future research dimensions.

7.3 Recommendations

Complex and multifaceted social interactions, coupled with varied contextual conditions, explain why a standardised and unified approach is likely to constrain policy exertion and limit its benefits (Abrahamson and Wilson, 2019a). As the ideal of an integrated LTC system would encounter constraints resulting from the social structure, it would be more pragmatic to focus on the issue of whether a process or agency will facilitate or impede LTC system implementation (Suter et al., 2009). In terms of the policy aspect, the priorities of LTC are to actualise the ideals of accessible, affordable and universal coverage of the national state policy, integrated through and transformed within administrative authorities, organisational bodies and individual providers. The priorities of LTC processes are to coordinate healthcare organisations (facilities, care settings) and stakeholders (specialists, care managers, supervisors) in order to reflect optimal practice, taking into account socioeconomic, sociocultural and contextual conditions. Care practice in everyday life concerns the way services are tailored to individuals' and families' needs and adapted to their lifeworld. This study provides a number of possible recommendations for policy, healthcare professional practice, LTC workforce education and research.
7.3.1 LTC policy

Reconsidering the positionality of family from a policy perspective

The LTC policy attempts to ingrain the initiatives of ‘actively ageing’ and ‘ageing in place’, as they are not only the ideal care pattern based on familial belief but also less costly to societal welfare than other options (Ranci and Pavolini, 2015; Yeh, 2020). However, when considering the cost-effectiveness of welfare expenditure, the tension between the political ideal and the situated condition in the real context emerges. LTC aims to alleviate the load of the family caregiving system; however, great responsibility is still placed upon the family, as the policy endeavours to extend the elderly’s life trajectory at home (Rozario and Rosetti, 2012). Consequently, the challenges of multiple responsibilities between work and caregiving, as well as the tension of competing resources between society and household, still remain in the family caregiving system in Taiwan.

To address the balance between occupation and family caregiving responsibility, the government could consider enhancing the volume of respite care and flexitime for employed family caregivers. The government should actively negotiate with enterprises to share public responsibility by providing their workforce with flexitime for family caregiving. Moreover, it is worth assessing the possibility of LTC paid leave for family caregivers in order to provide sufficient time to settle crises in the family and arrange the required care needs for ill family members. In this sense, these enterprises can alleviate the load off the social welfare system within the ageing society. In the meantime, the enterprises can benefit from retaining an experienced, productive workforce in their industry. From the governmental perspective, LTC paid leave could probably prevent a vicious circle of the overloaded social welfare system caused by disadvantaged households and unemployed labourers leaving the industry in middle age.
The eligibility criteria of the LTC-targeted population (as shown in Table 1.1) entirely focus on care users in terms of their age, functional capacity and ethnicity. As the family is part of the circle of care, the LTC policy should evaluate the positionality of the family caregiver in the policy initiative. Inconsistency between political ideology and policy implementation can be seen, as the policy is meant to address the overloaded family caregiving system, but significantly augments the infrastructure for family-centred and community-based care instead of balancing the development of community care with the institutional care model. It is worth taking another look at the care support available for family members, with the viewpoint that they are individual care users instead of care providers or affiliated LTC clients. The LTC policy needs to provide a consistent definition of its policy vision of family members, and organise an educational and supportive programme in a proactive way by taking into consideration roles and challenges such as caregivers’ place in the sandwich generation and their dual responsibilities towards society and family.

**Reconsidering the financial scheme**

Socioeconomic factors significantly influence healthcare access among disadvantaged groups. Therefore, this study suggests re-evaluating the means-tested co-payment scheme. Although low-income and middle-income households are entitled to an exemption (free-of-charge) and minimal co-payment rate (five per cent) (see Table 1.2), socioeconomic instability still makes healthcare expenditure unaffordable for financially constrained households. In this study, two dyads from the urban-based indigenous group were defined as middle-income households and utilised LTC services with a five per cent co-payment rate. However, they found it hard to afford the expenditure. One dyad, Dora and Maxwell, often deliberated whether or not to utilise the care services. Another stroke survivor, Hank, valued the affiliated relief support more than the service content itself (see section 5.5.3, p. 227). The urban-based indigenous population’s health inequality results from
deprivation of material resources following long-term competition with the mainstream population in society (Anderson et al., 2016; Santos et al., 2021).

Socioeconomic instability, coupled with socio-cultural disadvantages, has brought about multiple inequalities for minority and disadvantaged groups. These groups of people face greater challenges in accessing the LTC system and in accepting culturally appropriate services in an equitable manner. Although the means-tested scheme is intended to provide equal care and subsidy, the multiple inequalities mean that the small proportion of the copayment fee is still burdensome and overwhelming for people who already live constrained lives. This warrants a review of the purpose of the subsidy scale and an evaluation of its appropriateness for each population and their socioeconomic situation.

7.3.2 Healthcare professionals’ practice

Improving the transitioning process between discharge planning and LTC enrolment

The LTC system aims to support individuals living with long-term health conditions in community settings (Wunderlich and Kohler, 2001). Figure 1.4 (see section 1.2.3, p. 15) illustrates the tiered structure of the LTC system from the policy-making perspective and based on care users’ experiences of engaging with care providers within the LTC units. I will articulate subsequent recommendations for healthcare professionals with the term ‘unit’, as their healthcare practices and interaction with care users take place within these units. A discharge-planning programme built into hospital care in the NHI system should focus on enhancing continuity of care between hospital and community, preventing unnecessary readmission and optimising the utilisation of healthcare resources (Lin et al., 2013). Patients and their families are encouraged to participate in a shared discharge decision-making process in order to ensure that the healthcare meets their expectations and is practically
functional in the community setting. The LTC enrolment and the discharge-planning programme have the collective goal of supporting independent life for people living with chronic conditions and their families in the community. Thus, a better quality of LTC utilisation could be built through a more effective discharge-planning programme that would transition patients from acute care units in the NHI system to social and health care units in the LTC system (Chen et al., 2021) by enabling communication and collaboration between healthcare providers.

The PAC programme (see section 4.3.2, p. 165) has demonstrated the positive outcome of a transitional programme that connects in-patient and out-patient rehabilitation and forms a time-space for preparation and adaptation. The stroke survivors and their families had more time to realise the effect of the disease on their lives. They obtained a buffering time-space through preparing for physical and psychosocial needs, transitioning from reliance on the care provided by health professionals to the family caregiving relationship. The success of the PAC programme lies in the flexibility to examine the existing healthcare resources and to find an acceptable compromise in terms of the limit to hospitalisation length and the need for long-term rehabilitation post-stroke. It accentuates the significance of optimising transitional care. Therefore, I suggest improving intradisciplinary and interdisciplinary communication between healthcare professionals, as my research has revealed that the workforce has the best capacity and flexibility for optimising the healthcare system.

Considering that it usually takes at least ten days for a service to be put in place after LTC application (Chen et al., 2021), incorporating discharge-planning into the LTC enrolment process during hospitalisation may be an effective way to shorten the waiting time when patients return home. The discharge planning manager can refer the case to the A unit in the LTC system once they are notified of a discharge preparation, typically three days before discharge, and have confirmed that the patients are eligible for LTC services.
I suggest starting the discharge planning process earlier, five days before discharge, which would allow sufficient time for LTC preparation including residential environment modification, assisted device preparation, and allocation of human resources. If healthcare professionals in the hospitals, care providers in the communities, patients, and families could all be involved in this transitioning process, it would allow the LTC service to meet individuals’ needs more quickly and precisely.

The LTC system has an eligibility criteria and allowance standard for the eight levels of LTC service (see Table 1.1 and Table 1.2); I suggest involving the LTC manager in the A unit (see Figure 1.4) at the beginning of discharge planning and continuing this process using the assessment tools of the LTC system. Inter-disciplinary communication could also be improved through unified documentation and assessment tools; this would facilitate further intradisciplinary communication in the LTC system between the A, B and C units. Interprofessional communication between LTC and hospital care would probably reduce discontinuity and shorten delays during transitions. Meanwhile, intraprofessional communication across A, B, and C units could help to achieve the collective goal of patient-centred care and support for independent living (Cullati et al., 2019; Bajwa et al., 2020). Empowering discharge planning in the NHI system and case enrolment in LTC would facilitate integration between healthcare systems and further enhance communication across the A, B and C units in LTC.

7.3.3 Education

Empowering the LTC workforce

The LTC workforce have shown a capacity to act as frontline support for care users and to cover the inadequate family caregiving system. Utilising the strength and capacity of the LTC workforce would be the most pragmatic and fundamental way to optimise the efficacy of the LTC system. Considering that
the workforce agency is applied differently in different environments, it is crucial to enhance the in-work training programme that equips the care providers practicing LTC services in the resource-limited area with an appropriate mix of skills to meet the needs of patients.

I have suggested cross-disciplinary teamwork in LTC service delivery, as this would facilitate mutual communication among staff (therapists, care providers, care managers, etc.). The care providers could relay the frontline information about individual needs. The therapists could help to empower the care providers with skills to improve their proficiency and resilience in providing person-centred, adaptable care services in different contexts. For example, physical therapists could demonstrate advanced joint and limb movements to residential care attendants after evaluating the care recipient’s immediate condition and reviewing the care plan accordingly. It might help to alleviate the inadequate situation of the therapists in the remote area if the residential care attendants could provide some rehabilitative practice to their clients.

Establishing the LTC services appropriate for minority groups needs to be given more attention when considering LTC workforce recruitment; for example, it would be helpful to increase the recruitment of indigenous people into the LTC workforce and enhance cultural sensitivity in the training programme. The indigenous care workforce could also provide an education programme for non-indigenous healthcare professionals outsourced from the care facilities in the urban area. This would increase the healthcare professionals and care providers’ sensitivity and insight into delivering services with cultural awareness. This study suggests that interactive communication is important across care providers and system organisations. Mutual interactive negotiation is the fundamental method for enabling an integrated LTC system that responds to individual care needs.

To enable good LTC teamwork across disciplines and sectors, finding a balance between role task clarification and flexibility among the workforce
promotes role collaboration/interdependence while respecting individual roles and autonomy (Nancarrow et al., 2013). It is paramount to clarify the role tasks and positionality of the formal workforce, since there is a parallel existence of live-in migrant care workers and domestic LTC providers within the LTC system, as discussed in section 1.2.3. Moreover, in the category of domestic LTC providers, the stakeholders include physicians, nurses, therapists, residential carers, supervisors etc. Role task clarification should not be regarded as a boundary between disciplines; instead, it should help to identify a clear vision and purpose for each role in the team that will steer the direction and clarify the referral criteria for different care demands. The exertion of flexibility takes place on the basis of role task clarification that enables the team to supplement inability or unavailable resources in a particular situated context. Role clarification and flexibility need to be considered and practised together in order to create a team culture, alleviate conflicts, and promote communication among healthcare providers from different professions.

**Improving the working environment**

In the meantime, a sound working environment and rationale for payment must reflect the hard work of the LTC workforce as they take on more and more responsibility. For LTC providers who take part in in-work training, either as a learner or trainer, the corresponding rewards need to be practical in terms of payment, career development opportunities, etc. Moreover, the care providers supporting care service delivery in the remote area need extra payment to compensate for their extensive travel and heavier workloads. Hopefully, this will facilitate their willingness to extend their service delivery to the remote area.

### 7.3.4 Research

**Research on the LTC workforce**

This study did not enrol dyads who relied on live-in migrant care workers. However, this aspect is worth further exploration, as experiences of care by
different types of care workers would help to understand the care pattern. It would be significant to investigate the transformation of care patterns, tension and synergy that interplays among these diverse workforces, as it would improve understanding of the human resources structure in the LTC system.

In order to prepare a more robust human resources system, future research is recommended in order to explore the perspectives of the care providers and thus analyse the underlying pull and push factors that could either be incentives for retention or reasons for attrition. Formal care providers’ perceptions of their caregiving role in the LTC system also warrants further exploration. Care providers’ experiences of engaging with the LTC system would reflect not only the real picture of service delivery but also the communication processes between organisations and supervisors. This would help to clarify the roles, functions, positions and identities of the workforce members in the LTC system, ranging from health professionals in the medical system to social workers in the social welfare system.

Moreover, further research focusing on exploring the LTC workforce system should take into account other labour systems, as this would be significant for providing evidence and projecting the supply and demand of the LTC workforce. By developing a model informed by sociological factors (i.e. socioeconomic, cultural and individual factors) and drawing on empirical data or statistics, the findings of future research could steer policymakers to roll out more comprehensive plans for meeting the future needs of care workers, as well as providing guidance for and facilitating investments in enhancing the workforce training programme.

**Promoting research in and attention to institutional care**

As illustrated in the background chapter, the policy initiatives are intended to prolong life through the phases of health, sub-health, frail, and physically disabled/cognitively impaired by organising an A-B-C Tiers community care
model within the LTC system (see Figure 1.3). However, the support for patients with severe/terminally ill conditions, end-of-life status and/or development of institutional care have not been given a corresponding emphasis in the care continuum.

The research participants in this study ranged from levels three to six in terms of LTC service demands (see Table 1.2) and received LTC in residential and community settings. This study did not enrol care users who were severely ill or had opted for institutional care; hence, I did not discuss the institutional care pattern in depth. However, the research participants explained that their current care pattern had resulted from accumulative contextual considerations and social interactions. Of the 12 stroke survivors in this research, five engaged with care facilities from tiers A, B and C, and seven engaged with tiers A and B. Two stroke survivors in the mountain-based indigenous group did not participate in regular social activities at the LTC tier C station due to the geographical barrier and inadequate transportation service. Socio-cultural barriers impeded two stroke survivors from the urban-based indigenous group, as they were unfamiliar with the urban dwellers. Three non-indigenous people did not participate in social venues, as regular attendance at the outpatient rehabilitation programme already provided them with adequate peers and social life.

This warrants further research regarding the most appropriate care model for individuals with severe conditions, terminal illness or end-of-life status. Exploration of their experiences and perceptions of receiving residential palliative care or institutional care could improve the understanding of their life transition when they engage with different LTC models. This would be conducive to a holistic preparation for diverse needs and different LTC preferences on the care continuum along the ageing trajectory.
7.4 Summary and Reflections on My Research Journey

Prior to my doctoral studies, my clinical and master’s experiences shaped me as a nurse in terms of my pursuit of personal and professional development. This was my first time independently conducting research. I started out on the research journey wobbling in my plans and decision-making, but every baby step helped to put my doctoral studies on a firm footing. Each stage of the study, including developing the research questions, research design, data collection and analysis, was a new learning experience. I would say that the full devotion of my supervisory team and their commitment to overcoming challenges contributed to the completion of my doctoral studies. I gained far more than I could contribute whilst researching this field. This research journey has granted me reflexivity, persistence, empathy and a firm footing in my academic career. These characteristics helped me to grow into a responsible and problem-sensitive nursing researcher.

My initial interest in a post-stroke discharge-planning programme in the NHI system motivated me to research the LTC system. I was originally torn between the discharge-planning programme and LTC system for my research focus due to fear that I might miss valuable views if I disregarded one of them. In the end, my findings stressed an inseparable relation between hospital and community care resources. My study provided recommendations for the discharge-planning process, emphasising collaboration and coordination among the healthcare systems in order to support stroke survivors' transition across the care continuum. When I look back, it seems it was unnecessary to struggle with figuring out the correct or best decision, because there are no right or wrong perspectives. However, though I struggled at times, I always found ways forward through small steps! My findings suggest that the perspectives about knowledge are communicable and mutually informed in the same field. The findings show that the policy is there, but in actuality the LTC workforce is key due to their interpretation of the policy, which allows them to tailor their standardised service to meet individual needs.
I also gained a similar embodiment when I discussed friendship with my PGR buddies. We had specific definitions of friendship. One said that friendship meant people shared the same hobbies and had fun together due to these hobbies. Another said that friendship meant different things in different stages of her life. Her friendship was separated into different categories, such as undergraduate, working career, and PhD career. There is no right or wrong definition of friendship, as people have their own interpretation. However, we conveyed a comparative perspective, as friendship meant that people could share remarkable memories because they co-existed in the tangible environment.

I considered that for research, decisions are limited, whereas perspectives embrace the wider world, stimulating the process of decision-making and giving birth to a reasonable perspective that is closer to the fact. Although I had got over the fixation of figuring out the best decision, I appreciated the exploration of an under-researched field from multiple perspectives and the involvement of the decision-making process. Involving indigenous populations was the most crucial decision and the most challenging part of this study, especially the recruitment of the urban-based indigenous group. Sometimes, I faced the dilemma of whether I should stick to the original recruitment design or compromise it due to the timeframe and eligibility in the chosen field site. When I was caught up in these thoughts, I usually told myself: “don’t be frustrated! It is challenging, but that is exactly why it is worth it”. The spirit of exploring the policy context within healthcare is most clearly expressed in its intangible socio-cultural background. I am glad that I stuck to my decision to recruit equal samples from the indigenous, urban-based indigenous and non-indigenous groups by expanding the fieldwork site and extending the timeframe for data collection. Once I overcame the barriers and challenges, I was introduced to a much wider perspective that helped me understand the field. The outcomes affirmed that the urbanised indigenous group were the golden factor that expanded my perspective and allowed me to make sense of the data in the context.
I experienced a sense of inclusion and some joy in the data collection process in the field after overcoming these challenges. The research participants sometimes shared their real perceptions about life and LTC utilisation, but asked me not to add these to the fieldnotes. This reflected the fact that they were concerned about my role and my connection to other care providers. However, eventually, they accepted my involvement in their lives. At these moments, I was pleased that I was recognised as an insider and that the research participants felt like conveying themselves after considering the pros and cons. Moreover, I had a fantastic time experiencing the cultural events and festive atmosphere in the indigenous tribes. My fieldwork was full of unique experiences, as I was able to be included in the community and to participate in a traditional wedding ceremony and harvesting thanksgiving festival only available to tribal members.

Moreover, I felt joy as I found I was improving in understanding research. In honesty, I could not control my research and did not know where to start with data analysis. I read textbooks and followed their content to outline the analytical process of this thesis. This resulted in a situation in which the description did not present the analytical steps I had carried out and did not make sense of the emergence of the findings. I felt downhearted as my supervisors pointed out the knots, and could not understand how it had gone wrong. After an in-depth discussion and reflection, I recollected all the analytical memos, contextualised my analytical thinking and justified the process step by step. The rewritten draft appeared different and authentically reflected my conduct of ethnographic analysis. Initially, I feared making mistakes; thus, I opted to follow the structure of textbooks and neglected the value of originality in this study. I realised that I had forgotten that I was the researcher and the decision-maker of this study; thus, I should uphold the quality of data and ensure the equal representation of my participants. I was delighted that I could embody the building process of my research ability. It is a process to internalise knowledge from a textbook, apply it practically in order
to make it appropriate to the context, and respond best to the research aim and questions.

I experienced a sense of conflict when analysing data from the three contexts. I spent a long time in the indigenous community, and thus became close to the care providers and participants in healthcare. On the other hand, the context for the non-indigenous group was relatively understandable due to my non-indigenous identity from living in an urban setting. I experienced the least commonality and rapport-building with the urbanised indigenous people. Understanding the data from urbanised indigenous people further strengthened the tension between the insider and outsider perspectives. Because of this, they linked the three contexts that illuminate my data more clearly. The intensity and powerlessness I felt during participant recruitment and data collection helped me to understand the lack of support the participants experienced within the healthcare system. The tensions I faced in the process enabled me to sympathise and empathise with their disadvantages due to my fieldwork experiences. These experiences reflected the reasons I opted for focused ethnography in order to understand the nature of the data within the healthcare implementation context. They helped me to understand not only the vulnerability and lack of support experienced by the urbanised indigenous people but also the problems that meant the LTC providers were powerless to make changes. These ethnographic experiences helped me to move away from preconceptions and prevent centredness, because I could not imagine a world I could not perceive. This also directed a suggestion for further exploration in the LTC system from the perspectives of LTC providers.

I appreciate the persistence that enabled me to complete this research. I did not simplify the research process for a quicker accomplishment of a doctoral degree. I turned down the kind offer from the gatekeepers to assign me eligible participants in a straightforward way. I insisted that I would carry out the research at a pace that enabled me to collect high quality data in an under-
researched population. It was a remarkable and precious opportunity to spend the full length of fieldwork in remote areas in order to fulfil my intention to give voice to vulnerable populations that tend to be muted and voiceless in the community. It seemed that a doctoral career would be a rare opportunity to spend the full recommended length of fieldwork, nine months, in the indigenous community in order to complete my ethnographic research. Therefore, I took every baby step in order to achieve the firmest learning experiences.


CARDINAL, L., LANGLOIS, M.-C., GAGNÉ, D. & TOURIGNY, A. 2008. Perspectives pour un vieillissement en santé: Proposition d’un modèle conceptuel [Perspectives for healthy aging: Proposition of a conceptual model]. *Direction de santé publique et Institut national de santé*


HELMAN, C. G. 2005. Cultural aspects of time and ageing: Time is not the same in every culture and every circumstance; our views of aging also differ. *EMBO reports*, 6 Spec No, S54-S58.


MILANOVIĆ, Z., PANTELIĆ, S., TRAJKOVIĆ, N., SPORIŠ, G., KOSTIĆ, R. & JAMES, N. 2013. Age-related decrease in physical activity and


MINISTRY OF THE INTERIOR. 2018. *Operation main point of subsidy scheme for improving accessible facility in existing residential buildings* [Online]. Available: https://www.cpami.gov.tw/%E6%9C%80%E6%96%B0%E6%B6%88%E6%81%AF/%E6%B3%95%E8%A6%8F%E5%85%AC%E5%91%8A/29-%E4%BD%8F%E5%AE%85%E7%AF%87/31406-%E5%8E%9F%E6%9C%89%E4%BD%8F%E5%AE%85%E6%94%B9%E5%96%84%E7%84%A1%E9%9A%9C%E7%A4%99%E8%8A%AD%E6%96%BD%E7%94%B3%E8%AB%8B%E8%A3%9C%E5%8A%A9%E4%BD%9C%E6%A5%AD%E8%A6%81%E9%BB%9E.html [Accessed 23 October 2020].


NORTHOFF, G. 2013. What is culture? Culture is context-dependence! Culture and Brain, 1, 77-99.


QURESHI, A. I., SALEEM, M. A. & AYTAC, E. 2017. Comparison of endovascular treatment with intravenous thrombolysis for isolated M2


WOLFENDEN, B. & GRACE, M. 2012. Identity continuity in the face of biographical disruption: 'It's the same me'. Brain Impairment, 13, 203-211.


Appendix A: Retrieval of Literature

A1 Searching strategy

This appendix provides details regarding the results obtained with the combination of search terms

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Appendix B: Ethical Approval

B1 Ethical Approval from the University of Edinburgh
B2 Ethical Approval from National Cheng Kung University in Taiwan
B3 Entrusted Agreement of Ethnical Examination for Individual Case
B4 National Cheng Kung University Human Research Ethics Committee:
   Consent Letter of Ethical Approval Application for Thesis Degree
Dear Flora,

APPLICATION FOR LEVEL 1/2/3 APPROVAL

PROJECT TITLE: To explore the experiences of people who receive long-term care services from the perspectives of aboriginal and non-aboriginal people in the Taiwanese community: A focused ethnographic study

Thank you for submitting the above research project for review by the Section of Nursing Studies Ethics Research Panel.

I can confirm that the submission has been independently reviewed and was approved on July 2nd, 2018.

Should there be any change to the research protocol, it is important that you alert us to this as this may necessitate further review.

Yours sincerely

Sarah J Rhynas
Lecturer
Nursing Studies
B2 Ethical Approval from National Cheng-Kung University in Taiwan

審查通過證明

案卷編號：107-092-2 番

計畫名稱：探討原住民、非原住民及非原住民身分之中風患者及家庭照顧者使用長照服務的經驗：焦點民族誌研究

計畫主持人：廖吉玲

指導教授：Dr. Elaine Haycock-Stuart and Dr. Susanne Kean

計畫執行機構：英國愛丁堡大學

核准日期：107 年 07 月 01 日

有效期限：108 年 01 月 31 日

結案報告繳交截止日期：108 年 01 月 31 日

國立成功大學人類研究倫理審查委員會

主任委員 薄美財

中華民國 107 年 6 月 21 日
敬愛的 廖咨諒 您好：

非常感謝您向國立成功大學人類研究倫理審查委員會申請倫理審查。本委員會已就您此項計畫與研究參與者有關之面向進行審議，並同意您按照核准日期開始執行。審查文件（107.06.21）：
1. 研究倫理審查申請表
2. 研究計畫書
3. 計畫相關文件：
   3.1 研究參與知情同意書(長照服務人員)_意見修正後_0620
   3.2 研究邀請函（中風患者及家庭照顧者）中文及離族語
   3.3 研究參與知情同意書_意見修正後_0620
   3.4 研究倫理教育時數證明
   3.5 學位論文申請倫理審查同意函
   3.6 倫理委託審查公文

未來將持續追蹤審查此項計畫直至執行完畢，敬請按期繳交未報告，並請留意：
一、 如結案報告逾期未繳，自繳交截止日期起算三個月後，將視同您撤回此項申請案，此案之審查通過證明即失效，並將列入日後是否受理您的新申請案之參考。
二、 未來計畫執行內容如有變更，敬請提出修正計畫申請。

本委員會對於您承諾將戮力維護研究參與者權益，在此致上最誠摯的感謝與敬意。
Approval No. NCKU HREC-E-107-092-2
Project Title: To explore the experiences of people who receive long-term care services from the perspectives of aboriginal and non-aboriginal people in the Taiwanese community: A focused ethnographic study
Principal Investigator: Liao, Zih-Yong
Advisor: Dr. Elaine Haycock-Stuart and Dr. Susanne Kean
Affiliation: University of Edinburgh
Current REC Approval Period: 7/1/2018 to 1/31/2019
Due Date of Final Report: 1/31/2019

Dear Liao, Zih-Yong,

Human Research Ethics Committee at National Cheng Kung University (NCKU HREC), authorized by the Ministry of Education, has reviewed the project “To explore the experiences of people who receive long-term care services from the perspectives of aboriginal and non-aboriginal people in the Taiwanese community: A focused ethnographic study”. The project and your response to our review comments have been determined by our committee to be in conformity with the ethical guidelines for ensuring that the rights and welfare of research participants are adequately protected. Within the mandate for ethical review, the NCKU HREC hereby approves the implementation of your project.

If the documents reviewed need revision, or if any unexpected event which would affect participants’ rights and welfare should occur, please inform the NCKU HREC during the approval period. Please also notify the NCKU HREC when the project is not being conducted for any particular reason.

If you have any questions regarding this approval, please contact the NCKU HREC office at +886-6-2757575-51020. The NCKU HREC appreciates your commitment towards the ethical conduct of human research.

Yours sincerely,

Mei-Chih Huang, Ph.D.
Chairperson,
Human Research Ethics Committee,
National Cheng Kung University, Taiwan

Date: 6/21/2018
B3 Entrusted Agreement of Ethnical Examination for Individual Case

National Cheng Kung University Human Research Ethics Committee
Consent Letter of Ethical Approval Application for Thesis Degree

This is to inform that I, Elaine Haycock-Stuart, will supervise a student, Liao, Zih-Yong for her PhD study. The study is titled as “To explore the experience of people who receive long-term care services from the perspectives of aboriginal and non-aboriginal people in Taiwanese community: A focused ethnographic study.”

Given that the research proposal is well-written, and the research relevant ethical training courses are attended, the student is academically qualified to pass the guideline of research examination and seek ethical approval. Therefore, I recommend the student to apply for an ethical review from your prestigious committee, and I will keep supervising the student during this study to confirm that it is conducted in light of the opinions from your committee. I will take part in this study to ensure and also be responsible for safeguarding the research participants’ rights and interests of the student.
Entrusted Agreement of Ethical Examination for Individual Case

Original to National Cheng Kung University, Research Center for Humanities and Social Sciences

Subject: Kindly request the Human Research Ethics Committee of National Cheng Kung University to accept our PhD student, Liao, Zhi-Yong’s application of ethical review. The study is titled as “To explore the experiences of people who receive long-term care services from the perspectives of aboriginal and non-aboriginal people in the Taiwanese community: A focused ethnographic study.”

Explanation: Liao, Zhi-Yong, a student from the University of Edinburgh has proposed a study titled as “To explore the experiences of people who receive long-term care services from the perspectives of aboriginal and non-aboriginal people in the Taiwanese community: A focused ethnographic study.” The student seeks for an ethical examination based on the Article 5 and 18 of the Human Subjects Research Act enacted by the Ministry of Health and Welfare. The University of Edinburgh sincerely requests your prestigious committee to review this application. The correlated rights and interests of this entrusted case will comply with the entrusted agreement content announced by the committee.

School of Health in Social Science, The University of Edinburgh

Signed by: [Signature]

Date: [Date]
Discussion with [Name] (Advisor)
Appendix C: Study Information Leaflet

Participant information leaflet to stroke survivors & family caregivers (English Version)

RESEARCH PROJECT TITLE
To explore the experiences of people who receive long-term care services from the perspectives of indigenous and non-indigenous people in Taiwanese community: A focused ethnographic study.

Research investigator: Liao, Zih-Yong

Dear Sir/Madam:
My name is Liao, Zih-Yong and I am a doctoral student at the University of Edinburgh, United Kingdom. I would like to invite you to take part in a research project which is contributing to my doctoral work. You are invited to take part in observational sessions and interviews to help me understand and better explain to other healthcare professionals your experiences of using or receiving the long-term care (LTC) services. The observational session will take place accompanied by the LTC professionals, such as home care attendant or physical therapist, when they are delivering services in your home, and the observation will be noted down by me. The interviews will take approximately 45 minutes and will be audio-recorded. You and your family were chosen because this research project earnestly hopes to understand the LTC services from the perspectives of stroke survivors and their family caregivers. Please read the following information carefully.

The study purpose
The research is to better understand the experiences of people receiving the LTC services in state region.

Do I have to participate?
You do not have to participate in this research, the choice to take part is your decision. The perspectives of both the patient and main caregiver are important for this study and to take part in the study both the patient and main caregiver need to be willing to participate. Your healthcare and your rights will not be affected in any way by whether you take part or not in the study. If you are willing to take part, you will be asked to sign a consent form before the interview takes place.

The likely benefits and risks
There are no direct risks or benefits for participants in this study. Taking part in this study is not going to change the services you receive. However, this study will help me to understand the current LTC services you receive and your views may also help and inform future changes to LTC for other people. The study is not intended to cause
you any harm, if you experience some psychological consequences such as emotional distress and sense of anxiety incur talking about your care you have the right to stop the interview or withdraw from the researcher at any time without giving a reason. Your right of receiving the same quality of healthcare service will not be influenced because of withdrawal.

If your emotional discomfort is unable to alleviate after sharing your experiences, I am responsible for referring you to counselling services, or you can contact the counselling information attached as below:

- **Ministry of Health and Welfare, Executive Yuan**
  - Toll-free counselling number: 0800-788995

- **Community Mental Health Centre, Chiayi County**
  - Website: http://web.cyshb.gov.tw/cmhc/heart2.aspx
  - Counselling numbers: +886-5-3621150; +886-5-3620600 # 411
  - Services hours: Monday to Friday from 9 am to 4 pm
  - Address: 2F., No.3, Sec. E., Xianghe 2nd Rd., Taibao City, Chiayi County 61249, Taiwan (R.O.C.)

- **Community Mental Health Centre, Minxiong Health Clinic, Chiayi County**
  - Counselling number: +886-5-3621150
  - Address: No.7-2, Wenhua Rd., Minxiong Township, Chiayi County 621, Taiwan (R.O.C.)

**Confidentiality and publications**
Your confidentiality and right to anonymity will be observed at all times. The findings of this study will be published in peer reviewed academic journals, conferences and in a doctoral thesis. However, all data will be anonymised, and only anonymised quotations will be used. No one person will be identifiable from the written works. Data collected before requesting for withdrawal will be retained and analysed. The information you share with me is for the purpose of this study and the data recording will only be accessed by me and two academic supervisors (Dr. Elaine Haycock-Stuart and Dr. Susanne Kean). The information collected from you will be stored securely and password-protected and will be destroyed in accordance with the University of Edinburgh’s guidelines.

**What should I do if I want to take part?**
You can contact me through the contact information attached below if you wish more information or to discuss the study and if you decide to take part. You can choose the time and location for the interview that is most convenient for you. Your experiences are valuable for this research. With permission, the digital voice-recorder will be used during the interview.

If you have any questions about this study, please contact Liao, Zih-Yong (s1447314@ed.ac.uk) phone +44 770 901 2527, Dr. Elaine Haycock-Stuart (e.a.haycock-stuart@ed.ac.uk) or Dr. Susanne Kean (susanne.kean@ed.ac.uk) If you wish to discuss this research with a person not related with the study, please contact Dr. Sarah Rhynas (sarah.rhynas@ed.ac.uk)

**Concerns and complaints**
If you have a concern or complaint about the study, please contact the head of school, Prof. Charlotte Clarke, School of Health in Social Science, University of Edinburgh. (hos.health@ed.ac.uk) or submit a request for complaint investigation through the weblink as below: http://www.ed.ac.uk/files/imports/fileManager/WEB%20Complaint%20Form.pdf

Liao, Zih-Yong
PhD student in Nursing Studies
School of Health in Social Science
The University of Edinburgh
e-mail: s1447314@ed.ac.uk
研究計畫名稱：探討原住民、非原鄉區原住民及非原住民身分之中風患者及家庭照顧者使用長照服務的經驗：焦點民族誌研究計畫

研究計畫主持人：廖咨詠

親愛的先生和女士：

我是廖咨詠，目前就讀英國愛丁堡大學護理學博士班，我目前正在進行一項研究，作為學習護理研究的一部分。我想邀請您和您的家人參與我的研究計畫，協助我更深入地了解您們使用長照服務的經驗和感受，並從原住民族及非原住民族群的角度探討使用者對於長照服務的看法，進而幫助我更具體地向其他醫療照護人員解釋您們使用或接受長照服務的經驗。

如果您和您的家人決定參與，我將透過觀察及訪談的方式收集資料，我將跟隨長照服務人員一起到您的家中，在他們提供照護時於一旁觀察，此外，您和您的家人會被邀請接受個別訪談，分享在社區接受長照服務的經驗，訪談地點會在我們雙方都覺得合適的地點進行。訪談過程將會全程錄音，而觀察內容也將由我記錄下來。但是，如果您和您的家人對於回答某些問題或被觀察時感到不舒服，您們可以選擇不回答或是拒絕被觀察。訪談錄音和觀察筆記只會用於研究目的和學術發表，然後資料將被銷毀。發表在期刊或是學術研討會上的研究結果會經過匿名處理，您的身份無法從研究結果中被辨識。這項研究不會直接地影響到您和您的家人，但我希望研究結果可以幫助醫療照護人員提供更適當、更符合大眾健康需求的照護內容。
是否參與這項研究取決於您和您家人的意願，您們也可以隨時選擇退出研究，無需說明理由，您的決定不會為您和您的家人帶來任何負面影響。如果您和您的家人有興趣參與這項研究，請聯繫我：0910-204724 進一步討論研究參與事項。我會在（年/月/日）前等待您的確認，我很樂意回答您任何有關本研究的提問，期待您的回音，謝謝。

誠摯地邀請您的參與，

廖啓詠 敬上
Participant information leaflet to stroke survivors & family caregivers
(Indigenous Language Version)

ongko no kengkiu: 'ucea cohivi na tma’cong no zong-fong no cou ho puutu ho ina la hia

aut’uçu tola noana’a o leaut’ut’uçu.
atuhcu: kengkiu tamo mav’v’o ci cou.
atuhcu kengkiu: leao-cu-yong

maameoi ho maananat’ot’ohaesa:

zou leao-cu-yong na a'o, mi'on’aa seol'acao to mpso to hakase no ngosi to taingakoo na 'ai-tang pao, te'o kengkeu maitan'e nala hia aut'tuuçu tala leaut’uçu tamo maica ci tma’congo no zong-fong ('ela ma’payo'w' e ciengona ta feango), tata’za hocimu to’usni a’o ho cohivi na lamu 'to' moduleName tola noana’o aut'tuuçu muu ci ngosi . te’o ko’ko cohivi nala o’te totiski no hia aut’tuuçu to cou ho puutu. temu to’usni a’o ho peela cohivi nalake hia aut’tuuçu muu to la noana’o leaut’uçu muu ci ngosi.

hocimu kaebu i’u pu tate kengkiu tan’e, te’o i’mi to te’o hia biu’i’iyi ho tuucocosi ho tpotposi , te’o fifo tola noana’o aut’uçu muu ci ngosi ho uhta emmo mu, te’o ’o’aiti na lahe hia aut’uçu muu, a’vinano ta’u ake’a tuucocosi muu poa cohivneni a’o na lamu ‘to’ModuleName ho lahe aut’ut’uçu.ta’taoku’ing ho teto yupeahnguyu, ta’ta yaeza tpotposi na hia to yupeapahnguyu. at’inghi , o’a teko ’ahun yut’inga na nteko o’ta ‘ucea eusvata ci tahlangsatu. i’o te’o loku’ing ho tpotposi ci a’a’ausna, ta’uc’o tita kengkiu ho eusvavata to la’ai yoni tmopso ci ’oyonatompsu. ataveisi ta’uc’u apayo’a.

ina ta’u tpotposi to kengkiu ci tposu, o’a ta’us’a poa yuyafo na ongkomu.o’atahes’ala cohivi no mocmo na ongko no o’u tuucocosi. o’a temu nama ’ae’ aenguza no poa cohivneni no mocmo na a’a’ausnasi no os’o tuucocosi. os’oc’e ta’ta’ia ho cimu to’usni ’ela noana’o yaahioai muu ci leaut’uçu ho poa aususuhcu koa ummu muu na lahe hia aut’ut’uçu tamo botngono cimo maica ci tma’congo.

temu iachia ’tohlangsuh hocimu mici i’u pu tamo maica ci kengkiu, temu iachia tosvo hocimu nac’o , ’atemu nama eusvata na koa nac’o i’u pu, o’a tes’a ahtu koa kuzo suu ho ita micu cono eemo na teko ’tohlangsuh no i’u pu ho o’a. hociko mici i’u pu ta kengkiu tan’e, teko tenva a’o tan’e: 0910240724. teko ko ko tousvusvata note hia yaahioai tamo maica ci kengkiu. te’o totea na teko yut’inga ac’u to no hie no (年/月/日) , te’o ’aveooneoni ho yut’inga na teko ’ucea tuucocosi cimo a’usnu ta kengkiu tan’e. te’o totea na teko yut’inga tan’e.

Yoooho’w no i’u pu ta kengkiu : leao-cu-yong
Appendix D: Informed Consent Form

D1 Informed Consent Form to Healthcare Professionals
D2 Informed Consent Form to Stroke Survivors and Family Caregivers
D1 Informed Consent Form to Healthcare Professionals (English Version)

University of Edinburgh: Nursing Studies
Observation Consent Form

RESEARCH PROJECT TITLE
To explore the experiences of people who receive long-term care services from the perspectives of indigenous and non-indigenous people in Taiwanese community: A focused ethnographic study.

This is to certify that I, ........................................ (name of the participant), hereby consent to participant in the study conducted by Liao, Zih-Yong (research investigator).

By signing this form, I confirm that: (Please answer the questions by ticking the box)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>I have read the information leaflet and understand what this study is about.</td>
</tr>
<tr>
<td>2.</td>
<td>I understand and agree that the research investigator will spend time with me while I am delivering the LTC services.</td>
</tr>
<tr>
<td>3.</td>
<td>I understand that I do not have to take part. I am voluntarily taking part in this project.</td>
</tr>
<tr>
<td>4.</td>
<td>I understand that I can ask for the observation to be terminated at any time.</td>
</tr>
<tr>
<td>5.</td>
<td>I agree that the observation will be handwritten by the research investigator.</td>
</tr>
<tr>
<td>6.</td>
<td>The procedures regarding confidentiality have been clearly explained that pseudonyms will be allocated to all participants.</td>
</tr>
<tr>
<td>7.</td>
<td>I understand that observational notes will be only made available to the researcher, Liao, Zih-Yong, and academic supervisors, Dr. Elaine Haycock-Stuart and Dr. Susanne Kean, in anonymised form.</td>
</tr>
<tr>
<td>8.</td>
<td>I understand that the findings of this study will be published in academic journals, conference presentations, and also be provided to the administrative unit, but that I will not be named or identifiable in any publications.</td>
</tr>
<tr>
<td>9.</td>
<td>I understand that the research investigator will store data in her encrypted laptop and the University's secured DataStore space.</td>
</tr>
<tr>
<td>10.</td>
<td>I understand that the researcher will retain all data for seven years.</td>
</tr>
</tbody>
</table>
11. If I decide to withdraw from this study,
- [ ] I agree the primary investigator to retain and analyse data which has been collected.
- [ ] I disagree the primary investigator to retain and analyse data which has been collected.

12. I understand that any data already collected cannot be taken out once data analysis has been carried out.

13. I have been given the opportunity to ask questions about this study to Liao, Zih-Yong at 0910204724 or s1447314@sms.ed.ac.uk

<table>
<thead>
<tr>
<th>Participant’s Signature/ Date</th>
<th>Researcher’s Signature/ Date/ Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>____________________________</td>
<td>____________________________</td>
</tr>
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</table>
## D1 Informed Consent Form to Healthcare Professionals (Mandarin Version)

### 研究計畫名稱
探討原住民、非原鄉區原住民及非原住民分之中風患者及家庭照顧者使用長照服務的經驗：焦點民族誌研究計畫

### 研究機構名稱
愛丁堡大學

### 經費來源
無。本博士班研究計畫由學生自費完成。

### 研究計畫主持人
廖咨詠

### 職稱
博士班學生

### 聯絡電話
0910-204724

### 職責
執行計畫與知情同意程序

### 共同主持人
Elaine Haycock-Stuart

### 職稱
資深講師

### 協同主持人
Susanne Kean

### 職稱
講師

### 研究計畫聯絡人
廖咨詠

### 電話
04-24850891
0910-204724

## 一、研究目的

我是廖咨詠，目前就讀英國愛丁堡大學護理學博士班，想邀請您參與我的研究，協助我更深入了解長照服務在社區中的執行情況、長照服務使用者的經驗和感受，並從原住民族及非原住民族群的角度探討使用者對於長照服務的看法。

## 二、研究對象

這項研究將於嘉義縣阿里山鄉(原住民地區)，以及阿里山鄉以外的非原住民地區收集資料，收集資料的方式採用非參與式觀察法。詳細的採樣標準如下所述：

- **原住民族群**：成年人(20 員以上)具原住民身分(依據原住民身分法，被認定為山地原住民及平地原住民)，同時現居住在阿里山鄉，或是在阿里山鄉接受長照服務。
• 非原鄉區原住民族群：成年人(20 歲以上)具原住民身分(依據原住民身分法，被認定為山地原住民及平地原住民)，同時現居住或接受長照服務於阿里山鄉以外之嘉義縣行政區。
• 中風患者：成年人(20 歲以上)曾於中風。受訪者需能以中文、台語、或原族語溝通並表達其疾病經驗。中風患者但同時需診斷有失智症，考量失智症會影響患者認知功能，故不予收案。
• 家庭照顧者：成年人(20 歲以上)能以中文、台語、或原族語溝通，並參與中風患者的照顧或主要協調中風發生後的後續照顧及醫療事物。

三、研究方法與程序
我希望跟隨您到服務使用者的家中，於您提供長照服務時進行觀察。觀察結果將由我記錄下來，觀察時間依照當次長照服務項目所需要的時間為準。本項研究共包含 3 個次羣體，分別是原住民族群、非原鄉區原住民族群、和非原住民族群，將分別進行於嘉義縣阿里山鄉(2 個月，觀察原住民族)、嘉義縣非原鄉區(3 個月，同時觀察非原住民族及非原鄉區原住民族身分者)。第一階段做普遍性觀察，隨後重點觀察有中風患者的長照服務使用家庭，每個中風家庭預計觀察 3 次，每個次羣體中觀察 6~8 個中風家庭。目前規劃每週觀察 3 個長照服務項目，預估會有約 60 個觀察情境，實際進行觀察的時間點與次數還需要與您協調搭配後再確認。

四、參與研究應配合事項
若您同意研究者與您同行至個案家中，我需要您協助在觀察前代我向長照使用方聯繫，詢問他們是否同意在接受服務的時候有一位研究者在旁邊做不介入觀察，得到使用方同意後，我才會跟隨您至個案家中觀察，正式開始觀察前，我會再度徵求個案及家庭照顧者接受研究觀察的口頭同意，並提供研究計畫文宣給個案及家庭照顧者。

五、研究潛在風險與處理方式
本研究沒有已知的益處或風險。參加研究不會改變您目前的工作內容及工作條件，但這項研究將幫助我了解目前的長照服務執行狀況，而您的觀點和提供的資訊可能有助於未來的服務內容修正，對長照政策推展提供建議。

六、研究益處
本項研究最有可能對病人及家庭照顧者帶來影響，特別原住民族是少數民族，本研究期望透過資料蒐集和分析了解長照服務在政策規畫和提供時是否考慮到不同族群間的文化差異和健康需求。
如果大眾對於服務使用的經驗是正面的，那麼有助於達成正向成果的因素便能進一步反映到其他長照服務地區，或是體現到更具體的健康醫療系統規畫。然而，若是服務使用者表示服務提供項目有限制或是
沒有符合社區民眾的需求，那麼可以進一步調整改善，此外，這項研究可以促進社區民眾與政策決策者間的對話。

### 七、研究參與者之權益

1. 參與本研究您不需負擔任何費用。
2. 個人資料保護機制
   研究計畫主持人將依法把可辨識您身分的紀錄與個人資料視為機密處理，絕對不會公開。將來發表研究結果時，您的身份仍將保密。中央主管機關及人類研究倫理委員會在不危害您的隱私情況下，依法有權檢視您的資料。
3. 新資訊之提供
   過程中如有新資訊可能影響您繼續參與本研究意願的任何重大發現，都將即時提供給您。
4. 損害賠償或保險
   若您因參與本研究而發生不良事件或損害，得依法請求損害賠償。但可預期之不良事件（例如：因談個人經驗所產生的心情困擾），不在此限。您簽署本知情同意書後，在法律上的任何權利不會因此受影響。
5. 聯絡方式
   若您對研究有疑問時，您可以和研究計畫主持人聯絡，計畫主持人：
   廖咨詠，電話：(04)24850891，手機：0910204724，email:
   flora.0610@gmail.com。
6. 參與權益第三方諮詢管道
   本研究由英國愛丁堡大學委託成功大學人類研究倫理審查委員會已倫理審查通過，若您諮詢參與研究的權益或提出申訴，請聯絡該委員會，電話：06-275-7575 轉 51020，email:
   em51020@email.ncku.edu.tw。
7. 研究補償
   目前未有研究參與補償之規劃。

### 八、中止研究參與或退出

您可自由決定是否參加本研究，研究過程中不需要任何理由，可隨時撤回同意退出研究。如果您拒絕參加或退出，將不會引起任何不愉快，也不會有任何的懲罰，更不會損及您的任何權益（工作內容或醫療照護）。若您決定撤回同意退出研究，可透過聯絡計畫主持人-廖咨詠告知您退出研究的決定，計畫主持人會詢問您退出的原因，但若您不想回答可以拒絕提供理由。您選擇退出當前已收集的資料將被保留，以匿名、無法辨識身分的形式進行資料分析。計畫主持人或研究計畫監督單位，也可能於必要時中止該研究之進行。

若您決定退出本研究(請勾選)：
□同意計畫主持人使用已提供之資料。
□不同意研究使用已提供之資料，研究者應該將資料刪除。

若您同意保留進出當日前已完成資料的資料，計畫主持人將會以匿名、無
法辨識身分的形式進行資料分析，如果您後來對於資料使用有疑慮決
定撤回，可以連絡告知計畫主持人您的決定。需事先向您解釋以下情
形，若是中途退出或決定撤回資料的時間點為資料分析開始前，我將
會依照的意願去除您所提供的所有資料，但若研究已經進入資料分析
階段，將無法依您提出的要求刪除已蒐集的資料。

九、研究可能衍生之商業利益及其應用之約定
無商業利益衍生之情況，故不適用本研究。

十、研究材料之保存期限及運用規劃
本研究所獲得之研究資料，將會以電子方式儲存至加密資料夾及加密
個人電腦中，該個人電腦為計畫主持人所有，只有計畫主持人擁有系
統登入的密碼。此外，為了避免不慎遺失紙本文件，所有紙本文件將
會掃描，連同其他研究資料上傳至愛丁堡大學資料儲存空間
(DataStore)託管，此人員存取空間也是密碼保護的，只有計畫主持人
能夠接觸原始資料。保存期限為論文發表後七年，到期後資料將全數
刪除。根據計畫主持人博士班修業時程，論文將會在 2020 年 12 月
31 日前發表，因此保存期限訂在開始資料收集後，直到 2027 年 12 月
31 日止。

未來研究結果將做 1) 學術發表、2) 行政機關政策推動參考、3) 參與者
追蹤瞭解研究進度三方面使用。學術用途包括有博士論文、期刊文
章、學術研討會發表，行政用途則會由研究計畫主持人撰寫中文報告
書，提供給嘉義縣衛生局推動長照服務政策參考，若您有興趣瞭解研
究進度，我的聯絡方式已附在七、研究者參與之權益的第 5 點，您可以
直接聯繫我追蹤研究進度。本項研究預計在 108 年 1 月 31 日前完
成資料蒐集，並於 108 年 2 月~108 年 7 月進行分析，108 年 8 月~109
年 12 月前完成研究成果報告書，完成研究後，您可以聯繫我索取摘
要報告。除此之外，研究資料將不做任何其他用途。未來研究結果呈
現時，您的真實姓名及個人資料將不會出現在報告上。

十一、研究主持人聲明
計畫主持人或研究說明者已詳細解釋有關本研究計畫中上述研究方法
的性質與目的，及可能產生的風險與益處。

研究主持人簽名：
日期： 年 月 日
十二、參與者聲明
計畫主持人或研究說明者已完整地向本人說明本研究之性質與目的，
且已回答本人有關研究的問題，同時也解釋本人有權隨時退出研究。
□ 我已年滿 20 歲。

研究參與者簽名：

日期： 年 月 日

※ 本同意書一式兩份，將由雙方各自留存，以利日後聯繫。
D2 Informed Consent Form to Stroke Survivors and Family Caregivers (English Version)

University of Edinburgh: Nursing Studies
Interview Consent Form

**RESEARCH PROJECT TITLE**

To explore the experiences of people who receive long-term care services from the perspectives of indigenous and non-indigenous people in Taiwanese community: A focused ethnographic study.

This is to certify that I, .............................................. (name of the participant), hereby consent to participant in the study conducted by Liao, Zih-Yong (research investigator).

By signing this form, I confirm that: (Please answer the questions by ticking the box)

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have read the information leaflet and understand what this study is about.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I understand that I do not have to take part. I am voluntarily taking part in this project.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I understand that I can stop the interview at any time without a reason.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I agree that the interview will be audio-recorded and transcribed by the research investigator.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. The procedures regarding confidentiality have been clearly explained that pseudonyms will be allocated to all participants.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I understand that recordings and transcripts will be only made available to the researcher, Liao, Zih-Yong, and academic supervisors, Dr. Elaine Haycock-Stuart and Dr. Susanne Kean, in anonymised form.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I understand that the findings of this study will be published in academic journals, conference presentations, and also be provided to the administrative unit, but that I will not be named or identifiable in any publications.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I understand that the research investigator will store data in her encrypted laptop and the University’s secured DataStore space.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I understand that the researcher will retain all data for seven years.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. If I decide to withdraw from this study, I agree the primary investigator to retain and analyse data which has been collected.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ I disagree the primary investigator to retain and analyse data which has been collected.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I understand that any data already collected cannot be taken out once data analysis has been carried out.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I have been given the opportunity to ask questions about this study to Liao, Zih-Yong at 0910204724 or <a href="mailto:s1447314@sms.ed.ac.uk">s1447314@sms.ed.ac.uk</a></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Participant’s Signature/ Date
Signature/ Date/ Contact Information

Researcher’s
<table>
<thead>
<tr>
<th>研究計畫名稱</th>
<th>探討原住民、非原鄉區原住民及非原住民身分之中風患者及家庭照顧者使用長照服務的經驗：焦點民族誌研究計畫</th>
</tr>
</thead>
<tbody>
<tr>
<td>研究機構名稱</td>
<td>英國愛丁堡大學</td>
</tr>
<tr>
<td>經費來源</td>
<td>無。博士班研究計畫由學生自費完成。</td>
</tr>
<tr>
<td>研究計畫主持人</td>
<td>廖咨詠</td>
</tr>
<tr>
<td>職稱</td>
<td>博士班學生</td>
</tr>
<tr>
<td>聯絡電話</td>
<td>0910-204724</td>
</tr>
<tr>
<td>職責</td>
<td>執行計畫與知情同意程序</td>
</tr>
<tr>
<td>共同主持人</td>
<td>Elaine Haycock-Stuart</td>
</tr>
<tr>
<td>職稱</td>
<td>資深講師</td>
</tr>
<tr>
<td>協同主持人</td>
<td>Susanne Kean</td>
</tr>
<tr>
<td>職稱</td>
<td>講師</td>
</tr>
<tr>
<td>研究計畫聯絡人</td>
<td>廖咨詠</td>
</tr>
<tr>
<td>電話</td>
<td>04-24850891 0910-204724</td>
</tr>
</tbody>
</table>

十三、研究目的
我是廖咨詠，目前就讀英國愛丁堡大學護理學博士班，想邀請您參與我的研究，協助我更深入地了解您與您的家人使用長期照護的經驗和感受，並從原住民族及非原住民族眾的角度探討使用者對於長期照護的看法，進而幫助我更完整地向醫療照護人員解釋您使用或接觸長期照護服務的經驗。

十四、研究對象
這項研究將於嘉義縣阿里山鄉(原住民地區)، 以及阿里山鄉以外的非原住民地區收集資料，之所以選擇您和您的家人是因為我十分希望從中風患者和其家庭照顧者的角度來了解長期照護服務，詳細的收集標準如下所述：

- 原住民族群：成年人(20 歲以上)具原住民身分(依據原住民身分法，被認定為山地原住民及平地原住民)，同時現居住在阿里山鄉，或是在阿里山鄉接受長期照護。
• 非原鄉區原住民族群：成年人(20 歲以上)具原住民身分(依據原住民身分法，被認定為山地原住民及平地原住民)，同時現居住或接受長照服務於阿里山鄉以外之嘉義縣行政區。

• 中風患者：成年人(20 歲以上)曾經中風。受訪者需能以中文、台語、或鄂族族語溝通並表達其疾病經驗。中風患者但同時被診斷有失智症，考量失智症會影響患者認知功能，故不予收案。

• 家庭照顧者：成年人(20 歲以上)能以中文、台語、或鄂族族語溝通，並參與中風患者照顧或主要協調中風發生後的復健照顧及醫療事物。

需特別向您解釋，中風患者和家庭照顧者將採「配對方式」加入訪談法資料收集，您與您的家人都需要同意接受訪問，期望能收集到完整、豐富的訪問內容，因此，若您的家人表示不願意接受個別訪談，或是您的家人不同意單獨受訪(在沒有其他人的陪同下，接受我的訪問)，我將需要尋找其他配對組合。

十五、研究方法與程序

您被邀請參與觀察及個別訪談。我將會跟隨長照服務人員到您的家中，在照護服務提供的過程進行觀察，觀察結果將由我記錄下來，目前每個中風家庭預計觀察 3 次，觀察時間依照當次長照服務項目所須的時間為準。但實際進行觀察的時間點與次數還需要與您的長照服務人員協調搭配後，再與您聯繫確認。

觀察法資料收集後期，您將被邀請並詢問參與個別訪談的意願，12 位中風患者及 12 位家庭照顧者，分別來自原住民族、非原鄉區原住民族及非原住民族群，將被邀請參與訪談。預計與您和您的家人各訪談 1 次，訪談將會分開進行，您的家人不會在您受訪時在場，每次個別訪談時間大約 45 分鐘，並將進行錄音。若整理訪談內容有疑問，想進一步向您請教、釐清時，我會與您聯繫做第 2 次訪談。

十六、參與研究應配合事項

訪談的部分須要與您和您的家人個別、單獨進行，無法讓任一方陪同，這項研究設計是希望中風患者和其家庭照顧者能在不相互影響、有所顧忌的情況下表達自己的感受。若是中風患者或是其家庭照顧者當中有任何選擇退出訪談，那麼本組訪談將不再繼續進行。

十七、研究潛在風險與處理方式

本研究對參與者沒有直接風險或利益，參加研究不會改變您未來接收的長照服務內容或品質，但這項研究將幫助我了解目前長照服務的執行現況，而您的觀點可能有助於未來的服務內容修正，對長照政策檢討提供建議。
這項研究可能不給您帶來任何傷害，但若是因訪談過程中分享疾病和照護經驗而感到沮喪或焦慮，您有權利在不須提供任何理由的情況下，隨時中斷訪談或退出研究。您接受相同質量醫療照護的權利不會因為退出研究受到影響，如果您的情緒不適無法在停止訪談後緩解，我有責任為您轉介心理諮商服務，若您希望自行聯絡諮商服務，以下相關訊息提供您參考：

- 衛生福利部推廣心理健康促進
  24小時免付費安心專線：0800-788995(請幫幫-救救我)

- 嘉義縣社區心理衛生中心
  電話心理諮詢服務：05-362-1150：05-3620600 轉 411
  服務時段：每週一至週五上午 9:00 至下午 4:00
  地址：61249 嘉義縣太保市祥和二路東段 3 號 2F(嘉義縣衛生局 2F)

- 民雄諮詢站
  電話心理諮詢服務：05-362-1150
  地址：621 嘉義民雄鄉中樂村文化路 7-2 號

十八、研究益處

本項研究最有可能對病人及家庭照顧者帶來影響，特別原住民族是少數民族，本研究期望透過資料蒐集和分析了解長期服務在政策規劃和提供時是否考慮到不同族群間的文化差異和健康需求。

如果大眾對於服務使用的經驗是正向的，那麼有助於達成正向成果的因素便能進一步反映到其他長期服務地區，或是體現到更具體的健康醫療系統規劃。然而，若是服務使用者表示服務提供項目有限制或是沒有符合社區民衆的需求，那麼可以進一步調整改善，此外，這項研究可以促進社區民衆與政策決策者間的對話。

十九、研究參與者之權益

8. 參與本研究您不需負擔任何費用。
9. 個人資料保護機制
   研究計畫主持人將依法把可辨識您身分的資料及個人隱私資料視為機密處理，絕對不會公開。將來發表研究結果時，您的身份仍將保密。
   中央主管機關及人類研究倫理委員會在不危害您隱私的情況下，依法有權檢視您的資料。
10. 新資訊之提供
   過程中如有新資訊可能影響您繼續參與本研究意願的任何重大發現，都將即時提供給您。
11. 損害賠償或保險
若您因參與本研究而發生不良事件或損害，得依法請求損害賠償。但可預期之不良事件（受訪者因談及個人疾病或接受照護的經驗所產生的心情困擾），不在此限。
您簽署本知情同意書後，在法律上的任何權利不會因此受影響。

### 12. 聯絡方式
若您對研究有疑問時，您可以和研究計畫主持人聯絡，計畫主持人：
廖咨詠，電話：(04)24850891，手機：0910204724，email：flora.0610@gmail.com。

### 13. 參與權益第三方諮詢管道
本研究由英國愛丁堡大學委託成功大學人類研究倫理審查委員會已倫理審查通過，若您有參與研究的權益或提出申訴，請聯絡該委員會，電話：06-275-7575 轉 51020，email：em51020@email.ncku.edu.tw。

### 14. 研究補償
目前未有研究參與補償之規劃。

### 二十、中止研究參與或退出
您可自由決定是否參加本研究，研究過程中不需要任何理由，可隨時撤回同意或退出研究。如果您拒絕參加或退出，將不會引起任何不愉快，也不會有任何的懲罰，更不會損及您的任何權益（例如：醫療照護）。若您決定撤回同意或退出研究，可透過聯絡計畫主持人——廖咨詠告知您退出研究的決定，計畫主持人會詢問您退出的原因，但若是您不想回答可以拒絕提供理由。計畫主持人或研究計畫監督單位，也可能於必要時中止該研究之進行。

若您決定退出本研究(請勾選)：
- [ ] 同意計畫主持人使用已提供之資料。
- [ ] 不同意研究使用已提供之資料，研究者應該將資料刪除。

若您同意保留退出當日前已蒐集的資料，計畫主持人將會以匿名、無法辨識身分的形式進行資料分析，如果您後來對於資料使用有疑慮決定撤回，可以連絡告知計畫主持人您的決定。需事先向您解釋以下情形，若中途退出或決定撤回資料的時間點為資料分析開始前，我將會依照您的意願去除您所提供的所有資訊，但若研究已經進入資料分析階段，將無法依照您提出的要求刪除已蒐集的資訊。

### 二十一、研究可能衍生之商業利益及其應用之約定
無商業利益衍生之情況，故不適用本研究。

### 二十二、研究材料之保存期限及運用規劃
本研究所獲得之研究資料，將會以電子方式儲存至加密資料夾及加密個人電腦中，該個人電腦為計畫主持人所有，只有計畫主持人擁有系統登入的密碼。此外，為了避免不慎遺失紙本文件，所有紙本文件將
D2 Informed Consent Form to Stroke Survivors and Family Caregivers (Indigenous Language Version)
### meino ‘oyonatmopsu ‘aitung pao
sei no hakase no ngosi
tposu no tmoemu no i’upu kengkii ( tma’congo no zong-fong ho inala
aut’ucu )

<table>
<thead>
<tr>
<th>ongko no kengkii</th>
<th>kengkii nola hia noana’va aut’ut’ucu tomo tma’congo no zong-fong ci cou fuengu ho cou geesangsi ho pootu: m’av’ov’o ci cou</th>
</tr>
</thead>
<tbody>
<tr>
<td>i’mizi no kengkii</td>
<td>‘aitung pao ngakoo to’usnu no peisu iachia tamo kengkii</td>
</tr>
<tr>
<td>atuhec kengkii</td>
<td>Leao cʉ young ongko no tmarksu hakase</td>
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<tr>
<td>tenva</td>
<td>0910-204724 ongko no yaahioa Atuhec ta kengkii tan’e</td>
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<td>to’usnu kengkii</td>
<td>311usanne kean ongko noma’cohio le eʉsʉsʉsʉtʉ</td>
</tr>
<tr>
<td>lenlaku conohie</td>
<td>Leao cʉ young tenva 04-24850891 0910-204724</td>
</tr>
</tbody>
</table>

二十五、’o koa kengkii tan’e:
zou leao cʉ young na’a’o, mi’on’a tmarks to tai-ngakoo ne ’aitung pao hakase no ngosi, os’o ’ucea poa i’upu na suu ho ’e mimu cono emoo ho te’o ’ucea cohivi na lamu ’to’tobuŋu holaha noana’va aut’ut’ucu tola le-aut’ut’ucu suu ci ngosi, ho peela cohivi namo o’te totiski nola hia bobaito tola aut’ut’uca ci cou ho pootu. Te’o peela poa cohivneni tola yahioai ci ngosi ho peela asuhca poa umnu na tehela hia aut’ut’ucu muu.

二十六、’e te atuhec ma’usni:
te atuhec kengkii ’ela yonta psoseongna ci cou ho pootu, peela tuuccosi ho cohivi ho pootposi, ho os’o i’eima na suu ho ’e mimu cono emoo, os’o ’ucea cohivi na ’to’tobuŋunu ho lahe noana’va aut’ut’ucu tola le-aut’ut’ucu ci ngosi. Mo mais’i ta peohnasi tan’e ’e te’o a’pu’pha ho tposi ci te’o tuuccosi:

* ‘o la yonta fuengu ci cou: ’o micu asa’o no 20 nizusai ci micu saasmoyuskac’uha no mamameoi cila amzocni ta psoseongana ci cou
a’toana ho noa aut’ut’uca to le-aut’ut’uca ci ngosi.
* 'ola yone ngeesangsi ci cou: ’o micu asa’o no 20 nizusai ci micu saasmoyuskac’ahu no mamameoi ’ola afu’u noa aut’ut’uca to le-aut’ut’uca ci ngosi.
* yaa tma’cong no zong-fong (ma’payo’u’e ciengona ta feango): ’o micu asa’o no 20 nizusai ci micu saasmoyuskac’ahu no mamameoi ci moso la tma’congo no zong-fong.
Limunu hoci meelu bua kokungo hoci o’te bua puutu ho cusuvsuvata na a’a’ausna nosu tma’congo. O’a isi a’upa ’o micu ac’ahu no o’tena meelu aumomote’u.
* ’ola himho aut’ut’uca tamo cono emoo: ’o micu asa’o no 20 nizusai ci micu saasmoyuskac’ahu meelu bua kokungo hoci o’te bua puutu ho yupeahngyu cila le-aut’uca tamo maica ci tma’cogo no zong-fong, ho meelu yupeahngyu to le-aut’uca ci ngosi.

Te’o afnasa poa cohivneni, ’o tma’congo no congfang ho i’ola aut’ut’uca, te “aepoha” poa no’upu tate tuucocosi ho tpotposi, temu aepolu tmoemu hote tuucocosi, tata’za hoci meelu ateuyunu nomo amso ho man’i ci te co’cohivi, ko’koeno, i’elaa aut’ut’uca suu ci mimu cono emoo, honci o’ta keba hote tuucocosi, honcoiken no’te tiowa ho ci’u echa tuucocosi na suu, (hoci uk’a no’upu suu ho te’o tuucocosi) te’o ea note keba hote tuucocosi ci mocmo.

二十七、’ote’o hia kengkiu ho atoyangza:
ho os’o koa yooho’a suu ho poa i’upu ta te tuucocosi, ta’u fiho to le-aut’ut’uca suu ci ngosi ho uhto emoosu, ho ’o’aiti ho isi pou aut’ut’uca na suu, ta’u tpotposi na os’o hu’ausni ho isi pou aut’ut’uca suu, ’emo cono tuucocosi cimo cono emoo te i’toteuha usa ho hahuysvata, nate hia noana’o no hahuysvata tec’o totiski no hia pou aut’uca suu to le-aut’uca suu ci ngosi. At’inghi na hiesi no uhtan’e ho hahuysvata, ta’u tuucocosi tola aut’uca suu ci ngosi, hocu cusuvsuvata suu.

No ataveisi no auteuyuna na os’o tpotposi, ta’u yaeza iachia tuucocosi suu na ’to’tohungs hoci ko keba. Te 12 masku uesu cimo tma’congo na zong-fong ho 12 masku uesu cila aut’uca nate tateuyuna no ta’u tuucocosi ci cou fuengu, cou ngeesangsi, ho puutu.
Ta’u asona mai i’masku tuucocosi suu ho ina la aut’ut’uca suu ta mimu cono emoo, ta’u aavaza
ho tuucocosi, hoc’u tuucocosi na suu, o’a tehe no’upi no ’oahngsusu, te asona 45 hun ’omo cono tuucocosi, tena yaeza loku’in, honci pano ntee o’ta asnsana, ho ’ucea i’vaha tuucocosi suu, ta’u asona i’vaha uso suu ho tuucocosi.
二十八、’o teko hia to’usnu hote kengkiu:
ho ta’u tuucocos, te’o poa nopaevai na suu ho ina ’oahngusu, ianan’ova
tuucocos, te ko’ko o’te yupa’eikio yupa hmahv na temu ‘to’tohunga hote
tuucocos. Ho peela esansana na teko ’ueea eusvsvta. Hoci cihi ta suu
hocieno o’te ina ’oahngusu nate o’te mici yut’ingi hote tuucocos, tec’o
’osni tosvo ’o te’o hia tuucocosu.

二十九、nante sokoeva no ’tohunga ho isi kengkiu:
uk’a cite smoyo no koa kuzo muu ta te kengkiu tan’e, uk’a cite liekisi,
o’a te titha yaa peisu, o’ate h’unano koa kuzo no tehela hia aut’ut’uca
muu ta le-aut’ut’uca ci ngosi, tec’o at’ingha titha to’usni a’o ho cohivi
nala a’a’ausna no hia aut’ut’uca tamo tma’cono no zong-fong ho
aatiski ma’payo’u’e feango.’e esko eusvsvta nenusino tee meela
to’usnu ho poa ausuhcu umnu na tela titha aut’uca muu.

Uk’a cite ahtu koa kuzo suu ta isi kengkiu tan’e, at’inghi hoci
panonteko o’te ’ueea eusvta no hiasu tma’cono honcieno na iko ’oha
ta’u’umnu no eusvta no lahe hia aut’ut’uca, teko iachia
ta’to’tohungya hociko o’te ’ueea yut’nga hocu tosveni ’e hia
tuucocosu. O’a tes’a ahtu h’unasi la la hia aut’ut’uca suu. Hociko la
asnguca ngohange vna ’tohungusu, te’o peela eusvta to lepemos’os’o
ho to’usni. Hocikoeno iachia biiebimi tamo yonta peohna ci ’oyona
to’usnu:

- 衛生福利部推廣心理健康促進
  24 小時免費安全專線：0800–788995(請幫幫-救救我)
- 嘉義縣社區心理衛生中心
  電話心理諮詢服務：05-362-1150：05-3620600 轉 411
  服務時段：每週一至週五上午 9:00 至下午 4:00
  地址：61249 嘉義縣太保市祥和二路東段 3 號 2F(嘉義縣衛生局 2F)
- 民雄諮詢站
  電話心理諮詢服務：05-362-1150
  地址：621 嘉義民雄鄉中樂村文化路 7-2 號

三十、’o koa umnu ta kengkiu:
i’e kengkiu tan’e te aso’na atva’esi koa umnu tala aut’ut’uca cimo tma’cono
no zong-fong ho ita la aut’uca ta mimu cono emoo, avahoh ‘e cou a’toana ci
moc’o kakutia, i’e isi a’p’nya ci isi tpotposi, ho tac’u titha tosvsvvta.
nenusino tena a’umnu to’usnu ta ’oyona tmops ho poa aususuhcu umnu natela hia aut’ut’ucu tamo man’ov’o ci cou.

Hoci koa umnu no mocmo ci yatatiskova ’e ito eususvuta, nenusi note yaeza to’usni ’o mocmo cila yaahioai tamo maica totiski ci le-aut’ut’ucu, ac’umnu no to’usni ’o le-pemos’os’o ho poa asuhcu umnu na tele hia aotothomy. Hoci o’ti umnu nala hia aut’ut’ucu, te peela teoteovali ho poa aususuhcu umnu.

I’e kengku eni, te peela to’usni ’e oyonatmops no lepemos’oso ho poa aususuhcu umnu.

### 三十一、’e koa umnu tamo i’upu ta kenhkiku tan’e:

1. ho miko i’upu, o’a teko mofi no peisu.

2. te aulua ’e ongkosu ho i’e isi tpotposi ho o’te psoyaska.
   ’emo ayuhcu kengku tan’e, te boemi no hoolicu ho umnu ci efuefunga na ongkosu ho inate tpotposi no tuucocosi ho o’te poa cohiavnieni no mocmo, ’upena ho cic’umnu eususvuta na a’a’ausna no kengku, tee’o efungu na ongkosu. Ac’umnu to ateuyunu ’oyonatmops, tehec’o to’usni aeufunga ’e tspus eni ho o’te poa kuzo no ongkosu.

3. nante ti’a’ausna honci yaa akameose esmi ci kuici a’usa:
   honci yaa esmi nonte kuici a’a’ausna homo uhta emoo mu ’emo yaahioatan’e, mais’a hoci yaa ti’usnu, ho pohcinghi ta mimu cocoemoo, ho yaa alolongu ta feango honci o’ti ma’ngongoheungu, te i’mi no te’o hia to’usni ho acocoveozaa, ta’u eusvuta to taicini to leaut’ut’ucu, eusvusvuta nante atva’esi umnu nonte hia aut’ucu suu, tata’za honciko cohivei ’emo maica ho aveua ta’to’tohungva, tena ko’ko o’te yupa kuku no ataveisi.

4. te faeni suu nate faeva ci tpotposi.
   Hoci pano ntee faeva ci mo meoino elua ci tpotposi ho isi tuucocosi suu, tamia ’osnia eusvuta suu.

5. tmuhnoi no koa kozo ho paosien
   honci pano te na’no koa kuzo no ongkosu ta isi kengkiu tan’e ho tpotposi, teko meelu boemi no hoolicu ho koksoo ’emo tmtmopsu ta kengkiu ho m’ea peisu no tmuhnoa, at’inghi na isi ayoca cohivi ci osko yut’inga ho isi tuucocosi, o’a mo no’upu tan’e. (i’o osu yut’inga no tuucocosi ta tma’congsu ho ina hia aut’ut’ucu).

6. ’e tko hia lenlaku:
   honci pano tekola ’ucea tuucocosi, teko meelu lenlaku a’o leao cu yong tenva: (04) 24850891, tenva no emucu: 0910204724,
   tmopsx no tenao: email: flora.0610@gmail.com

7. ’ote peela tuocosi ci ’oyonatmopsu hoci pano ntee koa kuzo no kenli suu ho miko i’upu ta hioa tan’e:
<table>
<thead>
<tr>
<th>8. nante hnoo no i’upu ta hioa tan’e</th>
</tr>
</thead>
<tbody>
<tr>
<td>o’a mocu isi ayaca nante hnoo ta kengkiu tan’e</td>
</tr>
</tbody>
</table>

### 三十二、tosveni े kengkiu hociko o’tena i’upu.

Teko meelu ziyu no i’upu hocieno o’te ita kengkiu tan’e, ho isi tuucocosi ho isi eno hu’ofeihni na hia aut’ut’uca suu, teko iachia eusvuta hociko nac’o ho ‘ucea tosveni, o’atemia poa nac’o, o’ate h’unasa sovacu, (o’ate h’unasa tosveni natela hia aut’ut’uca ho ina tekola hia yahioi ho tmopsu.) hociko ‘ucea tosveni ho i’upu ta knkigiu tan,e,teko osni lenlaku tamo atuhcu yaahioa tan’e ci leao-cu-yong ho eusvuta na hiasu o’tena mici i’upu.te’si asona tuocosi na ‘tohun’usu no koa tosvo. Hociko o’te ‘ucea eusvuta ‘ua teec’o, at’ngi temza tposi na a’a’ausnasi ho siya. Ho eusvuta to atuhcu ’oyonatmopsa, o’ate poa yuyafo na ongkosu.

Hociko asansana ‘ucea tosveni े hia tmoptmopsa ta kengkiu tan’e, (teko tposi tan’e)
- ○ os’o teomneni tamo atuhcu kengkiu tan’e े isi tpotposi,
- ○ o’a os’o teomneni tamo atuhcu kengkiu tan’e े isi tpotposi.tee asnsnna aapayo’a
  ‘e oho tpotposi tan’e.

honciko teomneni ho siya na’a े oho tpotposi ci o’u tuucocosi suu, te’ona efecfanga े ongkosu ho o’te poa cohivneni no mocmo, ho peela tpotposi na hia’u kengkiu,honciko ataveia ta’kuv’a na hia tititho ta tposa ho ’ucea tasvoveia, takola lenlaku ho eusvuta tamo atuhcu kengkiu tan’e na ’tohun’usu, te’o aueva poa cohivneni na tesi a’a’usna honciko akameosa tosveni ta taicosi ho tasvoveia ‘e oho tpotposi, honci’u o’temocu tpotposi na hia’u kengkiu, te’o peela yooveinei suu, at’inghi hoc’i’uca aepanga na hia’u kengkiu ho tpotposi, o’a na te’o peela yaino hiasu e’e ho afsa na os’ocu afu’a kengkiu ho tpotposi ci tposa.

### 三十三、nante sokoeva no phieni े isi tpotposi to kengkiu:

O’a teko sokoeva no titha phieni े isi tpotposi ci kengkiu ho ea peisui.

### 三十四、’ete hia sona’va ta isi kengkiu ci tposu:
i'e isi tpotposi ci tposu no kengkiu, tena sia ho sohulena to ten-nao ho o' te peela paavi no mocmo, zou i' o mo atuhcu kengkiu tan'e ci leao-cu yong 'ote atuhcu a't'uca ta tposu tan'e ho efanga 'o o'yomza na maavo ci tposu to ten-nao. A'vinane te acuha tas'ongkoi 'o afu'u matpotposu no saiptuku te ko'ko o' te payo'a. tena yaeza to mocmo ci tposu no kengkiu ho pa'i'usna to 'oyona tmopsu ne 'ai-tung-pao ho poa to-eimoha hote sia to sooko no matpotposu. Ho pomu. I' e matpotposu no kengkiu tan'e, lahec'o titha kengkiu no hakase, hocieno sia to tposu ho titha tonsvsvsvu. O'a isi titha no mocmo ci o'a 'emo maica. la topitvuha hola aut' uca ataveisi no eusvsvuta 'e tposu no kengkiu eni, no ataveisi tenac'u acuha saapayo'a, hoci tamza to hia nona'o homo tmopsu 'o hakase, i'e tposu eni, tena eusvsvuta no auyusi hie no tosoha 2020/12/31, ko'koeno te siya 'e tposu eni ac'auh no tonsoha 2027/12/31.

ina tena hu'a'ausna atvei no kengkiu, 'emo coni): tena eusvsvuta tola maotmotmopsu ci cou. 'emo youso): tena eusvsvuta to 'oyonatmopsu cila atuhcu yaahioai no koa umnu eahaahafo, 'emo tuyu): poa cohivneni ho yaeza asuhca i'eima 'o moso i'upu ci oho tuucocsi ho tposi 'e tposu eni.
i'e isi titha ta maotmotmopsu tan'e , a'upu 'o tposu no hakase, tposu no sinvung, tposu no eusvsvu; i'o isi titha to 'oyonatmopsu, tena pahcingha tomo bua ciukoku ho faeni to 'eiseikeoku ho poa cohivneni tola noana' o loan't' uca tomo maica ci tma' congo tela cohivi na tela atva'esi umnu no hia aut' ucau.hocko 'ucea cohivi na hia monmon'i ta hioa tan'e ,os'ocu tposi to( 七) na teko hia lenlaku a'o.
i'e kengkiu eni, tena aepunga no tonsoha 108/1/31'ote hia auteuyunu ta matpotposu, a'vinane aepunga na tposu no kengkiu no tonsoha108/2~108/7, tenac'u aepunga no 108/8~109/12 na hia 'e'elua ci matpotposu kengkiu hocu eusvsvuta. hocic'u aepunga 'e kengkiu tan'e, tako meela tuucosu ho mayo to tposu no ae'aepunga.

三十五、e' e no tmoemu tamo atuch yaahioa:
'omo atuhcu yaahioa ta kengkiu tan'e, isi cu acuha eusvsvuta ho poa cohivneni na a' a'ausna note koa umnu ho koa kuzo.

tmaongko:________________ hiesi no tposi:____年_____月____日

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三十六、e’e no tmoemu tamo i’upu ta hioa tan’e:
ihin’i cu a’umta etoyangza ta mihin’i atuhcu yaahioa ta kengkiu tan’e na
ho poa cohivneni a’o natehin’i atuhca ’ucea cohivi tuucocosi ho ina te
hin’i ’ucea yuu’i’ia ho tpotposi, ho poa cohivneni hoci’u meel tosvo
hoci’u ahaa’o nac’o no taicosi.
□mi’ocu asa’o no tompuska

teraongko；_____________hiesi no tposi：____年____
月____日

※ i’e tposu no tmoemu, mo yuso, teto yaezi ho aut’uca, te ko’ko titha
hoci la youpa tuocosu.
Appendix E: Interview Guide

*To understand how services may have changed over time:*

Could you please describe the long-term care (LTC) services you have received?
可以描述一下，接受過的長期服務項目有哪些呢？
Which services you currently use?
目前還在使用的服務項目有哪些呢？
Could you tell me what happened when the stroke occurred?
可以請你描述中風的經過嗎？
Could you please describe the daily living after you got home after being discharged from the hospital?
可以請你描述出院後回家後的生活嗎？
What has changed (in daily living) after the stroke onset?
中風後的生活發生了什麼改變？
(If the stroke survivor is incapable of answering this question, I feel like to ask he/she to describe one-day life before and after the stroke respectively.)
What difficulties you have encountered?
您曾遇到什麼困難呢？
How is the adaptation?
適應的如何呢？可以描述適應的過程嗎？
Does any incident happen after returned home?
返家後有沒有發生什麼意外？

*To understand types of assistance or sources he/she might need in daily living:*

Could you please talk about the assistance you required in the daily living?
您能談談日常生活中需的幫助有哪些呢？

*To understand post-stroke family caregiving at home:*

How has your family discussed the post-stroke care?
家人間如何討論中風後的照顧呢？
Could you tell me reasons why you serve as family caregiver?
可以告訴我成為家庭照顧者的原因嗎？
How did you think about the caregiving work?
你對於照顧工作有什麼想法？
What difficulties you have encountered?
您曾遇到什麼困難呢？
What do you do within that circumstance?
您如何處理這種狀況？
How did you talk about your care demands to your family?
你如何向家人談照顧的需求？
If the stroke survivor experienced resettlement, such as previously institutionalisation, being cared for by another family member, post-disaster resettlement, etc.:

Could you please talk about reasons why you changed the residence?
可以請你說說改變居住地點的原因嗎？
Could you please describe how life was going there?
能請您描述一下那邊的生活嗎？
How do you perceive the differences between those places?
您感覺這些地方有什麼不同？
Could you please talk how your social life has changed after stroke?
可以請您分享中風後的社交生活嗎？

If the stroke survivor used to institutionalisation:

Could you please explain the circumstance/ or the reasons why you choose the institution as your residence?
可以說說當初為什麼決定要去住機構？您能否分享一下您選擇住機構的原因呢？可以請您描述當時的情況嗎？
What makes you return home? Or what makes you resettle at here?
是什麼原因讓你回家/來到這裡？

To understand the residential care services:

How has your life changed after the involvements of the residential care services?
在有了居家服務之後，生活有什麼變化？
How has your daily life been assisted?
你的日常生活得到了怎樣的幫助？
How is now and the period after you went back from hospital after the stroke different?
現在的你跟剛返家那時候有什麼不同呢？

If Rehabilitation is accessible to the dyads:

How do you perceive your rehabilitation?
你覺得復健的怎麼樣？
What has changed after accepted the rehabilitation?
接受復健後發生了什麼變化？
Could you please describe the content of your rehabilitation?
能描述一下您的復健內容嗎？
Positive feedback→Why do you think it is important to accept rehabilitation?
為什麼您認為復健很重要？
In what ways, the rehabilitation influences your life?
復健運動如何影響你的生活？
Negative feedback

Why do you think that way?

Could you please describe your perceptions about good rehabilitation?

What a good outcome of the rehabilitation should have looked like?

To understand perception of attending the LTC stations in the community:

Would you describe your experiences of attending the LTC station?

How has life changed after you attending the LTC station?

The perceptions of the general LTC services:

Where do you know the information of the LTC services?

Would you share what LTC services mean to you?

How has your daily life been assisted?

Could you please describe your perceptions about good care?

How you express your issues when you encounter it?

How the LTC services could be improved

If religion or belief has been mentioned, I would like to probe as follows:

Could you please explain how religions/ beliefs influence on people in their daily living?

How have religions/ beliefs impacted on people’s attitudes/ ways of thinking after they got sick?
### Appendix F: Example of the Development of a Category

This appendix uses a section of Clara’s interview transcripts as an example to demonstrate the development from raw data in Mandarin and English transcripts to initial codes, descriptive codes and descriptive categories in the first cycle of analysis.

<table>
<thead>
<tr>
<th>Coded Transcripts in Mandarin</th>
<th>Translated Transcripts</th>
<th>Initial code</th>
<th>Descriptive code</th>
<th>Descriptive category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clara：我說：「三天我也是要讓你去，讓你有辦法可以出去，有辦法可以跟人群在一起，這樣我就比較放心。」(1)你恐怕不是自己一個人在家裡，我如果去做工 作，自己在家裡要是跌倒沒人看到(2)。你恐怕你出來做復健，你至少還在人群裡面，我不在家我也比較放心(3)。</td>
<td>Clara: I said that “No matter how I make you go out even though it's three days, let you be able to go out, get along with the crowds so that I can be at ease slightly.” (1) At least you are not staying home alone. I would have worried during my work… I would have worried whether you fall or not in this period and no one would have noticed what if you fall over. (2) At least you have been off for the rehabilitation, and you are in the crowds anyway. Therefore, I feel more reassured when I am not home. (3)</td>
<td>(1) Concerns about the safety when the stroke survivor staying alone at home.</td>
<td>Accident event Worrisome of the family caregiver</td>
<td>Sense of worrisome</td>
</tr>
<tr>
<td>Clara：我會給他用這個復健科，我是感覺到這樣 這裡好出，出來他比較快 樂，我也比較放心。 (4)</td>
<td>Clara: I felt that it was a very good choice to utilise the rehabilitation. He is happier after getting out, and I am rather reassured. (4)</td>
<td>(2) Family caregiver couldn’t have concentrated on her job.</td>
<td>Life was combined</td>
<td>Sense of interdependence</td>
</tr>
<tr>
<td>(5) the importance of having social circle</td>
<td></td>
<td>(3) With the LTC service (the residential care service enables the stroke survivor could attend the rehabilitation), the family caregiver felt at ease while she was out for her work.</td>
<td>Safeguard the safety during the rehabilitation. Alleviate the load of family caregiving. Make the rehabilitation available.</td>
<td>Role and function of LTC services</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Attaching social meanings to the community facility, the rehabilitation centre.</td>
<td></td>
</tr>
<tr>
<td>Don't let him stay home. It does nothing good for the sick person for not getting along with the crowds. (5) If you are capable of getting out, you just go off and exercise. You feel rather happier and I feel happy as well. He is fairly cheerful and I am very cheerful too. (6)</td>
<td>(4) She can be at ease slightly.</td>
<td>The wellbeing or the life status of the stroke survivor could provoke the shared sense of emotional resonance between the dyad or perhaps amongst the household.</td>
<td>Co-experienced post-stroke life trajectory</td>
<td></td>
</tr>
</tbody>
</table>
Appendix G: Example of the Descriptive Codebook

This appendix demonstrates the development of categories, including ‘Individual's post-stroke recovery trajectory’, ‘Family caregiving system’ and ‘Place attachment’, guided by the descriptive codebook.

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Individual's post-stroke recovery trajectory</td>
<td>contains (1) the proceeding of mindsets; (2) the practical and meaningful expectation the dyads attached; (3) their experiences of community-dwelling post-stroke life “term was learned from Hawkins et al. (2017)”</td>
</tr>
<tr>
<td>1. sense of loss</td>
<td>A sense of loss emerges because of the stroke-induced incapability. Signposting: The stroke survivors encountered falls and accident events owing to the physical incapability. Also, the stroke survivor lost their social role (e.g. having occupation) and domestic role (e.g. an income resource, the primary force). Lapse laziness and lackadaisical, described in Hawkins et al. (2017)’s study about “Post-stroke trajectory: the process of recovery over the longer term following stroke”, were discovered in my research</td>
</tr>
<tr>
<td>1.1 accident events</td>
<td>(1) Any accidents happened in the post-stroke trajectory; (2) what situations usually bring harm to the stroke survivors and at which circumstances?</td>
</tr>
<tr>
<td>1.2 distressed about the role transformation</td>
<td>The stroke onset has brought changes to social life of the stroke survivors, including social role (away from colleague, friends, the previous social circle), as well as role and function in the households (cannot make money).</td>
</tr>
<tr>
<td>worrisome of the family caregiver</td>
<td>It shows the situations that have strained nerves of the family caregivers, made them felt anxious and couldn't relax.</td>
</tr>
<tr>
<td>2. acceptance</td>
<td>(1) Stroke survivors accept the facts that they need assistance and rehabilitation. (2) Altered expectations of the care services along the post-stroke trajectory.</td>
</tr>
<tr>
<td>Name</td>
<td>Description</td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
</tr>
<tr>
<td>2.1 recognising rehabilitation and exercise are important</td>
<td>The dyads attach the significance of engaging with rehabilitation in the post-stroke life. (1) They felt unwell or anxious once the stroke survivors couldn't have appropriate chance to take rehabilitation treatment. (2) The family caregiver felt unsatisfied once the stroke survivors don't actively engage in rehabilitation.</td>
</tr>
<tr>
<td>2.2 returning to normal life</td>
<td>The dyads show their expectations that the stroke survivor can recover and their family can return to the life pattern as before the stroke occurrence.</td>
</tr>
<tr>
<td>3. sense of interdependence</td>
<td>The stroke survivors are used to the assistance and care provided by the family caregivers, therefore, they feel unsecured or anxious once the family caregiver or the significant other (care provider, health professionals or crutch) is not aside.</td>
</tr>
<tr>
<td>3.1 time was combined with family caregiver</td>
<td>The dyads cannot have personal time or their life cannot carry on without being co-present in a place due to physical limitation of the stroke survivors.</td>
</tr>
<tr>
<td>3.2 life was combined with family caregiver</td>
<td>Day-to-day life are depended on the family caregivers. Daily living cannot carry on without the family caregivers.</td>
</tr>
<tr>
<td>4. alteration</td>
<td>What has urged the dyads to altering the concurrent caregiving pattern?</td>
</tr>
<tr>
<td>4.1 expecting the stroke survivors can be more independent</td>
<td>(1) What were the family caregivers’ concerns for the post-stroke care; (2) worrisome situations from the perspective of family caregiving;</td>
</tr>
<tr>
<td>multi-tasking role of the family caregiver</td>
<td>the sandwich generation or the middle generation who assumes the multi-tasked challenges for looking after the elder parents and the young kids, multi-generational obligations. The family caregivers felt tired, stressful, and burdensome for care taking role.</td>
</tr>
<tr>
<td>financial concern in the household</td>
<td>The stroke survivors disclose the embarrassments of not being able to work and keeping paying out in the household. The family caregivers concern about household income/ economic stability.</td>
</tr>
<tr>
<td>4.2 expecting of a new relationship</td>
<td>What drove the dyads to transition from one status to next stage? What action did they take?</td>
</tr>
<tr>
<td>Name</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>fear of being a burden to other people</td>
<td>The stroke survivors disclose their worries for bringing inconvenience/troubles to other people owing to their physical incapability and their assistance-required, dependent states.</td>
</tr>
<tr>
<td>unequal devotion or expectation of gender to the family caregiving role</td>
<td>(1) reveals different combination of family caregiving, including male and female spouses, son and daughter, spouse and adult children. (2) vibes of family caregiving in different relationship.</td>
</tr>
<tr>
<td>4.3 engaging with the LTC system</td>
<td>(1) Where, how, at which situation and from whom they got to know the LTC services? (2) At which situation the dyads realised the opportunities of the LTC and their availability of applying the services? (3) Where were the LTC service information from? (4) How did the users access to the information?</td>
</tr>
<tr>
<td>insufficiency of family caregiving system</td>
<td>The family caregivers or the family caregiving resources cannot fully support the stroke survivors.</td>
</tr>
<tr>
<td>communication about the LTC services</td>
<td>(1) communication between the care providers and the care recipients, the stroke survivors; (2) between the care receiving household and the care delivering units; (2) how's the communication when the unexpected, special occasions happened</td>
</tr>
<tr>
<td>5. sense of independence</td>
<td>The dyads understood and accepted the rare chance that the stroke survivors could fully recover. Alternatively, the dyads (1) expect that the stroke survivor don't need to totally dependent on people's assistances; (2) the stroke survivors could partially look after themselves, be capable of self-care; (3) the expectation could come from either the stroke survivor themselves, the family caregivers, or the consensus between the dyads</td>
</tr>
<tr>
<td>5.1 being independent of overcoming challenges</td>
<td>self-autonomous daily living because of self-care skills and coping strategies</td>
</tr>
<tr>
<td>5.2 me time to do my matters</td>
<td>Owing to acquiring the self-care skills, the stroke survivors can be relatively independent in their life, they could freely arrange their daily living; be available to do their own things without</td>
</tr>
<tr>
<td>Name</td>
<td>Description</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>dependent on, feeling tangled or been bonded with other people</td>
<td></td>
</tr>
<tr>
<td>“ME TIME to do MY MATTERS” (in vivo code from the family caregiver perspective)</td>
<td>(1) be available to have own time; (2) be free and flexible to arrange a time to do what matters them, such as occupational work, relaxing, housework, etc.</td>
</tr>
<tr>
<td>6. identification</td>
<td>Embodiment of bodily self, psychological self, and sociological identity by interacting with people and situated environment in the social world.</td>
</tr>
<tr>
<td>6.1 applying self-efficacy</td>
<td>When physical ability improves, they experience a sense of achievement and to certain degree take back control of their life. Bodily self and psychological self are built in encompassing the restoration of control and confidence.</td>
</tr>
<tr>
<td>6.2 establishing self-identity</td>
<td>The stroke survivors re-identify themselves and re-define themselves in the social world.</td>
</tr>
<tr>
<td>7. Well-being</td>
<td>Subjective consciousness and emotion. The dyads expressed their satisfaction and happiness as they embodied improvements and re-establishment/ continuation in their life. It reflects their psychological state, physical state, and spiritual state.</td>
</tr>
<tr>
<td>7.1 positive thinking</td>
<td></td>
</tr>
<tr>
<td>II. Family caregiving system</td>
<td>What has linked post-stroke trajectories between the stroke survivor and the family caregiver? Bonds between the individual trajectories of the dyads.</td>
</tr>
<tr>
<td>Intergenerational relations in families</td>
<td>(1) contains the vertical interactions and linkages among generations regarding the family caregiving; (2) shows how has the care (demands-supplies) been given and supported among family members of different ages/ generations.</td>
</tr>
<tr>
<td>filial piety</td>
<td>(1) a virtue or a moral concept which has been passed-on as a principle of familial mutual support and caring obligation in the Taiwanese community; (2) a culture that children demonstrate their gratefulness for the bring up appreciation from their parents, especially when they are ageing and becoming dependent on the care of their adult children.</td>
</tr>
<tr>
<td>Name</td>
<td>Description</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>familial obligation across generation</td>
<td>Reciprocity of providing mutual support; commitment to provide care for family once they need.</td>
</tr>
<tr>
<td>Tensions of human resources in family and in society</td>
<td>Competing human resources in the family and in society</td>
</tr>
<tr>
<td>Intergenerational relations in society</td>
<td>(1) Social structural transformation led to new phenomena in familial obligation (2) Conventional caregiving pattern that adult children look after elderly parents have been transformed. (3) The caregiving in a family no longer predominates by the pattern that the adult children (middle-aged generation) support the older generation; instead, the older generation might be a strong support to the middle-aged generation in response to new social phenomena.</td>
</tr>
</tbody>
</table>

### III. Place attachment

<table>
<thead>
<tr>
<th>Meanings were given to a place, situated space, and environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional attachment</td>
</tr>
<tr>
<td>staying at home provides energy and thrust to survive</td>
</tr>
</tbody>
</table>

#### Functional attachment

<table>
<thead>
<tr>
<th>residential environment and setting modification (in the sense of physical infrastructure)</th>
<th>(1) Demands for the modification in the residential area to cope with post-stroke complications; (2) their preferences to the living environment; (3) a safe, reassured feeling while the stroke survivor moved, mobilized; (4) physical facility such as stairs, slope, etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td>public infrastructure improvement in the common area</td>
<td>(1) Are the accessible facilities well-prepared? (2) What difficulties they encountered while trying to upgrade facilities in public environment? (3) How have the public environments meant to the dyads? Is't a &quot;no-go zone&quot;, a barrier-free environment, or an elderly-disabled friendly environment in the community or rehabilitation centre?</td>
</tr>
</tbody>
</table>

| Social attachment                                                          | cultural, language, and ethnicity                                                                 |


<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>economic reliance</td>
<td>Daily subsistence, livelihood and household economic stability relied on an environment.</td>
</tr>
<tr>
<td>defining an environment through identifying social characteristics</td>
<td>(1) the characteristics of living environment and housing type in the tribes (indigenous region) and the urban area (plain-land non-indigenous region). (2) How have the characteristics of living environments influenced the research participants?</td>
</tr>
<tr>
<td>advantages of geo-relationship in the indigenous region</td>
<td></td>
</tr>
</tbody>
</table>
Appendix H: An Example of Observational Notes- Indigenous People’s Decision about Resettlement

This appendix contains an observational file elaborated on ‘Indigenous people’s decision about post-disaster and post-stroke resettlement’, of which an analytical dimension about people-place relationship emerged.

Yellow colour means a few parts of word selections by the stroke survivor is worth to be coded or pondered.

Sentences marked in grey are the preliminary analytical thinking parts.

Orange belongs to my personal thinking.

Blue colour indicates that I complemented some words to finish those incomplete sentences in the interviewing session in order to clarify the meaning, or the complementary information regarding the content being mentioned.

Purple colour means the information obtained from the individual interview with the dyad.

Pink colour indicates the information gathered from non-participant observation, or informal conversations with other research participants.

Green colour means the information from the resident care attendant.

[Context]- Relocations of Indigenous People in Chiayi County

Alishan Township was devastated by Typhoon Morakot and the record-breaking torrential rainfall resulted in floods, landslides, and mudslides. Plenty of houses and villages in the mountainous region were destroyed or recognised as a dangerous zone. Under supports from the government, the Red Cross Society of the Republic of China, World Vision, and other charities, a few placements were selected and constructed as permanent housing communities. Among those post-disaster reconstructions, Zhu-lu community located in Fanlu Township, a plain land area in the west of Alishan township, is the most populated place for indigenous people in non-indigenous areas in Chiayi County. Zhu-lu community with 155 households contains mostly indigenous households, including 39 households from Chashan village, 23 households from Shanmei village, and 22 from Laiji, 21 from Dabang, 19 from Lijia, 15 from Leye, and eight from Xinmei. The disaster-stricken households settled in Zhu-lu in 2012, nowadays Zhu-lu community has become the largest community that urban-indigenous inhabits in Chiayi County nowadays.
Difference between the two communities, Soglio and Zhu-lu, lies in the permanent housing sites they belong to, respectively Alishan Township as an indigenous region and Fanlu Township as a non-indigenous region, as well as the distance from their original habitants. Local government of Chiayi County initially planned to relocate all the Tsou disaster-stricken households to Fanlu Township for the sake of safety, however, some of the Tsou population protested and strived for their rights of dwelling in indigenous region. The local government invited experts from fields of geology, structural, water and soil conservation, forest compartment 152 eventually was selected as the permeant housing site, Soglio today. Soglio community is able to accommodate 42 households. Soglio standing 1,500 meters above the sea level is called Toe’uana in the Tsou language, which means a safe and flat land far away from riverbed.

[The dyad of Andrew and Georgia in the indigenous group: decision of relocation]

The dyad of Andrew and Georgia were happy to relocate in this community. When I queried about reasons they opted for resettling in this community among various locations including plain-land area, the stroke survivor answered that “no specific reason... just want to stay here... stay in the mountainous area”. He further said, “we even fought for having this land to be our houses with Council of Agriculture”. His wife stated that she prefers to stay in the mountainous area, the weather is cool, their livelihood is also based on mountainous area, find no reason to resettle in the plain-land area. They do not want to be away from their livelihood because they mainly depend on agricultural products on their own land or doing part-time jobs in farming.

[The dyad of Linda and Prima in the urban-based indigenous group: preference of residence]

After one year of institutionalisation, Linda, a stroke survivor, made the decision to return to the mountain, where was her first choice of relocation at that time. She stated “[I] psychologically/ emotionally perceived it is better to go back to mountain.” She addressed the reason for returning to mountain area lies in her familiarity with the environment. She further described that, “I was able to hear clan members spoke in the indigenous language. The residents in the institution usually spoke in Taiwanese. I felt getting on well with the surrounding as hearing our own language.”
[A stroke survivor in the indigenous region that I conducted observation but excluded from interview because of old age: preference of residence]

An old woman who is at 90 years of age and the responsibility of her post-stroke caregiving was shared by her three sons in the monthly rotation. She wasn’t enrolled in the dyads’ group due to her problem of hearing. Household of her oldest son reside at a lower layer of the hillside, and households of her second and youngest sons live in the same manufactured house, dwelling next to each other, at a higher layer of the gradient. It took around five minutes’ walk to each other’s house. Because her second and youngest sons live together, she doesn’t need to move during rotation between them. Once the 90-year-old stroke survivor looked for respite care for a month, in an institution in the plain-land area as her families were not available for caregiving. The elder woman cried when her family visited her, and asked “Can I go home? When can I go back?”, stated the residential care attendant. The residential care attendant shared that she might feel uncomfortable living in an unfamiliar environment. It seems to me that a concept of people-place relationship emerges and also be evidenced by many stroke survivors.

[People-place relationship]

So far, environments appear to be a factor in determining the quality of life for indigenous people with long-term conditions, no matter where they live (regardless of their residence). The young stroke survivor in the fieldnotes described her delights in waking up to the voice of her clan members, speaking in the indigenous language. She further explained that “the residents in the institutes usually spoke Taiwanese. She felt getting on well with the surrounding as hearing their own language.”

Both the younger and the elder stroke survivors expressed their anticipation in “going home”. It appeared that some factors make them yearn for the home environments. As a result, they felt relatively comfortable staying home. Even if better quality of healthcare services were provided and abundant rehabilitation programmes made available at the institution, the young stroke survivor still revealed her preference for returning home. They exhibited a strong sense of attachment or sense of belonging to home, or the environment they are familiar with. Place attachment involves the interplay of affective link between individuals and their environments (Altman and Low, 1992). It is stated that place attachment consists of
interactions between affect and emotions, knowledge and beliefs and behaviors and actions regarding a setting. According to Scannell & Gifford’s (2010) definition to theory of place attachment, the home space is conceptualised as a material and affective space, shaped by people’s everyday practices, lived experiences, social relationships, memories and emotions. At home, people interact daily with its physical aspects, thus creating a homely routine which strengthens their attachment to the place. However, this routine is not achievable when the stroke survivor dwells in the institution. The stroke survivor stated that: “I feel more relaxed when I was at home. I perceived emotional security when she lived in my own house. I perceived a sense of discomfort in speaking out my demands to the staff in the institution. I feel more comfortable talking about my daily needs with my family.” A study of the place attachment by Nanninga et al. (2015) aims to increase the understanding of stroke survivor’s needs to re-establish their attachment to meaningful places at home and in the community. Their experiences in the clinical, post-discharge and reintegration phases of the rehabilitation were discussed from three spatial and interrelated scales that are all, such as body, home and community. It indicated that the participants’ selves had changed, while the spatial and social contexts of their homes had remained the same. Their spatial scope became smaller in both a social and a geographical sense. It was difficult to achieve a feeling of being at home in their bodies and own living environment again.
Appendix I: Code Landscaping with Fair Representation of the Participants’ Narratives

This appendix provides the participant excerpts as references corresponding to their positions on the post-stroke recovery trajectory.

<table>
<thead>
<tr>
<th>Position of participants</th>
<th>Loss of self</th>
<th>Acceptance</th>
<th>Interdependence</th>
<th>Alteration</th>
<th>Independence: regain self</th>
<th>Identifying self-identity</th>
<th>Well-being state</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban-based indigenous group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-indigenous group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Bridget
- Yuri
- Andrew
- Hank
- Dora
- Linda
- Elisa
- N4
- N2
- N3
- N1
<table>
<thead>
<tr>
<th>Indigenous population</th>
<th>Urban-based indigenous population</th>
<th>Non-indigenous population</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Andrew:</strong> “Sometimes, sometimes I felt unwell in my mind. […] The biggest reason is cannot cooperate with them, including my children, my son and daughter-in-law.” Georgia: “I told her (the residential care attendant) that, ‘you just tidy up his bedroom. Don’t do other matters.’ […] Dealing with the stock is difficult because my legs hurt. It was my help to replenish the stock when my legs were affordable. It’s been thankful to assist in showering, tidying up the room, as well as replenishing the stock.”</td>
<td><strong>Linda:</strong> “My mood becomes more cheerful. […] I worried that whether she can hold me up because I am tall and heavy. But when I saw that she is an indigenous people, I was relieved in my mind, because the indigenous people are all with good strength.” Prima: “Now I could do my own things in this two-hour timeslot. For example, I received an urgent document and required me sorting it out (at the administrative sector) in the mountain, so I utilized these two hours back to manage it.”</td>
<td><strong>Julian:</strong> “To recover, the body, mind, and spirit have to align and proceed together, which leads to a better recovery. If only the body makes the effort, while the mind and the spirit keep getting injured, the recovery seems to lack momentum/energy to keep moving forward.” Ginger: “He quite enjoys attending rehabilitation at the hospital, and also feels cheerful to go to the day care (centre, the neighbourhood LTC station). What’s more, also… we attend classes, I feel he doesn't think that much negatively on the whole after taking the classes.”</td>
</tr>
<tr>
<td>A2</td>
<td>Bridge: “Cooking the meals fixes on her schedule. It’s me who feels bad about that. […] Because she is very busy, I dare not to nag.” Bridget: “If someone can bring me there (the LTC station), I can be there. But I feel bad of bringing trouble to other people.” Deborah: “It will be good if she can get on her feet, and the best or ideal is being able to walk, because her body (her health) not only impacts our family but also takes up a considerable amount of expenses in the financial aspect.”</td>
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<td>U2</td>
<td>Ella: “During the bamboo harvesting season, my husband was very busy. If I had kept calling him (to assist), he would have had to come a long way, and I also felt it was inconvenient to keep calling him. I made all an effort to figure out how I could do that by myself. […] I had to use my hands to pull this leg (the leg at the weaker side).” Bob: “After (back to the community) a year, the health clinic came here, came to the community. The clinic in charging this region told me that, ‘there is a shuttle bus comes to the community, do you want to send your wife for rehabilitation in hospital?”</td>
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<td>N2</td>
<td>Hobart: “The grounds are uneven. For example, where we take the shuttle bus, the ground is not fairly flat. It's easy to feel that I was nearly tripping over after a few slightly-wobbled walks. She (the residential care attendant) seized me immediately. What a quick reaction … She is always thoughtful and considering of everything. … The LTC services don't add to the burden financially and psychologically. I am fairly happy and I eat well and sleep well.” Clara: “I felt that it was a very good choice to utilise the rehabilitation. He is happier after getting out, and I am rather reassured. Don't let him stay home. It does nothing good for the sick person for not getting along with the crowds. If you are capable of getting out, you just go off and exercise. You feel rather happier and I feel happy as well. He is fairly cheerful and I am very cheerful too.”</td>
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<tr>
<td>A3</td>
<td>Yuri: “What could be improved… nothing… I felt satisfied to have her. […] Because I feel bad about</td>
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<tr>
<td>U3</td>
<td>Hank: “Change is only fruits. No other thing has been changed. […] The influence</td>
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</table>
| N3 | Leonard: “I found that there was a church near the house of my son. I knew the priest and missionary very
bringing inconvenience to other people. (It will be) asking for trouble for myself, bringing psychological troubles to my mind”.

Molly: “She has fallen down twice according to my memory… (it happened) at midnight. We were annoyed that she never called us (for assistance). I came to know when I heard the clatter of chair movements in her room. I opened the room and saw her making attempts to get up by grasping the arm of the chair, but she couldn’t. The chair fell and she kept getting dragged. She tried to stand up but couldn’t make it”.

is I can have a better mood (for having the fruits). I emotionally felt more comfortable, no other influences. It’s just... I felt that my wishes… my wishes have been fulfilled.”

Hank: “They (his friends) were good to me before. Now when we went out and got together, it became the way that they were all well. I saw them walking (well), but I couldn’t. I was inconvenient and, thus, felt sorry for them.”

Ivy: “In the past, I just went home to have a look for a while during the lunch break and then back to work in the afternoon. I took shower for him, prepared the lunch box, chat a bit and I was off to work. The tiredness is to worry what would happen while my father was at home.”

well. Staying there made me feel just like home […] Sometimes, missionary priests from the Taipei branch came for mission delivery services. We knew each other so that I felt happy. Therefore, I yearned to stay in this place.”

Louis: “Once one-third of the residents disagree, you cannot make the construction even if the government offers the allowance because it belongs to public assets, unless there is authorised legislation that compulsorily demands that once the elderly population in a community achieve a certain proportion, then it is forcefully required to establish a barrier-free space. The legislation has been made and is eligible for the new community but does not include the old communities. This could be recorded matter-of-factly.”
<table>
<thead>
<tr>
<th>A4</th>
<th>Novia: “There are some people, some friends who we can chat together. […] (I am) Just feeling good. I am in a good mood. Now… I always walk by myself, I walk there with my own”.</th>
</tr>
</thead>
<tbody>
<tr>
<td>U4</td>
<td>Ella: “I usually go there (rehabilitation centre) for exercising in the early morning. Maxwell worried about money, no money for filling up the car, so (we) didn’t go to rehabilitation. Also, (we are) worried about requiring paying 50 NTD (approx. £ 1 each time). […] I have no money for petrol either. How to say… it’s too exhausted.” Maxwell: “She cannot fetch or hold anything, also changing diaper, and so on. Moreover, I need to prepare for her wherever we go. However, I am also in this situation (which means he is also an inconvenient person relying on walker). Certainly, I am obliged to do that but I am grossly tired. However, it’s not right to giving up her”.</td>
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<tr>
<td>N4</td>
<td>Driscoll: “I could no longer do everything. I lost my freedom. I cannot get in, not able to walk inside. I need other people to support by my arm, or I will fall down.” Driscoll: “I would prefer to be cared for by one of us. … (Because) I could speak out more immediately and freely to my own children.” Delia: “she (the residential care attendant) is not our child and she is not dedicated that much… Our children would do it with all their heart.”</td>
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</table>
Appendix J: Coding in a Matrix

This appendix displays how the environmental properties were lifted as an analytical indicator in comparing and contrasting the descriptive codes. **Content in blue** means descriptive categories emerged in the first cycle of coding; **content in yellow** means the axial codes emerged from the comparison in the context.

<table>
<thead>
<tr>
<th>Fieldwork sites</th>
<th>Indigenous region</th>
<th>Non-indigenous region</th>
<th>Urban-based indigenous context</th>
<th>Axial codes</th>
<th>Accessibility (inequitable access to the LTC system)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environmental properties</td>
<td>Natural environment (mountain geography)</td>
<td>Built environment (urban geography)</td>
<td>Sociocultural and socioeconomic environment</td>
<td>Macro-context for LTC policy implementation</td>
<td>Situated LTC system Availability</td>
</tr>
<tr>
<td>Multiple systems of care resources</td>
<td>Transportation insufficient volume vs sufficient volume of transportation</td>
<td>Rehabilitation Insufficient volume vs sufficient volume of rehabilitation</td>
<td>Workforce insufficient vs sufficient supply of physical therapist</td>
<td>Infrastructure of facility Insufficient vs sufficient facility setting-up</td>
<td>Infrastructure of system organisation in-coordinated accountability &amp; authority clarification among administrative</td>
</tr>
<tr>
<td>Role and functions of LTC services</td>
<td>Coordination of organizations</td>
<td>Affordability</td>
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<tr>
<td>+</td>
<td>Swift transferring vs delayed transferring</td>
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<tr>
<td>+</td>
<td>Coordinated vs in-coordinated organisational system</td>
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<tr>
<td>+</td>
<td>No burden vs felt stressed out about the co-payment</td>
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<tr>
<td>+</td>
<td>use up maximum allowance vs value free service, social care or relief support</td>
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</table>

**Micro context for Adapted LTC services**

| Supplementing the unavailability of the family caregiving system | | |
| + | + | + |

**Appropriateness**

- and legislative systems
- in-coordinated goals for collective (group of people) in the populated urban area
- Insufficient workforce to load large care users

- Swift transferring vs delayed transferring
- Coordinated vs in-coordinated organisational system
- No burden vs felt stressed out about the co-payment
- use up maximum allowance vs value free service, social care or relief support
| **alleviate the load of family caregiving** | + | + | + |
| **Supporting in regaining role function in household and society**<br><i> <> place attachment</i> | + | + | + |
| **Enabling synergetic works among multiple social and healthcare systems**<br><i> <> Coordination</i> | - | + | - |
| **Adapting strategies to meet individual household’s need**<br><i> <> Individual’s post-stroke recovery trajectory</i> | + | + | + |