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Childhood narratives of adults with spina bifida: A qualitative analysis

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Abstract

Childhood narratives of adults with spina bifida: A qualitative analysis

Background

Spina bifida is a congenital condition that can lead to a range of impairments that vary in severity. Although incidence has declined since the 1970s, medical progress means that there is a growing community of adults ageing with spina bifida. This thesis looks at the lived experience of that community, through the stories they tell about their childhood experiences and the relevance those stories have for them now. This lived experience is derived from interviews with research participants born with spina bifida in the 1960s and the 1990s and also the personal experience of the author, born with spina bifida in the 1960s.

Methods

This thesis is made up of three interwoven strands. Firstly, there is an archival investigation of the treatment of babies born with spina bifida from the late 1950s onwards. This includes medical progress that led to improvements in mortality but also selection of who would benefit from that progress. This illustrates the lesser value put on the lives of those born with spina bifida and their resulting stigmatisation, setting the socio-historical context for the rest of the thesis. Secondly, narrative enquiry is used to explore the lived experience of the research participants, via semi-structured interviews. The interviews were analysed using reflexive thematic analysis in order to construct themes. The third strand is the personal account of the author. This is used throughout the thesis, including the discussion of

the research interviews, responding to the data in a reflexive way, rather than as a separate section.

Findings

The increased survival of children born with spina bifida led to a reaction amongst a significant part of the medical (and political) establishment towards selection for treatment. This is exemplified by the situation in Sheffield in the 1970s, where a third of babies with spina bifida were selected for surgery and the remaining two thirds were selected for death. A connection is made between selection in the 1960s and 70s and the contemporary high rates of termination of pregnancies where spina bifida is detected. It is argued that these are associated with the stigmatisation of both those born with spina bifida and their parents. Whether they were consciously aware of it or not, this formed the societal background that the research participants grew up in – how people born with spina bifida were regarded, talked about and treated.

Three themes are discussed following analysis of the interview data. *"I was baptised in hospital"* deals with the experience of the 1960s research participants of growing up with the story that they were not expected to live and yet went on to do so. The significance of growing up with such a story is considered through a number of different lenses, including the way that it subverts the medical model of disability and the participants' own association of this story with a sense of determination to overcome obstacles in life. A second theme, *Things have got better (up to a point)*,

explores the striking differences between the experiences of the research participants born in the 1960s and those born in the 1990s. These differences include the way that parents discussed – or did not discuss - spina bifida with the participants and the effect that this had on their sense of identity and self-worth. Another important difference discussed is the experience of school and how the development of a more inclusive approach has led to better self-confidence and self-esteem. In both cases, progress is related to both a reduction in the stigma associated with spina bifida and a growth in the ideas behind the social model of disability. However, despite the improvements described, the negative effects of assessment for disability benefits was something experienced in both groups. The third theme, *The transformative power of love*, considers the transforming effect of being loved by a partner who accepts you as you are, countering the years of othering that went before. The personal experience – and personal journey - of the author is interwoven through the other discussions above. This takes the form of recollection of their own life with reproduction of some supporting historical material, and also of reflexive interaction with both the interviews and associated themes and with the material on selection.

Conclusions

The thesis helps provide an understanding of the lived experience of adults with spina bifida. The experience of those born in the 1960s, particularly the negative experiences of education and parental communication is related to the state-enabled stigmatisation of spina bifida. The importance of love as a counteracting force to the negative effect of stigma on mental health is discussed. The relevance of this for the

provision of counselling and psychotherapy services for this community is considered.

Lay Summary

Spina bifida is a condition that people can be born with that can result in a range of health problems. Thanks to medical progress there is now a growing number of people in their 50s and 60s. The needs of this community and not yet well understood, though there seems to be a physical decline in many people, along with a decline in mental health.

This thesis looks at the lives of people with spina bifida through the stories they tell about their childhoods. People born with spina bifida in the 1960s and 1990s were interviewed. An investigation into the way that children born with spina bifida were treated by the medical profession was also carried out.

The research found that in the late 1960s and 1970s the medical profession carried out a policy of only treating a minority of babies born with spina bifida, with the majority being left – or encouraged – to die, a policy approved by the government. This established people with spina bifida as undesirable in the eyes of wider society and this is reflected in the experiences of people born with spina bifida in the 1960s, who describe secrecy and shame that had effects into adulthood. Those born in the 1990s describe a much better experience. The importance of love, of finding someone who accepts you as you are, is discussed. The importance of these things for those providing counselling to this community is considered.

Dedication

This thesis is dedicated to:

My late wife, Elaine Murray O’Donnell, for reasons that will become clear.

My parents, Louis and Martha O’Donnell, for 61 years of love and support.

Acknowledgements

This thesis has its origins in the Counselling Diploma course at the University of Edinburgh. It is no exaggeration to say that it was a life-changing experience for me, including inspiring me to go on to the research described here. I am grateful to my fellow students – too many to mention - and to my tutors: Adrian Martinez and Jo Hilton (year 1), Barbara Malinen, Liz Bondi and Seamus Prior (years 2 and 3).

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My counsellor, John Cassie, has been with me from the start and been invaluable for the reflexive parts of the work and for helping me make sense of my past experiences. Well met, John.

Thank you to my friends and family for encouragement and tolerance of my occasional self-absorption.

And last but not least thanks to my partner, Jill. I couldn’t have made this journey without you supporting me every step of the way. Sometimes literally.

With so much help and support, it only seems fair to state that any remaining errors, mistakes and missteps are all my own.

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Chapter 1: Introduction

This thesis is concerned with the lived experience of people with spina bifida, a congenital condition that can lead to a range of impairments. The research question that this thesis addresses is:

What are the childhood narratives of adults with spina bifida?

In other words, lived experience is examined through the stories that adults with spina bifida tell about their childhoods and the significance that those stories have for them now.

The literature review that follows begins with an explanation of what spina bifida is, along with an exploration of the different aspects of the experience of disability/chronic illness and other concepts that are used to discuss the research findings. The intention is to provide a 'backpack' that will allow the reader to share in the exploration of the research findings. In the course of that exploration, further concepts arise and are discussed.

Structure of thesis

The work reported in this thesis consists of three closely intertwined strands. I shall describe them here, so that the reader has a roadmap for what follows. The first is a literature and archival-based research of the developments in the treatment of spina bifida. This is included because it is a history that reveals a great deal about the attitudes of the medical profession, and society as a whole, towards people with

disabilities and people with spina bifida in particular. As I hope will be clear, this material and the process by which it was compiled is quite different to the literature review. It provides a context to the other strands, in which the narratives of the research participants can be placed and better understood – indeed, I think it is essential to an understanding of their lived experience and my own.

The second strand consists of semi-structured interviews with research participants. The research participants were all people whose spina bifida had been apparent at birth. They consisted of two groups, one of people born in the 1960s (or earlier) and one of people born in the 1990s. In the interviews, the research participants were asked to talk about their childhood experiences, including the family stories about their births. The rationale behind those two groups and the questions asked is explored in the methodology chapter.

The third strand of this thesis is my personal story, my own narrative; I too was born with spina bifida. It is my intention to be not only open about that personal involvement but to use it in a reflexive way throughout this thesis (Etherington 2004). The narratives of the research participants are therefore interwoven with my own account, an account that is in turn affected by my reflexive interactions with the research participants. I have tried to capture this dynamic process in as open and transparent a way as possible. This inter-weaving of my own narrative takes place through all of the chapters, including the methodology chapter. My intention is to be clear about the organic way in which this thesis was written, and the extent of my use of self in the interactions with the research participants and with the material that

makes up the literature review and methodology. Indeed, my understanding of the very question that the research originated with - “What do I want to know that I do not know now?” - has changed as the work progressed. All of this is discussed in more detail in the later methodology chapter. However, as there is no separate chapter for my own narrative, it may be helpful if I set out here the background to my personal contribution and the reasons why I decided to include it.

Personal experience of spina bifida

I was born with spina bifida in 1962 and had surgery shortly after my birth. The impairments associated with the condition had a significant impact on my childhood; as I now realise, this made me an anxious child. I had not thought about those early experiences for a number of years. A number of factors brought spina bifida to the fore for me again and made me think about those experiences and the effect they had on me – and the effect they still do have - a process that ultimately led to this thesis.

The main factor was that during the time of my Counselling Diploma, I had surgery on my spinal cord, to de-tether it from a lipoma, a fatty mass, at the site of my original surgery. This de-tethering surgery had been a possibility for a number of years, since a cycling accident in 1996 led to the discovery of the tethering. The tethered spinal cord caused a slow neurological deterioration, however I had always considered that the risk/benefit ratio was in favour of not having the surgery. That changed when my neurosurgeon became concerned that my spinal cord was now

showing clear signs of atrophy and surgery was recommended. The experience of surgery prompted me to think about my first surgery at birth and about my childhood.

As I embarked on my research project, I began to gather my own story in a more systematic way. I obtained copies of my old medical records which related to my birth and early surgery and these are reproduced in this thesis. I spoke about my birth with my parents – tentatively, as it was a subject that they had always been reluctant to discuss. I spoke about my revisited memories and feelings with a counsellor, who I saw regularly throughout the project. My memories and feelings further developed through my reflexive interaction with the research participants. This was a dynamic process, one through which I came to understand myself better and came to terms with a part of my past that I had shut away. As well as my interactions with the research participants, I also found myself reacting to the material on the development of treatments for spina bifida and the associated policy of 'selection', which also made me look at my childhood experiences in a different way.

I hope that in setting out now the three stands of this thesis and the interconnected nature of them, that the reader will understand that if they seem to be mixed together – and this is particularly true of my own narrative - it is because they cannot be separated. I have therefore used my own story, not in a self-contained section but spread throughout the other two parts of the thesis. In doing so, I hope to reflect the way in which my self-understanding grew in response to the material and also to show how the research participants' narratives were affected by the societal

background that led to the policy of selection for treatment (see Chapter 4) being acceptable, even though it was not directly discussed during the interviews.

Ageing with spina bifida

Ageing with spina bifida is poorly understood because this is the first time in history that there has been a significant community of people with the condition in their 50s and early 60s. While work is emerging on physical and mental health challenges to this community, there is as yet relatively little work on their lived experience. The intention of this work was to help to fill that gap and allow those involved in providing counselling and psychotherapy services to this community to be better informed.

Research interviews

The interview transcripts were analysed using thematic analysis and the themes that emerged are discussed. Three main themes emerged: *"I was baptised in hospital", Things Have got Better (up to a Point)* and *The Transformative Power of Love*

Different lenses were applied to interpret these themes. One is the use of theoretical counselling concepts. As a counsellor whose predominant orientation is in the person-centred tradition, I was particularly interested in the use of 'conditions of worth' as a concept that helped illuminate the childhood narratives and the potential importance of 'unconditional positive regard' when acting as a counsellor with this community. Another lens which is applied is the work of Arthur Frank on illness narratives and the significance of these to the lived experience of those with long-

term health conditions. The importance of different models of disability, both to this community and to the attitudes of society as a whole, is also discussed. Note that discussion is integrated into the Themes chapter, rather than presented as a separate stand-alone chapter.

Wider relevance

There is a wider relevance to the spina bifida story, in that because of its prevalence, spina bifida can be regarded as something of a pathfinder for issues faced by other people with disabilities, in terms of treatments, screening and organisation. To that end, I discuss societal changes in terms of the medical and social models of disability. The narratives described here will therefore, have a wider resonance for those who grew up with a disability, and those providing counselling to them.

Chapter 2: Literature Review

Introduction

This review is intended to provide a background understanding of spina bifida, as it is not assumed that the reader will be familiar with the condition, and of the key concepts used in the discussion of the research material.

Search strategy

The search strategy was based on the use of “spina bifida” as a search term, with results filtered by the combination of this term with relevant qualifiers. These included “perinatal surgery”, “mental health.”, “stigma”, “shame”, “ageing” and “relationships”. In this way I was able to form an overview of the substantial academic literature on spina bifida and also identify research of particular interest and relevance within it. I was particularly interested in qualitative research, with a particular focus on reports of lived experience. Technical quantitative publications – for example details of surgical procedures – were excluded, as being beyond the scope of this thesis. I also excluded publications in journals which were not peer-reviewed and those which were not published in English.

For basic concepts related to chronic health conditions and disability, a useful starting point was the reading list for the Edinburgh University course Identity and Experience in Health, for which I facilitated tutorial groups.

Initial searches were made using Google Scholar, followed by the University of Edinburgh Library search function. Use was also made of the citation feature of Google Scholar, to follow up publications which had cited research that had been of particular interest.

What is spina bifida?

Spina bifida is the most common congenital condition leading to physical disability (Oakeshott *et al*. 2019). It has also been described as "the most severe birth defect compatible with long-term survival" (Bowman *et al.* 2009, 801). In most people, the spinal cord is protected within the vertebrae that make up the spine. The importance of this to the smooth functioning of the human body is reflected in the fact that this protection of the spinal cord usually occurs early in our development, in the first trimester of pregnancy, often before the mother is aware she is pregnant. However, in spina bifida there is incomplete closure of the spinal column around the spinal cord, exposing it to the risk of damage. Spina bifida is divided into different types, depending on the degree to which the spinal cord is unprotected and the varying consequences that can result (Sandler 2010). These are illustrated in figure 1.

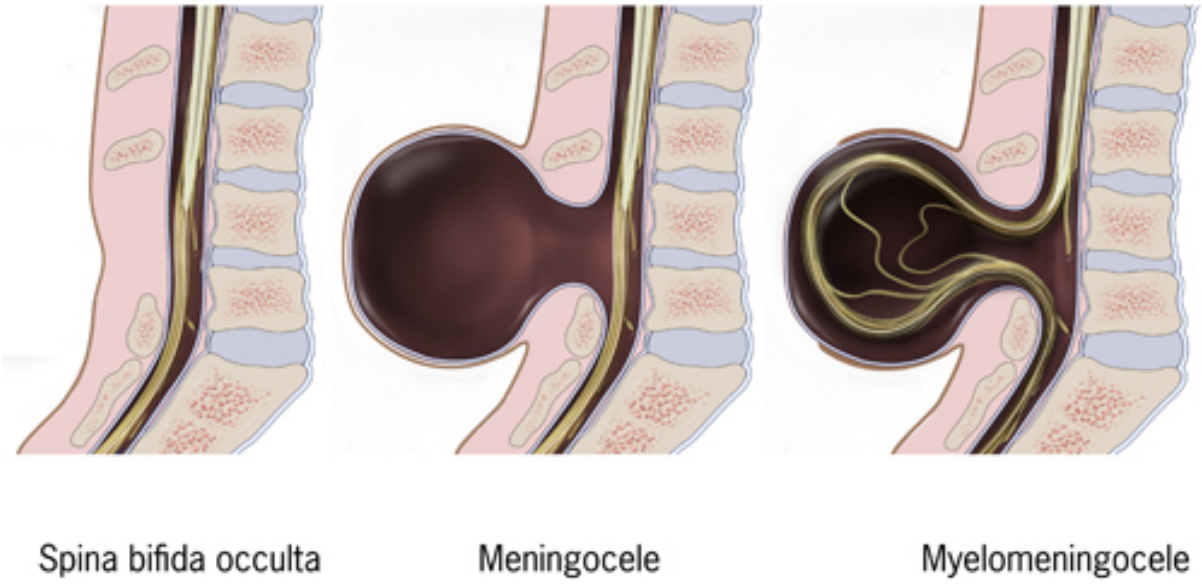


Figure 1 Types of spina bifida

(Centres for Disease Control and Prevention – public domain)

The least serious is spina bifida occulta. In this case, one or more of the bony vertebral arches that make up the spine may not be complete, however the spinal cord itself is unexposed and undamaged. This is the most common variant and may affect up to 5% of the population, most of whom will be completely unaware of it as there is usually no outward sign. A second type, meningocele, features a skin-covered swelling on the back which does not contain the spinal cord, which is generally not badly affected. This is the rarest of the types. The third type, myelomeningocele, is characterised by a swelling on the back containing the spinal cord itself, which is therefore susceptible to damage. See figure 2. These last two types are also called open spina bifida or spina bifida cystica.

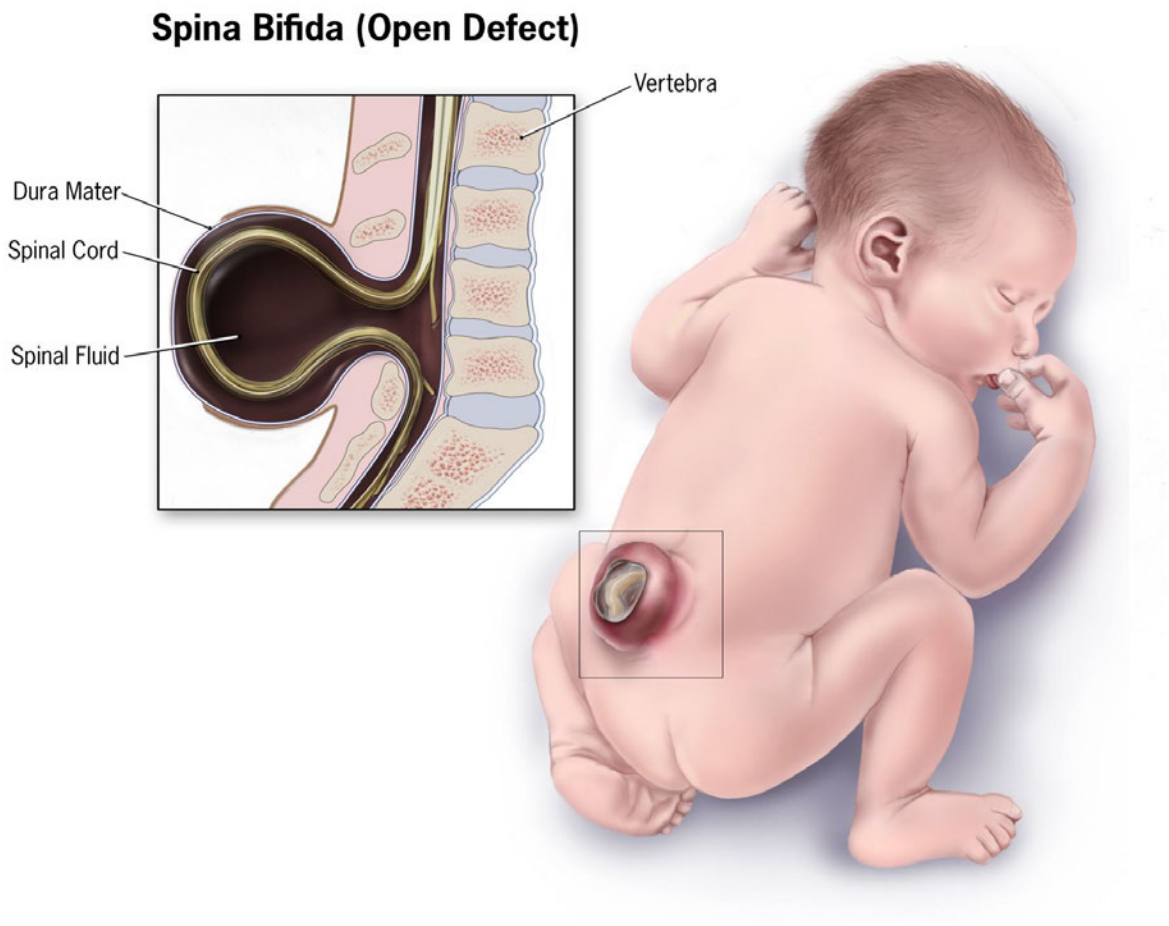


Figure 2 Myelomeningocele

(Centres for Disease Control and Prevention – public domain)

It is the “open” types of spina bifida that will be the predominant concern of the work in this thesis, since these are the types immediately apparent at birth and most commonly associated with impairment and with associated medical developments.

The range of impairments associated with spina bifida can include limb weakness and paralysis, bowel and bladder dysfunctions, neuropathy and deformity of the

spine (Bowman *et al*. 2009). These vary in severity depending on, for example, the size of the lesion and how far up the spine it is located.

Spina bifida occurs worldwide, though prevalence varies according to region and ethnicity (Mitchell *et al*. 2004). The incidence of neural tube defects (NTDs), of which spina bifida myelomeningocele is the most prevalent, varies from 0.17 to 6.39 per 1,000 live births, with the highest incidence being found in Northern China. (Bowman *et al*. 2009) However, Zaganjor *et al*. (2016) show wide variation both between and within countries and point out that many states do not have any means of collecting and producing data. Occurrence also varies by social class (Laurence *et al*. 1968, Nevin *et al.* 1981, Wasserman *et al*. 1998), with greater incidence in lower socioeconomic groups. In the Global North, the incidence has declined over recent decades. The reasons for this are not completely understood, however, there are two factors of known significance. One is the understanding that folic acid supplements can significantly reduce the incidence of NTDs such as spina bifida by as much as 70% (Mitchell *et al*. 2004). The second known significant factor is the widespread use of prenatal screening for spina bifida. This has been in use in the UK since the mid-1970s and women who have a positive test are offered the option of a termination of pregnancy. Up to 80% of them opt to do so (Mansfield *et al*. 1999, Olde Scholtenhuis *et al*. 2003, Ghi *et al*. 2006). Both of these factors will be considered in more detail later.

The cause of spina bifida is not yet fully understood. While there seems to be some familial component, there is no pattern that suggests mendelian inheritance of a

single gene defect (ie where both parents carry a particular mutation). The incidence of affected siblings is higher than in the general population, at between 3% and 8%, but is not the 25% that would be expected with a single recessive gene defect (Mitchell *et al*. 2004, Bowman *et al*. 2009). In recent years it has been suggested that spina bifida might be an epigenetic phenomenon (Goldberg *et al.* 2007). Current research is focussed on this theory (Zhang *et al*. 2015, Li and Niswander 2018, Huang *et al.* 2022).

Spina bifida as a long-term health condition

Spina bifida is a life-long condition and therefore theoretical work that has been carried out on long-term or chronic health conditions provides useful background for the work reported here. Overviews of chronic illness identify some key concepts which are explored below (Locker 2008, Nettleton 2013).

The sick role

Parsons' sick role theory (Parsons 1975) holds that illness is a deviation from normal behaviour. In other words, that illness is not just a biological condition but also a social one. Parsons argues that those who are sick can be excused from normal social obligations by meeting certain criteria, including seeking medical help and following the prescribed treatment. This includes the implicit acceptance that illness is an undesirable condition and also of the dominant role of the medical professional; the role of the sick person was to follow the instructions of doctors and to recover. Amongst the criticisms of this model is that it does not apply to chronic illness or disability, where the health of the person concerned is not likely to improve – though

Parsons himself insisted that he thought that his theory did apply to chronic conditions, giving the example of diabetes (Parsons 1975, 269). Levine and Kozloff (1978), in a review of Parsons' theory, noted that not all illnesses were treated equally "for some illnesses, the patient is not exempted from blame (venereal disease) and for others, he may suffer stigma (venereal disease, mental illness, and even cancer)." (1978, 321). They conclude that while Parsons' formulation had been a useful model, it had become limiting, citing the emphasis on the medical interaction, rather than on family and other interactions. Nettleton (2013, 65) points out that with long-term conditions (including disabilities) illness can become part of the affected person's identity. Reinforcing the point about not all illness being treated equally, Nettleton goes on to argue that in stigmatised conditions the person's access to the sick role may be considered illegitimate and that "the rights and privileges of the sick role may not be granted" (2013, 65). It will become clear that spina bifida is an example of such a stigmatised condition. The sick role theory may therefore be useful in understanding the experience of disability because it helps to explain society's attitudes to it. These are bound together with the concept of stigma.

Stigma

Scambler (2009, 441) defines stigma as: "a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group." Goffman's classic work on stigma describes it as resulting in a "spoiled self" (Goffman 1963/1990). Inherent in this is the idea that there are some single attributes, the possession of which is enough to mark the holder as not a "usual" person but a "tainted, discounted one" (1963/1990, 12). It is

not just a difference but a shameful difference (1963/1990, 156). Goffman was not writing solely about disability (his range of the stigmatised included such diverse categories as adulterers and hangmen) however it provides important insights to our understanding of the lived experience of disability.

Goffman states that “By definition of course, we believe that the person with a stigma is not quite human” (1963/1990, 15). As Scambler (2009, 441) notes, the “discriminatory social judgement” that stigma entails may be extended from the person or group to the health condition itself, which in turn may have an influence on policy. As we shall see later in this thesis, both of the comments above may have applied in the case of spina bifida.

Goffman distinguishes between the discredited – those with a readily observable difference – and the discreditable – those with a difference that they may try to keep hidden. In either case, it is a difference where “Shame becomes a central possibility, arising from the individual’s perception of one of his own attributes being a defiling thing to possess” (Goffman 1963/1990, 18). In the case of spina bifida, both types of difference may apply. For example, if someone is in a wheelchair or uses walking aids then this is an obvious observable difference. On the other hand, incontinence may be hidden, or at least desired to be so. This is a distinction that affected young people are acutely aware of. For example, Fischer *et al*. (2015, 959) quotes a young person with spina bifida: “People know about my disability but I make them think it’s only my legs that are part of it.” And from Lindsay (2014, 1303): “Nobody knows [how I urinate] everybody thinks I’m just ordinary.” Yet, as Sawin and Thompson (2019, 280) note “Almost all children with SB, even those with sacral lesions, have

impairments of bowel and bladder status from infancy," going on to state that "Bowel incontinence is reported to be significantly more stressful that impaired motor function." This problem does not end with childhood, nor is it one confined to spina bifida. In a book on colitis, Kelly (1992, 38) summarises the problem: "It is one of the basic distinguishing features of adulthood … that control of the anal sphincter is a taken for-granted accomplishment. The loss of that control is not only at odds with being an adult, it also suggests flawed moral character." Spina bifida therefore combines the stigma of observable difference with the additional stresses involved with concealing a hidden one.

Stigma can extend beyond the person with a disability. For example, the parents of children with disabilities can also experience stigma. Francis (2012) interviewed middle-class parents whose children had a range of health issues. Two types of stigma were noted – courtesy stigma due to the social proximity of a disabled child and a second type involving blame for that disability i.e. of 'bad parenting.' The latter was less likely when a child was visibly disabled e.g. in a wheelchair. However, parents did feel blame where there was no physical sign of stigma. As Francis notes "When children look 'normal', people expect them to behave accordingly, and they interpret deviance as a problem of character for which parents are responsible" (2012 937). Francis also argued that mothers experience or perceive stigma as blame to a greater extent than fathers, noting that in the decades following the 1950s "…mothers became scapegoats for everything from schizophrenia to serial killing" (2012 934). As we shall see, the research interviews provide evidence that societal attitudes to spina bifida did have an impact on the parents of research participants, particularly the mothers.

Stigma is something conferred by society and is expressed in how people with disabilities (or their parents etc.) are treated. As Scambler (2009, 246) notes, stigma can become internalised, which has the result that "people's self-concept is congruent with the stigmatizing responses of others; they accept the discredited status as valid." The consequence of this for people receiving stigma, is that their internal response to it often takes the form of shame.

Shame

While stigma is imposed from outside, shame is an internal emotion. Gilbert (1998, 4) notes that " … shame can meld into a sense of one's own identity (e.g. as flawed, a failure, unlovable etc.)" In other words, shame strikes at our sense of self. When we feel ashamed, we feel that we are a "bad person." Lewis (1998, 126) defines shame as arising "when one experiences failure relative to a standard (one's own or other people's), feels responsible for the failure, and believes that the failure reflects a damaged self," and identifies stigma as a cause of shame. This can have a significant effect on mental health. Kim *et al*. (2011) carried out a meta-review which concluded that shame was a clinically significant contributor to depressive symptoms. They note that a characteristic of shame is that "…the entire self is the central focus of negative evaluation" (2011, 70). It "forces the individual to confront the possibility of a defective, unworthy, or damaged self" (2011, 70). The result is feelings of "being small, worthless, powerless, exposed and inferior" (2011, 71). These are powerful feelings and all the more corrosive because they are a self-judgement. Kim et al. (2011), distinguished between the effect of "external shame" and "internal shame". "External shame" arises from a greater sensitivity to outside

evaluation (eg stigma); “What do others think of me?” “Internal shame” results from a negative view of the self as seen through our own eyes. (2011, 74). Interestingly, Kim *et al*. found that external shame was a greater contributor to depressive symptoms and hypothesise that this may be because we care more about what others think of us than what we think of ourselves.

The effect is not transient. Gilbert (1998, 27) notes that the effect of shaming in childhood is far-reaching: “Early intense shaming has been identified as a source of later interpersonal relationship difficulty…” This was looked at in more detail by Trindade *et al*. (2017), who looked specifically at illness-related shame through a survey of students with a chronic illness (including spina bifida). They note that shame is elicited by “…situations where one feels that he or she is different, unattractive, inferior or inadequate” (2017, 408). They go on to argue that shame can result in “experiential avoidance” – a suppression of feelings that can bring short-term relief but in the longer-term feelings can return with greater intensity. Trindade *et al*. (2017, 412) go on to conclude that illness-related shame can lead to a fear of compassion from others, which has a negative effect on social relationships: “Shame related to chronic illness may lead to the avoidance and resistance of feelings of compassion, care and affiliation from other people.” They argue that “experiential avoidance” is the main driver of this isolating behaviour.

This is reinforced by Matos-Pina *et al*. (2022), who compared the experience of shame by those with a chronic health condition and those without. They conclude

that chronic illness is associated with higher levels of internal and external shame, noting that this has a detrimental effect on mental health (2022, 412).

Johannsdottir *et al.* (2021) also note the association between disability-related shame and mental health, making the point that it is not enough to work with affected individuals and that the societal causes of this shame must also be dealt with. They make the connection with stigma and argue that "The shame-bound person has learned from others and now accuses himself of the "crime" of being surplus, unwanted and worthless" (2021, 346). In other words, the acceptance of society's stigmatisation of disability leads to shame and its negative effect on mental health.

Degenerative conditions and biographical disruption

Locker (2008) points out that chronic illness, even if not fatal, can have profound consequences for the lives of those affected, noting that all parts of life – family, social, employment – can be affected, influencing self-esteem and identity. Locker concludes that "… the individual is deprived of peace of mind and a sense of self-worth" (Locker 2008, 87). This can be exacerbated if the condition is one that progresses in severity of impairments.

Bury (1982) used the term 'biographical disruption' to describe the way that chronic illness affects not only the physical body but also the affected person's sense of self. He argued that chronic illness disrupted the structure of life, to the extent that the future that had been anticipated was now thrown into doubt and needed to be

reconsidered. In addition to describing biographical disruption in children and young people, Bray *et al*. (2014) note that the biographies of parents are also affected. The birth of a child with a disability means that the future they anticipated must be reconsidered.

There is some debate as to whether this concept can be applied to lifelong conditions. Williams (2000) argues that the concept of biographical disruption does not apply to such conditions because "…these biographies have not, in any real or significant sense, *shifted*. Continuity rather than change remains the guiding principle here, including important elements of *biographical confirmation or reinforcement*" (2000, 50), concluding that the concept of biographical disruption "…fails to account for a range of other possibilities in which illness may already be a central part of one's biography, either from birth, early childhood or in later life…" (2000, 60).

However, although spina bifida is a lifelong condition, it could be argued that the changes associated with ageing means that people with spina bifida can still experience biographical disruption. Bury (1982, 169) argued that "Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally seen as distant possibilities or the plight of others." The progressive nature of spina bifida may facilitate this, with significant changes occurring over time. Bury acknowledges that in chronic illness "…individuals constantly test the meaning attached to their altered situation against the reality of everyday experience" (Bury 1991, 454).

Larsson and Grassman (2012), in an analysis of qualitative interviews with people affected by long-term or life-long conditions, disagree with Williams' view, stating that "…we found hardly any support for the argument that ageing or time spent with a chronic condition and recurring body changes would make it easier to confront new complications or losses" (2012 1166). They go on to argue that biographical disruption is not a single event but a series of repeating events and that biographical disruption is therefore a concept that helps aid understanding of the experience of lifelong disability. They conclude that "biographical disruptions may occur repeatedly over the life span in chronically ill and disabled people … illness changes do not necessarily have to be wholly unexpected to be experienced as disruptive" (2012, 1167).

This conclusion is similar to that of Bray *et al.* (2014). They looked at the effect of stoma surgery on a group of children and young people with lifelong conditions (including spina bifida) and conclude that "Having an impairment or illness since birth is not the primary influence on the experiences of surgery of children and young people, and their 'time spent with their condition' did not make it easier or harder for them to confront their life or complications after surgery" (2014, 835).

It could be argued that this is true not only of those facing a change in physical health but also those whose condition is constant but whose environment changes. For example, a research participant, Mary, describes being forced to travel to a

’special school’ because the local school attended by her siblings had steps. This event certainly had an effect on her sense of self and contributed to a sense of estrangement from her siblings.

Carel (2016) discusses the concept of ‘bodily doubt’, that illness replaces our unquestioned ‘bodily certainty’ - the belief that what we can do today, we will continue to be able to do – with ‘bodily doubt’. This loss of certainty, of what we previously took for granted, is disruptive. As Carel (2016, 87) puts it “… the sense of bodily doubt does not quickly and quietly disappear once the activity has begun. Rather, it remains constantly there, weighing down every step.” In an argument analogous to that of Williams above, Carel suggests that in the case of congenital disability, there may be no bodily doubt because people simply accept their own ‘normal’. However, with spina bifida, there is increasing evidence of physical deterioration over time, now that there is an ageing population to observe this deterioration in (Lidal *et al*. 2021, Oakeshott *et al*. 2019). People experience a series of new ‘normals’. This can include problems with fatigue and mobility etc. but extends beyond that. For example, a recurring theme amongst my counselling clients with spina bifida has been lymphoedema, a disorder of the lymphatic system leading to swelling of the limbs, in their cases one of the legs (Todd 2013). This is a poorly understood condition, however the effects can be life-changing, particularly for a wheelchair user. The reason for this is that independent living can depend on the ability to manage transfers unaided. To move from the wheelchair to and from the driver’s seat of a car, a shower or toilet seat, or a bed. The development of a heavy swollen limb makes these transfers much more difficult, or even impossible. Almost overnight, the affected person can no longer do these things without help and can

therefore become dependent on outside help. It is perhaps not surprising then that Greene and Meskel (2017, 566), in a quantitative survey of people affected by this condition conclude that “Patients with chronic oedema have a reduced QoL [quality of life] as a result of their chronic condition…” I would argue that the unanticipated loss of independence could be described as an instance of biographical disruption.

Bodily decline is not always so dramatic. The emerging natural history of spina bifida could be described as accelerated ageing (Verbrugge *et al*. 2017). For example, there is evidence of reduced mobility as people get older (Lidal *et al*. 2021, Oakeshott *et al*. 2019). Knowing that this is a possibility means that bodily doubt is ever present. Bodily certainty, the belief that what we can do today, we will always be able to do, is not something that can be assumed. For example, in my own case, I might want to walk round a nearby park. I would once have done this without thinking. Now, it entails conscious planning – for example, what will I do if I need to rest and there is no vacant bench? Bodily doubt means that our belief is disrupted and uncertainty and anxiety result. It is perhaps not surprising that the ageing spina bifida population reports a decline in mental health alongside the physical decline.

Charmaz (1995) explores the importance of adapting to impairment or, as is the case in spina bifida, changes in impairment. Acceptance of illness or impairment does not entail allowing it to define us: “successful adaptation means living with illness without living solely for it” (1995, 658). Charmaz notes that in the case of people with degenerative conditions, “progressive losses repeatedly threaten their body and self-integrity. They risk becoming socially identified and self-defined exclusively by their

impaired bodies" (1995, 660) and argues that adaptation to impairment culminates in surrender to the altered body, unifying body and self. 'Surrender' here is distinguished from becoming resigned and giving up on life; "When people give up, they lose hope and crumble inward. Passivity, depression and debility follow." Surrender means accepting the altered self and adjusting to it. Charmaz argues that this improves resilience "They suffer bodily loses but gain themselves...They believe in their inner strength as their bodies crumble" (1995, 675). Once again, disability is wrapped up with our sense of self.

The disabled identity

Our sense of identity – our sense of self – is bound up with our body. As Woodward (2003, 2) argues "The body presents the unique location for the development of the self and for notions of continuity." Woodward (2003) reviews the different theoretical positions on to what extent the development of self is under our control, for example Cooley's 'looking-glass self', which includes not only our internal feelings but also how we imagine others see and think of us. Other views such as that of Mead and Goffman place more emphasis on communication and interaction with others. However, what is clear is that a change in the body – through chronic illness – can challenge our sense of self.

Shakespeare (1996) argues that a negative disabled identity results from impairment being the defining characteristic; a 'personal tragedy'. Shakespeare (1996) also argues that narratives of self that involve hiding or overcoming disability – for example in sporting activities - are inherently unhealthy, as they entail denial and

acceptance of “external disempowering agendas”. This is contrasted with the development of a positive self-identification, often associated with the social model (see later discussion). I am not convinced this is entirely fair – is there really a greater difference between Paralympians and most disabled people, than between Olympians and most able-bodied people? Isn’t there a least a case that Paralympians provide a positive role model? That aside, the argument that there is a collective aspect to self-identification – a shared political identity that fosters confidence and empowerment, is a strong one. Shakespeare (1996) emphasises that self-identification as disabled (‘coming out’) is a process, not a one-off event, due to the previous experiences of othering and the isolating experience of disability. In that sense disability is compared to sexuality, in the need to “reject the burden of difference.” The point is also made that disability is not the only identity that a person will have – sex and class, for example, may also be important to individuals.

Singh and Chopra (2021) describe the growth of a positive disabled identity in a woman with spina bifida in India, which illustrates the lived experience of that change from negative to positive identity. The involvement with other disabled people, the collective aspect, was crucial: “Knowing about the situation of other people with disabilities helped Ashima learn to accept herself as she was. From this point onwards she began to appreciate her disability identity and took pride in celebrating the disability.” This is supported by other studies, for example Bogart’s (2015) study on people with multiple sclerosis, which concluded that accepting a disability identity was associated with improved mental health. Likewise, Nario-Redmond *et al.* (2013) argued that the threat posed by stigma could be overcome by collective means, by identifying with the stigmatized group in a positive way. They concluded that (2013,

482)"…identifying as a member of the disability community was positively predictive of both collective and personal self-esteem."

Following a systematic review, Forber-Pratt *et al*. (2017, 198) conclude that " …disability identity can be considered a unique phenomenon that shapes persons' ways of seeing themselves, their bodies, their ways of interacting with the world and adapting to his or her disability". They summarise the process as "…the person with a disability simultaneously negotiates their physical impairment and the social meaning of their disability to form an identity." They point out that a unique aspect of the disabled identity is that it is formed around a difference that is probably not shared by their family and immediate community (though it could be argued that this may also be true of differences in sexuality). Forber-Pratt *et al.* (2021) emphasise the importance of helping adolescents to develop a positive disability identity. The part of the results section of this thesis dealing with the school experiences of the research participants would seem to bear this out.

Spina bifida has been found to be associated with a negative impact on young people's sense of self. Shields *et al*. (2006) carried out a systematic review of published research, to determine whether children with spina bifida had a lower self-concept than their peers. 'Self-concept' is a term encompassing how children think of themselves over a range of values relating to self-esteem. They concluded that children with spina bifida scored less than their peers in terms of "global self-worth, physical appearance, athletic competence, social acceptance and scholastic

competence." (2006, 740). This is in line with the conclusion of Pinquart (2012) that children affected by physical chronic illness have lower self-esteem than their peers.

Van Daalen-Smith (2006) interviewed a group of young women with spina bifida about their experiences. A recurring theme was anger at being made to feel different and excluded. Bullying and other negative attitudes experienced at school "…created a barrier to learning and consequently the girls said that they felt that they had never reached their full potential." (2006, 267). The women shared their experiences of othering and came to understand that they should not have been treated in this way. Supporting the evidence that collective activity is empowering, van Daalen-Smith reported that "To realize that their experiences were not their fault but stemmed from prejudice and ignorance was emancipatory for these young women whose lives had been defined by their spina bifida."(2006, 268). Van Daalen-Smith states that "the psychological impact of otherness includes an erosion of self-esteem, limited achievement, isolation, difficulties in relationships and an eventual internalization of one's otherness" (2006, 269). The antidote to shame, with all of its negative effects on mental health, is self-esteem. And the acceptance of a disabled identity, of being a part of a community with others, can be an important part of that. That process has been helped by changes in the ways that we think about disability.

Models of disability

Essentially, the medical model sees those with illness/disability as a problem to be fixed. The focus is not on the person but on what is 'wrong' with them. Disability is regarded as "biological inferiority, malfunction, pathology and deviance" (Smart and

Smart 2006, 30). As Locker (2008, 88) puts it: "…the disadvantages that disabled people experience are seen as the direct and inevitable consequence of their impairments and disabilities." To be a person with a disability then, is to be subject to a 'personal tragedy'. Once people are seen in this way, as *other*, it opens the way to treating them differently from other people. In this way, the medical model makes prejudice and discrimination against disabled people not only possible but a perfectly justified and legitimate activity.

The medical model is one of experts in control of passive and obedient patients (Smart and Smart 2006). If the disabled cannot be cured by the experts, then that is the disabled individual's problem; it is not society's role to accommodate them. As we shall see, one solution to that problem for children born with spina bifida was selection for non-treatment (Lorber 1973).

The social model, developed by UK disability rights activists in the 1970s, argues that disability is not necessarily a problem in itself – it is the attitudes and structures of society that make it so, turning impairments into disabilities (Shakespeare and Watson 2001, Smart and Smart 2006).

The social model changes our focus to the ways in which society can provide solutions to impairments and allow people with disabilities to meet their full potential. It now has widespread acceptance: "Disability is now regarded in policy circles as not simply a medical issue but also a human rights concern" (Barnes 2020, 26). For

example, the Disability Advice Service for the University of Edinburgh is explicitly based on the social model (University of Edinburgh 2023).

The advent of the social model was a liberating experience for many. As Shakespeare and Watson (2001, 11) note “Suddenly people were able to understand that they were not at fault: society was.” However, the social model too has its critics. Hughes and Paterson (1997) argue that the separation of impairment and disability into different compartments does not reflect the way that people experience their bodies. Certainly, it is difficult to see how, for example, the chronic neuropathic pain that is a feature of spina bifida is only a problem because of the social environment. Thomas (2012) agues for a distinction between disabilism – the social imposition of unnecessary restrictions - and impairment effects – the unavoidable impact of impairments on how we interact with our environment. Shakespeare and Watson (2001, 16) make a point relevant to this thesis: “The woman who takes folic acid in her pregnancy is being sensible, not oppressive to people with spina bifida.” They go on to argue that while the social model remains an ideological litmus test for many disability activists in the UK, “Not everyone wants to be part of a disability movement… identity politics can be a prison as well as a haven” (2001, 20). This struck a chord with me. As a counsellor who works for a disability organisation, I have yet to come across a client who has heard of the social model. Shakespeare and Watson (2001, 22) and Shakespeare (2014) go on to argue that the social model has outlived its usefulness and that the time has come for a paradigm shift to a more integrated model.

Ageing with spina bifida: the problems of success

As is discussed in a later chapter, spina bifida had a high mortality rate up to the late 1950s/early 1960s and this improved markedly in the following decades. Mitchell *et al*. (2004 1891) concluded “Spina bifida is the only birth defect for which there have been tremendous successes in both treatment and prevention.”

One outcome of this is a growing community of people with spina bifida in their 50s and early 60s – including the 1960s cohort from my research participants. As a significant population of people ageing with spina bifida has not existed before, the issues faced by this growing community are not yet fully understood.

The emerging natural history of spina bifida has been described in the series of papers by Gillian Hunt, which follow a cohort of 117 children born with myelomeningocele (i.e. requiring surgery) in Cambridgeshire between 1963 and 1971 (Hunt 1990, Hunt and Poulton 1995, Hunt and Oakeshott 2003, Oakeshott *et al*. 2010, Oakeshott *et al*. 2015). This study is remarkable in that it has been maintained over a long period of time, with a 99% follow-up rate. In view of the value of this sustained cohort study, it is worth noting that although Gillian Hunt died in 2016, the work has been continued by her daughters. The dedication to this work shown by Gillian Hunt and her family has resulted in a unique contribution to the understanding of spina bifida. Given the multi-generational nature of this work, it seems fitting then that when Gillian Hunt finally received her MD, aged 90, her youngest daughter graduated alongside her (McLean 2013).

The 50-year follow-up was published in 2019 (Oakeshott *et al*. 2019). It describes a physical decline, marked by the sharp decrease in the number of the cohort who were able to walk (defined as being able to walk 50m with walking aids), which declined from 50% of cohort at age 18 to 27% at age 50.

The research participants born in the 1960s interviewed for this thesis describe similar physical health issues. In that sense, they are typical of people ageing with spina bifida. However, they are not typical of most people born with spina bifida in the same time-frame. By the time of the 50-year follow-up described above, only 37 of the original cohort of 117 were still living (32%). The research participants here - those in their 50s and older, at least - were therefore unusual simply by being alive; 68% or so of those born alongside us are no longer here to tell their stories, something reflected in the title of the 40-year follow-up publication - *Expectation of life and unexpected death in open spina bifida* (Oakeshott *et al*. 2010). This is particularly the case for the 1960s cohort of research participants, born when mortality rates were higher and when the practice of selection for treatment (see Chapter 4) was in place in many centres (though not the Cambridgeshire centre on which Gillian Hunt's work is based).

Other studies provide further evidence of physical decline. Lidal *et al*. (2021), looking at people with spina bifida aged 50 or over in Norway, reported that 83% of those surveyed "had experienced an early onset of deterioration in ambulatory function"

(2021, 247). They also note that this deterioration, along with pain and incontinence, contributed to a reduction in social activity.

Spina bifida and mental health

There has been somewhat less work on the mental health of this community, however there are indications that the decline in physical health, and the changes in lifestyle associated with it, is often associated with a decline in mental health. A decline which was starting from a position already worse than that of the general population. Appleton *et al*. (1997) concluded that young people with spina bifida were at greater risk of depressive mood, low self-worth, and suicidal ideation, associating this with negative self-image.

The issue of mental health in young people with spina bifida was reviewed by Shields *et al.* (2008) who, following a meta-analysis of published results, concluded that self-image (which includes for example, self-esteem) was lower amongst children with spina bifida than was the case with their able-bodied peers. They conclude that a factor is the constant comparison of themselves with able-bodied classmates in, for example, athletic activities. This will feature in the later discussion of the research participants' narratives of their school days.

Mental health issues are not confined to childhood. Dicianno *et al.* (2014) concluded that depressive symptoms in adults (>25 years) with spina bifida were both common and not being treated and recommended that this should be addressed during adult

spina bifida clinics. Bendt *et al.* (2020, 10) looking at spina bifida adults in Sweden, also concluded that "…adults with SB have a complex set of medical, physical, cognitive and social needs that need to be addressed to improve their health and living conditions." However, such adult clinics are an exception – there are none in Scotland, for example. Indeed, the transition from childhood, when spina bifida clinics are the norm, to adulthood and less holistic healthcare, is increasingly seen as something requiring careful management, as it is associated with a decline in health. It has therefore emerged as a key priority for spina bifida associations worldwide (Patel *et al*. 2019).

The negative effect on mental health continues through adulthood. Showen *et al.* (2021) noted high rates of anxiety, depression and social isolation amongst the adult spina bifida community and found a correlation with urinary incontinence. Lidal and Larsen (2022), in a study of spina bifida adults over 50, noted the association of depression and anxiety with increased fatigue reported by this population. While they found that 36% of their participants showed "clinically relevant" symptoms of anxiety or depression, "few of them received any form of therapy for psychological distress." (Lidal and Larsen 2022, 7945). It is worth noting that these publications, in common with the rest of the relatively small literature around spina bifida and mental health, are based on quantitative research. There is relatively little in the literature that seeks to describe the lived experience of the ageing spina bifida community. A survey of 650 adults with spina bifida in Europe was carried out by the International Federation for Spina Bifida and Hydrocephalus and included qualitative data (Levy and O'Donnell 2020). This publication also noted a decline in both physical and mental

health associated with ageing and concluded that more in-depth individual interviews were needed to explore the lived experience of this community.

The research gap

While there has been a start in addressing mental health issues in people with spina bifida, this has concentrated on the needs of the younger population. For example, the *Mental Health Guidelines for the Care of People with Spina Bifida* drawn up by Kritikos et al. (2020) lumps everyone over the age of 18 together – yet this includes people at very different stages of life, meeting different challenges. The emerging literature on the mental health issues faced by the ageing spina bifida community indicates an increasing need for mental health services, including counselling, that meet the needs of this growing community. The work described here is a contribution to the understanding the lived experience of the ageing spina bifida community. It is hoped that this could enable better provision of the mental health services that they need.

Furthermore, in all the publications cited in this chapter, there is something essential that is almost entirely absent – the voices of the spina bifida community itself. From whether we should be born, whether we should be allowed to live, to how we should live, others speak for us (and sometimes, arguably, against us). This thesis, through using the question **What are the childhood narratives of adults with spina bifida?** to explore the lived experience of people with spina bifida, is a contribution to allowing those voices to speak and to tell their story.

Chapter 3: Stories about Methodology and Method

This chapter sets out the methodology used in the work contained in this thesis, including the theoretical and other assumptions underlying it. The main elements in the approach I have taken are narrative inquiry, reflexivity and thematic analysis. I deal with each of these in turn, though I hope that it will be clear that these elements are interlinked. As will become clear, stories and their meaning are central to this thesis. In keeping with the content, this chapter is also presented in narrative form.

A Story about Ontology and Epistemology

I am a latecomer to counselling and to qualitative research. My previous background is in science; my PhD was on bacterial plasmids (O'Donnell and Williams 1991) and I went on to a 30-year career as a professional scientist. My worldview was therefore positivist, rooted in quantitative research and the scientific method. It is fair to say that I was not aware of this as an ontological choice. Indeed, I was unaware that I was making a choice at all and I suspect that was not unusual amongst my scientific colleagues. I was simply ignorant of other ways of exploring and knowing; other paradigms. For me, and those I worked alongside, research consisted of the objective gathering of quantitative evidence that added to what we knew about the world.

This view was changed by experience – by my own lived experience of trying to understand something better that I felt I did not currently understand well enough. I

wanted to know more about something that could not be readily encompassed by quantitative research, something which threw the limitations of positivism into sharp relief.

That experience was starting to think about the research presented in this thesis, on the stories that people tell about their childhood experiences of spina bifida, including my own. During my Counselling Diploma course at the University of Edinburgh in 2017-2019, I had begun to think about my own experience of spina bifida, something I had not done for a number of years. My reasons for not thinking about something that had done so much to shape me – including the fact that it had done so much to shape me - only became part of my conscious awareness during my research and are described later. However, one thing that started the process was that I received spinal cord surgery, in a bid to halt physical and neurological deterioration related to spina bifida. One effect of that experience was that I began to think about my previous spinal cord surgery, which took place shortly after my birth.

I discovered that I had been in hospital for 2 weeks and I began to think about how the experience of perinatal surgery and parental separation – i.e. of infant trauma – could have affected me. This interest was heightened through the chance finding that it had once been common practice to carry out surgery on new-borns without an anaesthetic (Anand and Hickey 1987). As I looked into this, I found a wealth of data that described the molecular and biochemical effects of infant trauma, for example, Young *et al*. 2017, Mooney-Leber and Brummelte 2020). Those effects had been measured in an objective way, firmly integrated in (if undeclared as such) the

positivist paradigm. However, as I delved into this material, I realised that it did not tell me what I wanted to know. My knowledge had certainly expanded – I had never come across the hypothalamic-pituitary-adrenal axis until I read Mooney-Leber and Brummelte's (2020) paper, for example and I can see that, in its context, it is an important thing (it is a mechanism that regulates the body's response to stress). However, all this new knowledge did not serve to illuminate the things that I actually wanted to improve my understanding of. I came to realise that I was interested in human experience, both my own and that of others. Not only did the research I had found not answer my questions but in a fundamental way it *could not* do so. It simply lacked the epistemological vocabulary to engage with lived experience. And this led me to qualitative research.

Initially I found the world of qualitative research, with its different ontological and epistemological approaches somewhat disorienting. From a world where the concept of ontological choice did not exist, there seemed to be a bewildering array of different ways of looking at the world. However, I found that asking myself the question "What do I want to know, that I do not know now?" to be helpful in finding my way. I was also forced to think about what my assumptions were about the world - what were my beliefs? Consideration of these things is generally absent from quantitative research. Yet I came to realise that even if unacknowledged and undeclared, they do have an effect on ostensibly objective research. In my own published work on plant pathology, for example, there is no consideration of why I (and those who funded me) had prioritised plant diseases important to large-scale Western food production, rather than those with more social impact elsewhere in the world. (Mulholland et al 1996, O'Donnell 2000) Ostensibly objective work contained within it implicit

assumptions about value.

However, consideration of my values and beliefs was essential in deciding what, in the context of my research, I considered ‘reality’ and what counted as knowledge about that reality. It became clear to me that I was not in the business of uncovering an objective truth, that there was in fact no single objective truth to be uncovered – a dizzying realisation in itself. I was interested in lived experience – what it was like for people to grow up with spina bifida and what meaning did those childhood experiences have for them now. This was not something that could be measured by a piece of scientific equipment, no matter how complex. Indeed, it could not be measured at all – it could only be felt and, hopefully, understood (or at least understood better). Moreover, there was no one, single objective lived experience – everyone’s experience was different and equally valid. I would therefore be looking at as many different lived experiences as I had research participants (plus one, as I would include my own). Each of those lived experiences represented a reality every bit as meaningful as my own. I hoped that in amongst those varied subjective accounts, I would find significant areas of common understanding that would be of relevance beyond us as individuals. In other words, I would be developing an interpretation of my research material, one that would be subjective, however I would be as clear as I could be with myself (and with the reader) what the beliefs, assumptions and values were that contributed to that subjective interpretation. From this I would construct my own narrative based on the research material, one that would, of course, be subjective. It would be reality as constructed by me (and to an extent by the research participants), not an objective fact to be uncovered and measured. This implied a constructivist/interpretivist paradigm (van der Walt 2020)

which included those subjectivist assumptions about the reality of the world (ontology) and emphasises “the goal of understanding the ‘lived experiences’… from the point of view of those who live it day to day” (Ponterotto 2005, 129).

Having worked out what my assumptions were about the world, this formed the theoretical foundation for my research. Locating my work within the constructivist/interpretivist paradigm was not merely an abstract theoretical position. It carried with it implications for how I would carry out the work: “… a distinguishing characteristic of constructivism is the centrality of the interaction between the investigator and the object of investigation. Only through this interaction can deeper meaning be uncovered. The researcher and her or his participants jointly create (co-construct) findings from their interactive dialogue and interpretation” (Ponterotto 2005, 129). I began to think about what this would mean for my research in practice.

A Story about Autoethnography and Narrative Inquiry

Having acknowledged the subjective nature of my own lived experience, one way forward that I considered was autoethnography - an umbrella term covering a range of autobiographical methodologies, based broadly on personal narrative and experience, used to further wider understanding (Ellis and Boucher 2000, Ellis *et al*. 2011). In other words, the researcher is their own subject. This had an immediate appeal – it was, after all, my own experience that had sparked my interest. Autoethnography would allow me to continue to explore and analyse my personal experience and put it in a wider context (Ellis *et al* 2011).

During the Diploma course, I had been struck by my reading of Connie Johnson's paper on her own childhood experiences of disability and difference (which had some similarities to my own) and the effect on her role as a counsellor (Johnson 2011). It was a compelling *story* -a personal narrative that described the author's life which at the same time told a wider story about disability. The idea of making sense of the world through stories had a strong resonance with my work as a counsellor. It had often seemed to me that counselling clients came with a story, that they were trying to make sense of. One way of looking at the effect of counselling is that the client's understanding of their story changes and with that, the story itself can be transformed. As Holmes (2000, 92) notes, "our sense of self is inextricably bound up with our life-stories and the meanings they have generated." To a significant extent, we are our collection of stories.

I was encouraged by reading the work of other researchers who published autoethnographic accounts of their varied experiences of disability (Richards 2008, Moore 2012, Ellis 2014). In particular, I was inspired by the work of Anne Neville-Jan (2003, 2004, 2005) who wrote about her experience of spina bifida from an explicitly autoethnographic perspective – a rare example of the spina bifida lived experience in the academic literature. I found her use of self – use of her lived experience of spina bifida – to be empowering.

The thought of writing something similar to the autoethnographic researchers above had a strong appeal. I could see how it might be possible to explore my own journey, my own thoughts and feelings, and put them into a wider context. I had lacked the confidence that my own story would be worth telling and reading the work of others made me realise that this was not necessarily so.

However, I came back to the fact that I wasn't *just* interested in my own experience. Initially, I thought that those born around the same time as me, with the same condition, would have had the same or similar infant trauma in the shape of perinatal surgery and parental separation. How had that affected them? How did their understanding of that experience help them to make sense of their later lives? I felt that, just as the consideration of infant trauma had allowed me to look at my early life in a different way, that might be an opportunity that others might welcome too. As the focus of my research moved away from the narrow issue of perinatal trauma, to wider childhood experience of spina bifida, I was still interested – perhaps more so – in the experiences of others. In the end, I decided that autoethnography would not give me access to all of the terrain that I wanted to explore. Nevertheless, I also recognised that there was another driver for me; in exploring other people's worlds, it could shed more light on my own - including my motivations for engaging in the research in the first place. This did indeed turn out to be the case. The ground covered by this thesis is both broader and deeper than if I had taken an autoethnographic approach. Broader because of the range of experiences described. Deeper because as a result of engaging with the research participants, my own self-awareness grew. The things I have written about are not those that I thought I would write about at the outset. An important part of the reason for that shift

is that in sharing their experiences with me, the research participants gave me a different lens – or set of lenses – with which to look at my own.

Ultimately then, although I have included my own experiences, I concluded that the best way to do this was through my interaction with the research participants rather than autoethnography. I shall go into more depth on this reflexive approach later.

A Story about Stories

In order to explain my eventual focus on narrative inquiry, it is necessary to take a step back and pick up another strand of my own experience, one which, in different ways is woven into my spina bifida narrative. It is a part of my life that I considered completely separate from my spina bifida research. However, as I shall show, my work on this project has caused me to look at it in a new light and revise that opinion.

In 1993, my wife and I had our first child, Calum. Prior to this we had seen a genetic counsellor, to discuss the implications of my spina bifida for any child - we wanted to know the probability of any child also being affected by it. The outcome was reassuring – the chances were low and would be lower if my wife took folic acid supplements, which she did. The standard pre-natal blood test showed that our baby did not have spina bifida. I said in the introduction that I had not thought about spina bifida for many years. In fact, I had not done so since receiving the results of that test. This was partly because of the relief at the time – I recall that it felt like a weight being lifted – but mainly because of subsequent events.

Calum was to all initial appearances a healthy baby. However he developed recurring cold-like symptoms that progressed into pneumonia and at 7 months he was diagnosed with a rare genetic condition, Pompe disease. This was then untreatable and invariably fatal within the first year of life. Calum died at 8 months of age. For the next 10 years, I was involved in the creation of an international patient community and the drive for a treatment. This culminated in the development of a successful treatment and formulation of the 'Pompe Model' for the cooperation of patient groups, researchers and industry (House *et al*. 2019). The development of that treatment was something that I saw through the lens of quantitative science. Furthermore, it is located very firmly in the medical model of disability – indeed there was limited scope of anything else. The impairments associated with infantile Pompe disease were fatal. Children born with this condition can now receive a treatment which ensures their survival, albeit often with a range of impairments, meaning that the ideas behind the social model of disability are now more relevant to them. Interestingly Mikami's (2022) account of the Pompe story uses the term "biological citizenship" which seems to me to be a more inclusive take on the medical model and a variation that I find appealing.

One thing that occurs to me, looking at this story again in the context of this thesis, is that there is a similarity between the Pompe narrative and the spina bifida narrative (Chapter 4) – medical advances ensured the survival of children who would otherwise have died and who now have a range of ongoing issues. However, interestingly, there has been no suggestion – in the academic literature or elsewhere

- that the survival of children with Pompe disease is in itself a bad thing. This may be an indication that the policy of selection for non-treatment described in the next chapter would be unacceptable today.

My perspective was also changed through my encounter with the work of Arthur Frank. I realised that I had responded to my encounter with illness (albeit my son's, rather than my own) by creating a narrative. It was a narrative that others found compelling and had been of use (Mikami 2022). I had, in fact, created a 'quest narrative' (Frank 2013). Frank describes different types of illness narratives and one is the 'quest narrative' which he describes as follows: "Quest stories meet suffering head on; they accept illness and they seek to use it" (Frank 2013, 115). The Pompe story is, I believe, an example of this, though I was unaware of that when living it.

I will further discuss the relevance of Frank's work in the main body of the thesis, as illness narratives and their role will form an important lens through which to examine the interview transcripts. For now, I will note that it awakened me to the power of narrative and, in particular, the function it provides in relation to illness. It also served to reinforce the location of my research within the constructivist paradigm: "First, people's experiences are intensely personal; claims to the uniqueness of experiences are true and deserve to be honoured. Second, people's ability to have experiences depends on shared cultural resources that provide words, meanings…" (Frank 2013, xiii). For me, this neatly summarised the boundaries of relativism – ie the objective reality shared with the research participants - that I assumed for my research (Harper 2011).

Through the narrative lens provided by Frank, I not only recognised what I had done but began to understand my reasons for doing so. And that understanding of the role and power of narrative made me look at my growing interest in the experience of spina bifida in a different way. I began to see my research into the lived experience of spina bifida in terms of narrative. I had, in fact, created another quest narrative, albeit a very different one. What were the stories that people told about themselves? Indeed, what were the stories that I told about my own experience? I realised that stories were fundamental to the way in which I made sense of the world. That is why this chapter is itself presented as a narrative, the story of how my understanding evolved. I was struck by the argument put forwards by Clandinin and Connelly (2000, 17) that "…if we understand the world narratively… then it makes sense to study the world narratively." This intuitively felt right as a way forward for me. I felt that it might be true of my research participants too, even if it was not necessarily a way that they would describe themselves. As Riessman (2008, 8) puts it "… individuals and groups construct identities through storytelling." It would therefore be through their stories that I would try to access the lived experiences of my research participants.

A Story about Reflexivity

I realised that in recognising the central role of narrative, and that I too had my own narratives, I was also recognising that the separation between researcher and research participant was blurred. I could not claim the lofty detachment of objectivist science and my view would be a subjective one. Moreover, this would be a two-way street – I would inevitably find myself affected – changed – by my interaction with the

research participants and their narratives. In fact, I was not only jettisoning another relic of the positivist approach adopted in my science career, I was actively embracing the very interaction that scientific detachment sought to avoid happening. As I immersed myself in their stories, not only would my understanding of the research participants be changed but also my understanding of myself; they, in a sense, would change me. This then posed the question – how could I integrate this into a coherent theoretical framework that allowed me to conduct research in a transparent and ethical way?

Firstly, I needed to be honest and transparent about my subjectivity. I was part of the very community that I was researching. I was interviewing people about experiences similar to those that I too had had. It would, I suggest, take a super-human effort to set my personal experience aside, either in a bid for positivist objectivity or even the 'bracketing' advocated by Husserl (Finlay 2009). Instead, I would use my own experiences to be open, not only with those reading the finished work, but also with the participants, in a way that eroded the boundary between researcher and participant. It was apparent to me that this would have an effect on the way that the research was carried out. As Etherington (2004, 25) puts it "By allowing ourselves to be known and seen by others, we open up the possibility of learning more about our topic and ourselves, and at greater depth."

As I listened to the stories told by my research participants, my responses to those narratives provided an opportunity to reflect on my understanding of my own, to examine my own narratives from a fresh perspective. There is both an opportunity

and a danger here. As Etherington (2004, 180) argues: “Our personal history, when it is known to us and processed in ways that allow us to remain in contact emotionally and bodily with others whose stories remind us of our own, can enrich our role as a researcher,” before cautioning that “…if we are exploring topics through research which are part of our own history that is out of our awareness, we are in danger of using our participants vicariously, to explore their issues as a way of avoiding our own.”

I identified this as an important risk arising from the approach I had taken. In order to counter the risk identified by Etherington, I resolved to remain in personal therapy for the duration of the project, with the explicit aim of exploring my own narratives of childhood and re-examining them in the light of my responses to those related by the research participants. This commitment to self-awareness was an important component of my methodology and so, where appropriate, I have included my own narrative alongside those of the participants in the chapters where these are discussed, with my reflections on how my understanding of these has changed. In asking my research participants to be honest about themselves, I could ask no less of myself.

So I had arrived at a position where I was interested in narratives, the stories that people told about themselves (specifically in relation to their childhoods). I also acknowledged my subjectivity; I was born with the same condition and had my own narratives. I could not pretend to objective detachment. This meant a reflexive

approach was unavoidable if I, with my personal history, wished to research this topic – however this could also be a strength.

Indeed, through my interaction with the research participants, I began to see that my initial idea for my research project – to look at infant trauma – to some extent distanced me from my own lived experience. Was it, perhaps, a way of keeping difficult issues at arm's length? I came to the view that this was indeed the case. I had made a step towards looking at my lived experience of spina bifida, however the idea of infant trauma was, to an extent, an abstract one. I still had, at some level, the idea of looking at a part of the spina bifida experience in a detached, objective way. Infant trauma – by its nature something outside of conscious experience – was a sort of halfway house between the worlds of quantitative and qualitative research. It did involve my lived experience of spina bifida, however it did so in a 'safe' way, one step removed from my conscious experience. The honesty and openness of the research participants, their willingness to share the story of their own lives and experiences, was a catalyst that allowed me to do the same. This is therefore not the thesis I set out to write and, I believe, is all the better for it. My engagement with the subject, lived experience of spina bifida, is deeper and more meaningful and this is something that I hope to communicate through the text.

A Story about Interviews

Recruiting participants

Research Participants were recruited via Spina Bifida Hydrocephalus Scotland (SBHS), a charity supporting people with spina bifida. SBHS was founded in 1965 by

a group of parents who had children affected by spina bifida. It defines its purpose as: "Spina Bifida Hydrocephalus Scotland seeks to increase public awareness and understanding of individuals with spina bifida and / or hydrocephalus and allied conditions. It aims to support all those affected to identify their needs and to empower them to make informed choices and decisions." (SBHS, n.d.)

I approached SBHS to ask if they would be willing to publicise my project with their members and received an enthusiastic response. It is interesting to reflect on what the organisation meant to me at that point, how I felt about contacting them and how I felt about the positive response that I received.

I could remember my parents receiving the SBHS newsletters - typed and stapled together sheets of paper. I tried to read them but found them difficult to follow, perhaps because they were aimed at an adult audience. I was fascinated by them, possibly because I sensed that they might hold answers to questions about myself that I was struggling even to form. However, I also felt a vague sense of dread because they were associated with something “bad”, something beyond my understanding – my otherness. As my lack of understanding developed into a sense of shame about myself, I distanced myself from anything to do with spina bifida and made no attempt to stay in touch with the organisation once I had left home for university.

So in getting in touch again, I found myself wondering what the reaction would be, almost as though I was getting in touch with a person I had been ignoring for decades. The positive, enthusiastic response I received felt like being welcomed home. This relationship was to develop further when, during the period of my research, I was employed by SBHS as a counsellor. It was recognised by both myself and by SBHS that care would need to be taken to keep the two roles separate and current counselling clients were excluded from acting as research participants. In addition, in the material circulated to help recruit participants, SBHS made it clear that participation (or not) would have no impact on future access to the counselling service. However, it should be noted that one participant had been a previous counselling client and this required some consideration before the decision to recruit them.

The person concerned had been a client for a short number of sessions, which had come to an agreed, positive, ending over 12 months previously. There was therefore no ongoing relationship and no imbalance of power that might have left them feeling obliged to volunteer for an interview. The fact that we had spoken already probably did give the interview a ‘head start’ in terms of rapport, however it is interesting that there was little or no overlap with the material discussed. Nor did the previous boundaried counselling relationship unduly hinder the co-creation aspect of the interview. I remain of the view that inclusion of this participant was the correct decision.

Having secured agreement in principle to help me recruit research participants, I considered what the practicalities would be, as part of my Ethics Committee submission.

Interview format

I decided to use remote interviews, partly because of the anticipated geographic spread of research participants, but also because of the then-current covid pandemic. I chose online video interviews rather than telephone because of practical ease of recording and also because my experience of counselling during the pandemic had led me to conclude that video was both an easier medium through which to establish rapport and also information-rich in terms of body language. Although online counselling (and interviewing) is relatively new, there is evidence to support the view that online work can be effective. O'Connor and Madge (2016) note that online interviews have become a common method of data collection in social science research, while noting a lack of empirical research into the effects of this.

A review by Richards and Vogano (2013) concluded that online counselling could facilitate a similar experience to in-person counselling and that the disinhibition effect could actually facilitate openness by clients. However, while not contradicting that view, Smith *et al*. (2021) point out that while, by necessity, online work became prevalent during the covid pandemic, there are still large gaps in the evidence base and further research is needed. For the purposes of this thesis, my experience of online counselling gave me some confidence in using the same format for the research interviews. In doing so, I was mindful of the risks as well as the benefits of the online format. For example, the disinhibition effect discussed by Richards and

Vogano can be a double-edged sword – although it can facilitate openness, people may also say things that they are not quite ready to discuss. I was mindful of this possibility and none of the research participants got back to me to raise any concerns over what they had said. In a sense, the lack of discussion of continence issues (see later) may be an indication that over-disclosure was not a problem. I think that I was also helped by the fact that as a result of the covid pandemic, people had become more familiar with the use of online platforms.

For the interviews, I settled on the Zoom platform, rather than the University's preferred Microsoft Teams option because my experience was that many people – particularly those who do not work in a corporate IT environment – found Zoom easier to use. I used the Edinburgh University corporate Zoom platform which had secure storage and provided a written transcript of the session. I had anticipated that this would make the process of transcribing interviews easier and faster. Unfortunately, this was not the case – however Zoom developed its transcription software, it was not based on the Scottish accent…

My commitment to reflexivity had an impact on my approach to interviewing. For example, I felt it made no sense to proceed with a rigid set of interview questions. I decided that a semi-structured approach would be better, with space both for the participants to tell the stories that meant something to them and also for me to react to and follow them.

This approach to interviewing was compounded by another component of my subjectivity, that of my role as a counsellor. My interviewing technique was influenced by my counsellor experience – and conversely, the research material and my response to it would find its way into my counselling work.

As part of the semi-structured approach, each participant would be asked the same 3 questions but the content of the sessions would otherwise be down to what they themselves wanted to talk about – the parts of their lived experience that mattered most to them. I wanted to give them the freedom to express themselves as they wanted, rather than impose my agenda on them. As a counsellor, I felt quite comfortable about approaching the interviews with that level of uncertainty.

Each interview followed the same format. As a 'warm-up' at the beginning, each participant had been invited to bring something that reminded them of their childhood – an object or a photograph and to say something about it. Most did so and the choices were invariably interesting. Those who did not – either because they chose not to or just forgot – managed well without a 'warm up'. The interviews proper began with the first question "What are the family stories around your birth?" I chose this because the earliest memories – the earliest stories – would not be within the conscious memory of the research participants but would nevertheless be known to them and have meaning for them. The second common question "Can you tell me about a time when you felt, or were made to feel, different?" was designed to focus the research participants on a time (or times) in childhood where they were conscious of having spina bifida. This would also move them forward into their

conscious memories, if they had not already done so. The third question “What would you say you’ve taken with you from those days into adulthood?” was intended to focus the research participants on the meaning the stories they told had for them in their present. The research participants were all given these questions in advance of their interviews, to give them the opportunity to think about them.

The final part of the interviews consisted of the use of emotional touchpoints (Nelson *et al*. 2017). Each participant had been sent a list of positive and negative words (Appendix 5) that were used in current research (Sharon Levy, personal communication, 2022) and were asked to read through them and see if any particular memories were elicited by them. The purpose of the use of emotional touchpoints was to help the research participants find a label for any feelings that had arisen for them during the interview itself and to then explore the memories that were associated with those feelings. It proved to be a productive way of ending the interviews, both in terms of the material produced and in ensuring that the research participants had an opportunity to talk about things that had arisen for them.

One downside of this choice of interviewing method was that, by its nature, we discussed the issues that were relevant to the research participants, which were not always necessarily the ones that I wanted to pursue. For example, I knew from the literature and from my experience of counselling people with spina bifida (and from my own lived experience) that continence is an important issue. I chose not to ask a question about it mainly for the same reason that I didn’t ask about any other specific impairments associated with spina bifida – I did not want to make any assumptions

about what the research participants should talk about. I was also aware that it is a subject that many people find difficult to talk about. Clients with spina bifida almost always talk about it, however usually only after a secure therapeutic relationship has developed. A specific question on continence would therefore have risked disrupting the research interviews.

This view is borne out by the fact that with one exception - and that a mention in passing – none of the participants raised the subject. That in itself speaks to the importance of continence – it was “the dog that didn’t bark.” I suspect that had there been repeated interviews, the subject would have been raised, however as it stands the only mention in the discussion is in relation to my own experience.

The policy of selection was another subject not discussed with the research participants – it was a discovery that I made after the interviews had been carried out. I think this was probably fortuitous. Had I raised it with them, it might have tended to dominate discussions and the research participants had many interesting things to say that might otherwise have been crowded out.

Research participant cohorts

I decided to interview two distinct cohorts – people born in the 1960s (or earlier) and people born in the 1990s. There was, perhaps, an echo of positivist thinking in my desire to compare between two groups in this way. However, my reasoning was that the experiences might be very different. Early experiences such as perinatal surgery

and associated use of analgesics, as well as parental separation, were different in those decades. By the 1990s, prenatal testing for spina bifida was routine, so I reasoned that parents of children born in the 1990s would probably have been aware before birth that their child had spina bifida. This seemed like a different experience from the shock experienced by parents in the 1960s. I was curious to see if or how these differences might be expressed in the stories told by the research participants.

Ethics Approval and Participant Information Sheet

Once I had received approval from the School's Ethics Committee (including the Participant Information Sheet), SBHS emailed members in the two cohorts I was interested in – those born in the 1960s (or before) and those born in the 1990s - with a general description of the project and asking interested people to contact me for further details. They also repeated the information in their non-public Facebook group. People who emailed me to express an interest were sent a copy of the Participant Information Sheet (PIS). The PIS described the project and what the interviews would consist of. It also made it clear that I too had been born with spina bifida. I felt that this was an important part of helping ensure that the interviews had the peer-to-peer quality that I wanted to achieve. I was able to recruit 5 people for the 1960s cohort (though I had to extend this slightly to 1971) and 2 from the 1990s. This was fewer than I had originally intended and I considered whether to extend my request to the sister organisation for England and Wales. However, following discussion with my supervisor, we decided that the 7 interviews with the existing research participants gave sufficient material for this thesis.

Research Participants

The research participants were each allocated a sequential code, depending on when they contacted me and returned a completed consent form. They were also given a pseudonym.

A short description of each research participant follows, grouped into the 2 cohorts.

1) "Joan"

   Joan was born in 1961, in a rural area. She has lived and worked in Edinburgh since she left home. Her ambition was to work in a hospital environment and in this she succeeded, though increasing difficulties with mobility led her to take early retirement. Originally ambulant, she is now wheelchair-dependent and lives on her own in supported accommodation.

2) "James"

   James was born in 1962 overseas, where his father was serving in the armed forces. He was sent to the UK for surgery after his birth and was the only participant to have a shunt fitted for hydrocephalus. He has lived in the same area of North East Scotland since childhood. James worked in a variety of jobs and continues to be involved in different organisations. He lives with his wife and is ambulant, though increasingly less so.

3) "Mary"

   Mary was born in 1956 in the Glasgow area, as part of a Catholic family.

Although just a few years older than the other participants, those years took in the advances in perinatal surgery described elsewhere. Interestingly, Mary did not have surgery on her spina bifida lesion until later in life – an example of the earlier treatment as described by Zachary (1977), where the lesion was simply bandaged up to see whether it would heal over. In Mary's case it did, though she was a life-long wheelchair user. She did not develop hydrocephalus. At the time of the interview, Mary had been a widow for 10 years. She was the only research participant with whom I had previous contact – she had briefly been a counselling client over 12 months before. Sadly, Mary died in 2022, for reasons unconnected with spina bifida. We had contact during her short illness, at her request, though none of the content of those conversations is discussed here.

4) "Maureen"

Maureen was born in 1963, in the Glasgow area, as part of a Catholic family. Maureen described a sometimes difficult childhood. She moved abroad to find work, though eventually returned to Scotland to work in the NHS. She is ambulant though now uses a walking aid. Maureen is divorced, with two adult children. She is retired from work.

5) "Ailsa"

Ailsa was born in 1971, in the Borders. She describes a sometimes difficult childhood and how her life began to develop after leaving school. She works in the NHS. Ailsa is ambulant and married with 2 school-age children.

6) “Michael”

Michael was born in 1994, in the Glasgow area. He has been a wheelchair user since childhood and lives independently. Michael is a graduate and works as a writer.

7) “Eileen”

Eileen was born in 1999, in the Glasgow area. She benefited from a treatment for hydrocephalus that avoided the use of a shunt. She is ambulant with walking aids and occasionally uses a wheelchair. Eileen is a student and lives with her parents.

A Story about Diversity

There is a gender disparity in the research participants – 5 females and 2 males. Two further males decided not to proceed after reading the PIS (which is, after all, its purpose) and one got so far as to agree to interview and be allocated a code but did not log in for the interview or respond to follow-up contact. There were 3 further interested female potential participants who found the online and other aspects too challenging and further female participants that I had to turn down because they were outside the age parameters. There therefore seemed to be a difference between men and women in terms of their willingness to reflect on their experiences.

It is noteworthy that only two of the research participants have been affected by hydrocephalus and only one had surgery to have a shunt fitted. It may be that the

technical aspects of the interview - online via zoom - acted as a filter for some individuals because of the cognitive difficulties that can be associated with hydrocephalus. In a post-covid time, it would be worthwhile capturing the stories of that segment of the community via face-to-face recorded interview.

In terms of ethnicity, the research participants - the 1960s cohort in particular - reflect the diversity of Scotland at that time. Scotland was a very different place then and there was no significant non-white population – in fact, as late as the 1991 census, Scotland's population was 98.7% white (Walsh et al. 2019). Nevertheless, diversity was present in the form of a significant minority population, Catholics of Irish descent, that had suffered discrimination (Gallagher 1985). This is reflected in the make-up of my research participants.

There is another issue around diversity, one that is so big and obvious that it almost seems to escape attention; the spina bifida community itself is a minority. In fact, as the following chapter makes plain, it is a minority that has suffered discrimination in a way that other minorities have not, in recent times.

A Story about Thematic Analysis

Having concluded that my research would involve the generation of narratives, I then considered the question of how I would actually examine the content of those narratives. For my purposes, I was not in interested in a Narrative Analysis approach, which "… does not seek to find similarities across stories, and is not

interested in conceptual themes…" (Etherington 2004, 213). In the Narrative Analysis approach, stories are left to speak for themselves, whereas I was very much interested in similarities and themes, in adding my own interpretation of the material. My starting point was that I was interested in what was actually said, the stories that were being told, rather than how they were told, the social context etc. I therefore needed to consider how I could I look at my research material and make sense of it, to identify patterns and themes. I also took into consideration that I was interested in identifying patterns across the interviews, rather than looking at the unique elements of individual participants - as might be the case in, for example, the use of IPA (Smith 2004). I needed an approach that would enable me to do this analysis of transcripts while also accommodating my reflexive approach.

Analysis of interviews

The 6-step thematic analysis (TA) approach developed by Braun and Clarke (2006, 2021), seemed to me to provide a simple and effective method for engaging with data and developing themes, particularly suited to someone like myself, with limited experience of qualitative methods. As described by Braun and Clarke, TA was a flexible enough approach to accommodate my theoretical position and commitment to reflexivity. In fact, their later work (Clarke and Braun 2018, 107) emphasises the importance of reflexivity and the consideration of "researcher subjectivity as a resource (rather than a problem to be managed)." This seemed to me to fit with my own situation. Braun *et al.* (2015) emphasised that themes are developed through the researcher's active engagement with the data – the data is not simply searched for evidence to support pre-conceived themes. This again fitted with my own approach to the interview data; I did not know what I was going to find. I intuitively

felt that Braun and Clarke's (2019, 594) definition of themes expressed what I was trying to achieve: "Themes are creative and interpretative *stories* about the data, produced at the intersection of the researcher's theoretical assumptions, their analytical resources and skill." I felt that this approach would help me to bring the stories alive and to identify the extent to which there was a collective story to be told, rather than simply a collection of individual ones.

This led me to look at my own narrative again, using the lens supplied by the themes emerging from the interview transcripts. As described above (and in subsequent chapters), this changed what I have written about; my story is not what I thought it was. The content of this thesis has therefore become intertwined with its form. The means chosen have, to a significant extent, determined the ends.

The Braun and Clarke (2006, 2021) process was used as described below. It would be wrong to portray these as rigid phases, entirely separate from each other, not least because the analysis was an iterative process, with different phases being revisited. For example, I do not think that there was a point where I stopped familiarising myself with the data.

1. Data familiarisation and writing familiarisation notes.

The process of transcription, time-consuming though it was, was helpful in familiarising myself with the content of the interviews. However, there was also a

great deal of thinking time, of living with the data and reflecting on my own lived experience in the light of the interactions with the research participants.

2. Systematic data coding.

I used Nvivo software for coding. An example of the coding of short sections of interview text to different 'nodes' is shown in figure 3 below. There was no preconceived set of 'nodes' to which text was coded to – the nodes used arose through the reading of the transcripts, in a dynamic process.

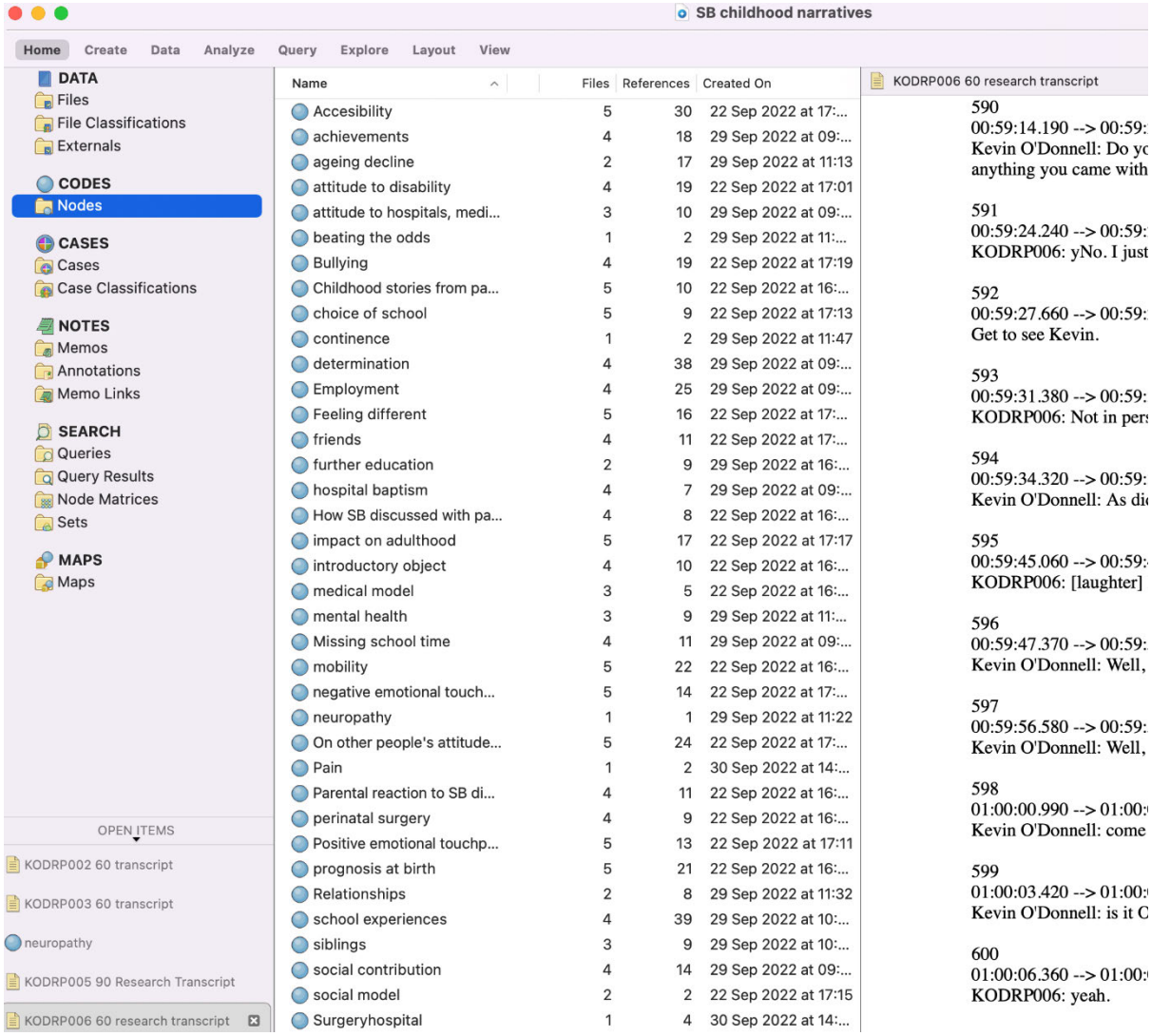


Figure 3 Screenshot of Nvivo nodes at 10/4/2022

3. Generating initial themes from coded and collated data

The first theme that I created was one around hospital baptisms. I was not yet sure what this meant, however, I felt that there was something gathered around that particular lived experience for that particular group of interviewees that might be important.

4. Developing and reviewing themes

See below.

5. Refining, defining and naming themes

There was a constant iteration and reiteration between these two phases, partly fuelled by my reflections on my own lived experience. The end result was the three themes reported on here. Appendix 6 shows how the different nodes contributed to the themes.

6. Writing the report

The report consists of the three themes: "*I was baptised in hospital*", "*Things have got better (up to a point),"* and "*The transformative power of love*." However, I want to be clear that this in no way exhausts the data in the interviews and does not represent an objective truth that was waiting to be uncovered. The themes reflect my own subjective view of what was important, as well as my own subjective life experience and I have endeavoured for this to be as transparent as possible. The reader will, I hope, have an understanding of my reasons for choosing to organise and interpret the data in this way, i.e. of why I thought these themes were important. In completing the analysis, I made use of the checklist suggested by Braun and

Clarke (2021, 345) as a means for reviewers of publications to evaluate the quality of thematic analysis carried out using their method.

A story about a historical Investigation

Before proceeding to analysis and discussion, there is a research chapter which is based on literature and other archival sources (Chapter 4). I hope it will be clear that this is quite different in method and in purpose from a literature review. The chapter is an investigation of the development of treatments for spina bifida and the reaction of the medical profession, and wider society, to those developments. In one sense, it can be seen as a story about the evolution of medical ethics (Levin-Decanini *et al*. 2017). It also deals with issues of power and the use of that power against individuals born with spina bifida, showing how we got to where we are today. In that sense, it might be considered as an example of Foucauldian genealogy (Garland 2014, Hook 2005). However, the important thing is that it is not merely background material; it provides an essential context for the analysis and discussion of the interviews that follow it.

As Gunn and Faire (2016, 2) note, historians have tended to "borrow their methods from the social sciences." This was also true of the research for Chapter 4. However, while I used the same search techniques for publications, for example, I applied them in a different way. I was not developing an overview of the thinking around a particular concept; I was uncovering a chain of events. In addition, my material was not confined to the academic literature. I was able to use my own medical records – although far from complete, my birth and neonatal surgery were included. I was also

able to access relevant parliamentary debate via the online version of *Hansard*. Both of these were helpful in bringing out the story of selection. As King (2016, 16) states "That which the Archive preserves and hides, the historian brings to light." I was also able to interview Robert Zachary's son, Professor Christopher Zachary, who provided illuminating background. There were limitations on the material available to me. It would have been interesting, for example, to read how spina bifida was covered in the popular press of the time but such material was not accessible to me.

Summary of Methodology and Methods

The constructivist/interpretivist paradigm provided the theoretical basis for the work in this thesis. I assumed that the research participants were each describing a reality different from, but equally valid to, my own. However these subjective experiences took place within a set of shared cultural information. I explored the lived experiences of my research participants through their narratives – the stories they told about their childhoods and what those stories meant for them in their lives now. I worked towards awareness of how I responded to those stories and the light they shed on my own and where appropriate shared those with the participants. The data was therefore co-created to some extent. The transcripts were analysed using reflexive TA. Through immersion in the text, I developed themes that allowed deeper understanding of narratives of childhood and the part they played in the lives of adults with spina bifida. The historical investigation of the development of treatments for spina bifida that follows provides an essential context for the analysis and discussion of those themes.

In closing this chapter, I would like to return to Arthur Frank: “An ethic of solidarity and commitment is expressed when the storyteller offers his voice to others… not to speak for them but to speak *with* them, as a fellow-sufferer” (Frank 2013, 132). That is my aspiration for this thesis.

Chapter 4: A story about medical selection – from eugenics towards compassion

Introduction

This chapter was originally intended to be part of the literature review. However, it became clear that the story it tells is different from the more theoretical literature. It describes the ways in which it was made plain – by the medical profession and by the government - that that the lives of those born with spina bifida were worth less than those born without a disability. This is essential to an understanding of the lived experience of the research participants and of myself.

Spina bifida prognosis

In the years before the surgical advances of the early 1960s, described later, spina bifida was associated with a high rate of infant mortality. For example, Sharrard *et al*. (1963) describe an infant mortality rate for children with myelomeningocele of over 90%. As I shall show, this was to improve dramatically.

In the absence of national figures, we have to rely on local data sets for a more detailed picture. For example, the figures from Birmingham, 1960-1962 (Knox 1967) and South Wales, 1956-1962 (Laurence and Tew 1971). The picture they give is consistent with the high mortality rates described above. However, they also reveal something else. Freeman (1973) notes the puzzling appearance of still births (ie

babies who are born dead) in the Birmingham and South Wales spina bifida mortality figures, at 25% and 22% respectively, and questions why this should be so.

Freeman goes on to note that a further dimension to this puzzle comes from Forrest (1967) who, in discussing mortality figures (1950-1965) from spina bifida in an English region (Northamptonshire), makes the same observation that prior to 1962 these included a large percentage of still births (10-40%) – see figure 4.

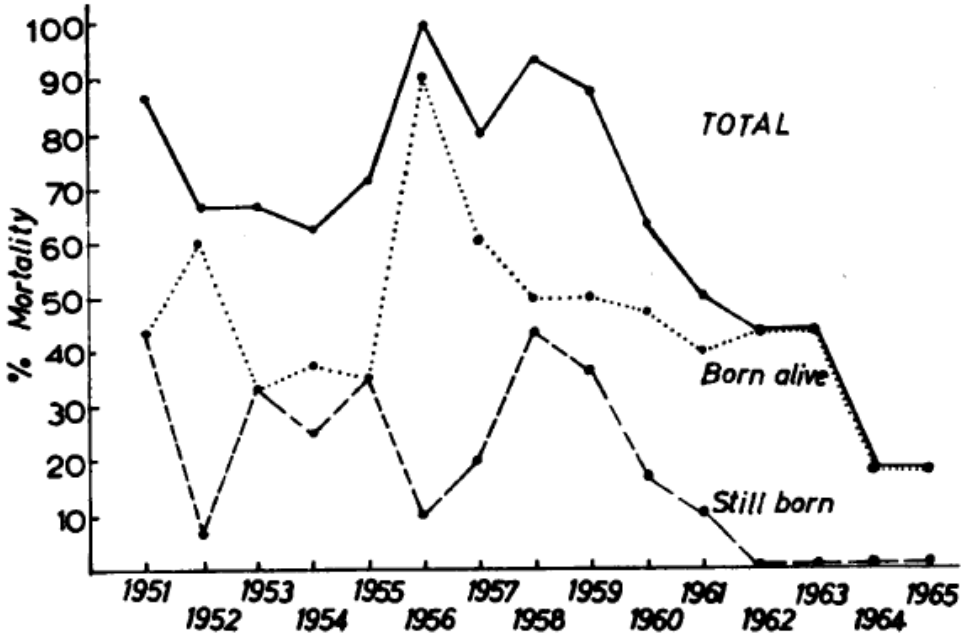


Fig 1 *Mortality from spina bifida, Northamptonshire 1951–65.* ———, *total.* ....., *born alive.* - - - - -, *stillborn*

Figure 4 Spina bifida infant mortality 1950-1965 (from Forrest 1967)

The graph in figure 4 shows a steep decline in mortality in the 3 years up to 1962 that can be explained by the improvements in perinatal surgery from that time.

However, the still birth component of spina bifida mortality drops to zero after 1962 and that is more difficult to explain.

Firstly, as Freeman observes, it is not clear why spina bifida should lead to still births at all. Secondly, even if this were so, it is difficult to explain why the number of still births should drop to zero through advances in perinatal surgery. Such surgery is, by definition, only helpful to those babies who are born alive. Forrest (1967, 16) comments on this discrepancy somewhat archly: “It appears that in a condition like spina bifida which is obvious at birth, the immediate survival of the infant depends to a large extent on the attitude of those in attendance.”

This seems a rather indirect way of commenting on what the figures appear to reveal, perhaps in a desire not to ruffle any professional feathers. The withdrawal of care from new-borns is discussed in principle but seldom in specifics, perhaps because of the legal and other risks involved. As Verhagen *et al*. (2010, 33) note, in a review of neonatal deaths, “Mortality rates do not clarify how the babies die or what is done at bedside. Consequently, discussions on what ‘‘ought to be done’’ are difficult to have when what is done is not accurately known.” Yet clearly *something* has been happening here, accidentally revealed only when it has stopped happening.

I suspect that the truth is close to the explanation attempted by Laurence and Tew (1971, 136): “Presumably obstetricians who would perhaps employ a deliberately

traumatic mode of delivery and refrain from resuscitation may employ more conservative methods if they feel that something useful can be done for these infants". One shudders to think what might be hiding behind the euphemism of "deliberately traumatic mode of delivery." However, the improvements in infant mortality associated with advances in medical treatment for spina bifida had the unintended consequence of revealing the fact that this practice existed. There is also something revealing in the use of the phrase "if they feel that something useful can be done." A judgement is being made on life or death by medical professionals who clearly feel that they are entitled to make it, perhaps even that it is their duty to do so.

The improvements in perinatal treatment for spina bifida between 1958 and 1962 - described below - ended this practice of "still births". However, as we shall see, the underlying premise remained - that the life of a disabled child had less value than that of a "healthy" one, to the point where it would be better if disabled children were not allowed to live. I am reminded of Goffman's (1963, 15) point "By definition, of course, we believe the person with a stigma is not quite human." A belief that makes permissible acts that would otherwise not be so. This attitude towards babies born with spina bifida would soon find another mode of expression. And whereas the practice of "still births" had been hidden, this one would be carried out in plain sight.

Progress in perinatal surgery

A major step forward was the development of an effective treatment for hydrocephalus, which affects around 80% of children born with spina bifida and was

a major cause of mortality (Shakeri *et al*. 2008). Hydrocephalus is a condition where the cerebrospinal fluid (CSF) that bathes the brain and spinal cord accumulates in the cranium and cannot escape. In most people, as more CSF is produced, the excess is absorbed into the bloodstream from around the spinal cord. However, in the case of hydrocephalus, malformations associated with spina bifida prevent this from happening. The resulting increased pressure on the brain leads to a range of damage (Isaacs *et al*. 2018). Prior to the late 1950s, nothing could be done to prevent this.

That changed with the development of ventriculo-atrial shunts, which represented the first possibility to alleviate the effects of hydrocephalus. These were sometimes referred to as Holter valves, after John Holter who invented them in 1956, following the diagnosis of his son Caspar with hydrocephalus (Aschoff 2004). While prototype valves had been tried before, none had been successful enough to warrant taking beyond that stage. However, Holter was, coincidentally, an expert on silicone and produced one in that material that was implanted in his son. He then started a company producing the shunts from his garage. The principle is simple – a tube is inserted to carry excess fluid from the cranium, via a one-way valve, into the abdominal cavity where it can be safely absorbed by the body, therefore relieving the pressure building up in the brain. A number of variants followed but the principle remains the same today. These were introduced to the UK in 1958 (Forrest 1967).

A further key milestone was the publication of research which changed the approach to perinatal surgery on the spina bifida lesion. Surgical practice was divided, with

some hospitals not operating until months after birth, in part to see if the infant survived. The question seemed to have been settled after the publication of a randomised control trial demonstrating that immediate closure of the myelomeningocele reduced the damage caused in terms of muscle paralysis, and did not, as had been feared, increase the incidence of hydrocephalus (Sharrard *et al*. 1963). The final sentence in this publication is striking: “The main conclusion of the trial was that operative closure of a myelomeningocele should be regarded as a surgical emergency” (1963, 22). Seldom does one publication have such a far-reaching effect. The treatment of babies born with spina bifida was transformed, as its recommendation was adopted worldwide.

With a major cause of mortality controlled for the first time, and the benefits of early surgery demonstrated, the outlook for children born with spina bifida greatly improved. This was reflected in a steady improvement in survival rates throughout the 1960s and 70s. By the end of the 1970s, the one-year survival rate was 85% - a reversal of the position 20 years before (Wong and Paulozzi 2001).

Selective treatment

If the improvements in perinatal surgery described in the last section paved the way for those of us born in the 1960s to have the opportunity to survive and have a life, the events that followed had a significant effect on the shape of that life.

It came as a surprise to me to discover that the improved mortality rate of children born with spina bifida was not universally welcomed. John Lorber, a co-author of the influential Sharrard *et al*. (1963) paper, became concerned that the reduction in infant mortality of spina bifida children had resulted in increasing numbers of children with lifelong disabilities, which he found unacceptable: “The pendulum has now swung too far: there are now many with dreadful handicaps who a short time ago would have died” (Lorber 1971, 300). Lorber was by no means alone in this view. Laurence (1974) describes the effect of the introduction of the universal surgery argued for in 1963 by Sharrard *et al*., on children born with spina bifida in South Wales and sets it out in concrete terms: “Thus, to save 7 relatively unscathed children who might have died, 22 additional grossly handicapped children will probably live” (Laurence 1974, 303).

It is worth pausing to make the point clear. It is being questioned whether the survival of 22 disabled children was a price worth paying for the survival of 7 non-disabled (or at least not *too* disabled, in Laurence’s view) children. Implicit in this is the assumption that this is a decision for doctors to make.

My own view is that this is not a valid question at all; I do not accept the underlying premise that a child born with a disability has less value (however defined) than an able-bodied one - a belief rooted in eugenics (Hubbard 2013). Yet that was the assumption behind Laurence’s statement – one which was widely held and which, as

we shall see, retains an influence today. As Nettleton (2013, 80) puts it “There is an assumption that to have some kind of impairment is to be a lesser person.”

Lorber’s concerns led him to not only advocate selection of children for treatment (or non-treatment) but also to practice it, and he described his scheme for doing so in increasingly bold terms (Lorber 1971, Lorber 1973, Lorber 1974, Lorber 1978, Lorber and Salfield 1981). Lorber painted a depressing picture of life with a disability, for the individuals, their families and for society as a whole. He argued that “The ethical validity of prolongation of profoundly handicapped lives, consisting of frequent operations, hospital admissions, and absence from home and school and with no prospect of marriage or employment, became less and less tenable” (Lorber 1973, 202). He goes on to state that of children born with spina bifida “At best not more than 10% of all the survivors (with and without hydrocephalus) were likely to have a chance of earning a living in competitive employment” (Lorber 1973, 202). That this represented an argument for levelling the employment playing field for disabled people seems not to have occurred to Lorber. He instead concluded that it would be best all round if they were not allowed to live. To that end he drew up criteria that enabled him to select which children would be treated and which would not, a decision which hinged on his opinion of the probable extent of their disabilities in later life (Lorber 1973).

Lorber implemented a scheme based on his criteria, which resulted in a regime where only 30% of babies born with spina bifida were deemed suitable for surgery

(Lorber 1973). The remaining untreated children were not given surgery to close their spinal lesions, or given shunts in the event of hydrocephalus. Nor were they given antibiotics (bear in mind that if the open spinal lesion is not closed, the children are susceptible to meningitis). They were not tube fed but fed only on demand. They were however, given analgesics “as required”. Lorber reported that all of the untreated children died within 9 months (Lorber 1973). They had been selected for death.

The selective treatment policy described by Lorber was certainly not an isolated one. In fact, he was able to point to other hospitals that shared his approach, later claiming that almost all centres in the UK did so (though as we shall see, the results were not quite the same). For example, Stark and Drummond (1973) give an account of selection at the Royal Hospital for Sick Children in Edinburgh. Over a 6 year period (1965-71), 163 newborns with myelomeningocele were assessed and 48% selected for surgery. Of the 52% who were not selected, more than 80% had died before the age of 3 months (somewhat different from Lorber’s 100% mortality rate but in line with results in other centres). The authors go so far as to make it clear that *their* policy of selection predated Lorber’s 1971 paper, stating that, in Edinburgh “routine early operation has never been accepted.” (Stark and Drummond 1973, 676).

Lorber responded to the relatively high survival rates of untreated children reported by other centres practicing selection, by criticising them for their lax approach: “if it is

decided to withhold closure of the back then it is essential also to withhold other treatment - such as antibiotics, tube feeds, incubator care, shunts, and resuscitation - in the newborn period" (Lorber and Salfield 1981, 828). There is no pretence here – it is intended that children not selected for surgery should die. Yet as we shall see, this was not yet the full picture of what Lorber's policy of selection entailed.

However, there were opposing voices. For example, Robert Zachary, another Sharrard *et al*. (1963) co-author, was a trenchant critic of the selective approach. In a 1968 paper (Zachary 1968, 274) he made his own views on the practices implied in selection plain: "To leave a child without food is to kill it as deliberately and directly as if one was cutting its throat." In a later paper, Zachary (1977) describes the problems faced by people with the condition and in doing so describes the approaches, medical and societal, that could alleviate them. He goes on to state: "I would emphasise that this is a *person* who has spina bifida, and it is very important that we always refer to them and treat them as persons" (1977, 1461). Unlike Lorber, Zachary was clear that the personhood of people with spina bifida was not conditional on our imagined marriage or employment prospects: "Our aim should be that life with spina bifida is the best possible life for that person in the family and in the community" (1977, 1462).

However, the main thrust of Zachary's 1977 paper, is to directly criticise Lorber's policy of selection and the scheme whereby it was put into practice (the only paper Zachary cites as a reference is Lorber, 1973 – there is no ambiguity about his

target). He describes selection as being based on a “cardinal error” that all children with spina bifida who are not operated on will die (1977, 1461). He points out that in his experience, with reference back to the days before routine perinatal surgery, children born with spina bifida and left untreated do not all die spontaneously – in many cases their lesions heal and they go on to survive childhood, albeit more badly affected than if surgery had taken place. This is a point also made by Freeman (1973,144), who notes that simply “letting nature take its course” is inhumane and lengthy and so concludes that universal treatment is the best option. How then to explain the 100% mortality in that untreated population under Lorber’s scheme? Zachary (1977) deals with that directly and his explanation is both clear and shocking.

Zachary reveals that the babies not considered suitable for surgery were administered sedatives at eight times the recommended dose. As he put it in his later autobiography “…on close examination this turned out to be eight times, yes, eight times, the sedative dose recommended in a standard textbook of pediatrics. No wonder the babies slept, did not demand any feed and died of starvation and dehydration” (Zachary 1987, 128). They were, in his view, being pushed into death. Zachary concluded “…there should not be any pretence that all these babies are dying spontaneously. Indeed one must ask ‘Are not these actions outside the law?’” (Zachary 1977, 1461). Zachary had made it clear that this was not merely a decision about whether to treat or not to treat – babies born with spina bifida were being actively killed. You may ask, as I did, why was nothing done to stop Lorber, following Zachary’s revelations?

One answer is that Lorber's actions had government support. For example, Lorber (1973) was able to cite a government report, *Care of the Child with Spina Bifida*, as approving selection (Standing Medical Advisory Committee (SMAC) 1973). This notes that "…some workers are now trying to imply a policy of selection." (SMAC 1973, 4) and lists as one of its 10 conclusions: "A decision not to operate implies the existence of a coordinated medical and nursing policy which recognises the emotional and ethical problems involved" (1973, 10). In other words, it notes that selection exists and gives the conditions needed for it to be acceptable. That Lorber was safe in assuming that this document gave him cover is perhaps borne out by the fact that it was quoted in Parliament in answer to a question inspired by the Zachary (1977) paper. As this represents the sole mention of this matter in Parliament (based on a search of Hansard for 'spina bifida'), I think the exchange is worth reproducing in full (Hansard 17 January 1978):

> Mr. Biggs-Davison
>
> asked the Secretary of State for Social Services (1) whether he is satisfied with the methods of treatment in the National Health Service of newborn babies with spina bifida; and if he will make a statement;(2) if, having regard to statements in the British Medical Journal of 3rd December 1977, and elsewhere, that newborn handicapped children are dying as a result of treatment given in the National Health Service, he will give his estimate of how many such children have perished thus, and state his policy in the matter.

Mr. Moyle

Advances in recent years in medicine and surgery have made possible the survival of babies with severe congenital handicaps who would previously have died. A guidance booklet "Care of the child with spina bifida" prepared by the Standing Medical Advisory Committee, following a multi-disciplinary conference which discussed the results of early surgical treatment of spina bifida, was issued by the Department in 1973. A copy has been placed in the Library of the House. This guidance, which I am satisfied is still valid, indicates that any decision about the advisability or otherwise of an operation upon a young baby must be taken in the context of a co-ordinated medical and nursing policy which recognises the emotional and ethical problems involved; and must take account of the wishes of the parents. The responsibility for determining the management and treatment of babies born with spina bifida, whether or not they have been selected for operation, lies with the individual doctors treating those babies, as in all medical matters. The decision which the doctor takes must conform with the ethical standards of the medical profession. I regret that information in the form requested is not available.

The Minister's answer therefore leans heavily on the SMAC (1973) report and uses it to avoid answering the more specific questions, while managing to outsource responsibility, should that prove useful at some future date. However, the answer is remarkable for what is not said. Zachary (1977) had made it plain that babies born with spina bifida were being selectively killed. The Minister has been asked for the

Government's response to this. The Government has, in effect, shrugged its shoulders. Lorber must have been delighted with this Ministerial response which essentially dismisses criticism of his actions.

Further support came from a working group convened by the Newcastle Regional Hospital Board – and chaired by the Bishop of Durham, no less. This concluded after much convoluted discussion that, "… the policy of selection for the treatment of spina bifida is in our opinion justified" (Working Party 1975, 88). Lorber was, therefore, able to quote from this report as justifying his scheme (Lorber and Salfield 1981, 829). This helps explain why he was so confident about carrying out his activities so openly.

It might have been hoped that a finely crafted "J'accuse!" such as Zachary's 1977 paper, published in a leading medical journal, would have led to a collective coming to of the senses regarding the process of selection and what it actually entailed. However, in line with the parliamentary exchange quoted above, that does not appear to have been the case. As late as September 1978, Nursing Mirror published two side by side articles from Lorber and Zachary (Lorber 1978, Zachary 1978) under the heading *Spina bifida – to treat or not to treat?* These re-state in more general language the arguments made in the BMJ papers cited previously. Rather than draw back from his support of selection, Lorber doubles down on it. In my opinion, his article was quite extraordinary. It was illustrated by a dozen photographs, mainly of the bodies of affected children, shaped in ways that are

outside what is considered normal (and in ways which are, in my experience, not typical of most people with spina bifida). Yet every one of them is a person who, by the use of their image in this context, has had that personhood stripped away, leaving only a prop to allow Lorber to say “See? They are not like us.” This, Lorber says, is spina bifida – he is arguing from what he sees as a worst-case (ie most *different*) scenario, to make the case that it would have been better if these children had not been allowed to live beyond infancy. As Pruitt (2012, 182) states: “Rejection by the able-bodied world, in Lorber’s view, justified nontreatment.” It could be argued that Lorber was not an objective observer of such rejection but went to some lengths to make sure that rejection took place. Lorber’s (1978) Nursing Mirror article displays the very bodies of people with spina bifida as evidence of our inferiority, using the images to tell/sell his story. Siebers (2001, 746) notes that disabled bodies “…quickly become sources of fear and fascination for able-bodied people, who cannot bear to look at the unruly sight before them but also cannot bear not to look,” going on to argue that the perception of disabled bodies in this way is central to discrimination and changing it an important step towards dealing with other forms of discrimination. For Lorber, this fear was a useful tool.

In addition to his litany of physical and mental failings, Lorber brings further arguments into play. For example, the children may show “extreme obesity, in spite of advice about diet” (1977, 16), and “Sexual precocity is frequent, especially in girls” (1977, 17). Clearly, these are not only disabled children but also *bad* children. There is a sense of no stone being left unturned in what is very much a hard sell in favour of his policy of selection.

Zachary's contribution (1977) suggests why Lorber may have felt this hard sell was necessary. Zachary repeats his point from 1977 about large doses of sedatives being administered to that majority of spina bifida children not selected for surgical treatment and goes on to observe that although "the consultant" (ie Lorber) might decide on such treatment, it would not be them who actually administered the sedatives. That would fall to the nursing staff. Lorber's article then, is aimed at the people he needs to convince to put his scheme into practice. As Zachary (1977, 19) puts it "No doctor who is going to undertake involuntary euthanasia (involuntary, since the baby gives no consent) should be so unfair as to attempt to involve nursing staff in this action."

It would be comforting to believe that those supporting selection – such as the government minister quoted earlier – simply did not understand what Lorber's approach actually entailed. However, Zachary had made it absolutely plain what was going on and still nothing was done. As shown above, Lorber's selective killing of babies with spina bifida had tacit state (and Church of England) approval. This approach to the lives of disabled people seems all too redolent of another country, at an earlier time. However, as Hubbard (2013), in a review of the development of eugenics (the application of selective breeding to humankind), points out, the involuntary euthanasia of the disabled enacted by Nazi Germany in the 1930s was based on ideas about eugenics developed in the preceding decades in the UK and USA. These ideas were so strongly rooted that in 1941, when the UK was engaged in a war against Nazism, the leading UK biologist Julian Huxley still felt able to write

in support of eugenics: "…it would therefore be better if one could 'discover how to diagnose the carriers of the defect' who are 'apparently normal.' If these could but be detected, and then discouraged or prevented from reproducing, mental defects could very speedily be reduced to negligible proportions among our population" (Hubbard 2013, 76). Although different in some important respects, the underlying principle of selection and eradication remained the same in Lorber's scheme and, as I will later discuss, remains today in the form of prenatal screening.

The end of selection

The way that children born with spina bifida are treated today, is much closer to Zachary than to Lorber. Immediate surgery, in the Global North at least, is the established norm. It would be satisfying to write that this is because in the battle of ideas described above, Zachary's triumphed. That a significant section of the medical establishment realised the error of their ways, changed what they were doing and resolved to do things differently. However, that isn't entirely what happened.

There was, to be fair, signs of a reaction against selection. In 1983, a hospital in Oklahoma published the results of their own policy of selection, citing Lorber as an inspiration (Gross et al 1983). As in Lorber's case, their untreated infants had a 100% mortality rate. However, they were not met with compliant silence but with a barrage of criticism (Pruitt 2012).

For example, Freeman (1984, 564) pointed out that the 100% mortality rate was "contrary to the experience of most others in the field" and that no information on cause of death was provided. He went on to compare their approach to that of the Spartans, abandoning sick babies on a hillside. "The Spartan system was workable and both more efficient and more uniform than that of the Oklahoma group, but that did not make it a correct process" and concluding that "We can hardly believe that death was in the best interest of all of those infants in the Oklahoma series for whom no treatment was recommended" (1984, 565). The practice was quickly abandoned (Freeman 1998).

However, I should also note that at least one country took Lorber's approach to its logical conclusion. The Netherlands developed a scheme intended to enable involuntary euthanasia of infants without prosecution, The Groningen Protocol (Verhagen and Sauer 2005a 2005b). Although not formally part of Dutch law, it was drawn up with the participation of a District Attorney and approved by the Dutch Association of Paediatrics. This allows for doctor-administered lethal injection in the event of certain conditions being met, including "hopeless and unbearable suffering" by the infant. Verhagen and Sauer stated that this had been administered on 22 occasions during the previous 7 years. In each case the condition of "hopeless and unbearable suffering" had been met and no prosecution had taken place. Every single one of the 22 children involuntarily euthanised had been born with spina bifida.

This approach was strongly criticised by de Jong (2008) who systematically dismantles the Groningen criteria and, in particular, their relevance to spina bifida, stating that claims made by Verhagen and Sauer in relation to spina bifida "cannot be substantiated" (2008, 19). He argues that criteria such as "hopeless and unbearable suffering" amount to a subjective opinion on 'quality of life' and that this does not form an acceptable ground on which to base a decision to end an infant's life. He goes on to question the use of inaccurate information about the prognosis for a child with spina bifida as a basis for securing parental consent for ending life, for example the statement that a child would need at least 60 operations a year to offer temporary relief, whereas a typical figure for surgery is 3 to 4 operations in the first year of life. de Jong concludes that "in such situations the fundamental concept of 'informed decisions' is obviously violated" (de Jong 2008, 20)

McLone (2008), drawing on 30 years of clinical experience, also argues that the application of the descriptor of "hopeless and unbearable suffering" to children born with spina bifida reveals a lack of understanding about such children who, in his experience, do not suffer pain from their condition. He concludes, regarding the Groningen Protocol itself: "If the same level of understanding used for children with spina bifida is applied to infants with other birth defects, the Protocol might even be more life threatening than the defects themselves" (McLone 2008, 34).

This false impression of the prognosis for children born with spina bifida is something that I will return to later. However, it is perhaps not unreasonable to wonder if the strident case made by Lorber in defence of his policy of selection for non-treatment

is one that cast a long shadow. It is possible that in his escalating attempts to justify selection, he helped contribute to a negative perception of the prognosis for children with spina bifida that has outlasted the policy itself.

In fact, the prognosis for children born with spina bifida has steadily improved. McLone (1989) noted that from a mortality rate of 90% in the 1950s, 85% of children born with spina bifida at the time he was writing could now be expected to reach adulthood. Not only that but they could expect an improved quality of life – 75% of them would be ambulant. Medical advances continued to take place, for example clean intermittent catheterisation – driven, it should be noted, by the fact that there was now a growing adult population of people with spina bifida who had problems that needed to be treated.

Declining incidence of spina bifida

Forrest (1967) estimated that 3,000 children were born with spina bifida every year, in the UK. That figure saw a dramatic decrease over the next 30 years. Best *et al*. (2014) report an average of 101 children born with spina bifida in England and Wales every year between 1998 and 2013. That decrease happened alongside a change in the way that babies born with spina bifida were treated – ie an end to selection for non-treatment - and perhaps helped facilitate it. This was partly because the economic argument for selection, that disabled children were a financial burden to society, lost much of its power. Bluntly, there was less money at stake.

Lorber noted this decline in incidence in a paper entitled “Spina bifida – a vanishing nightmare?” (Lorber and Ward 1985). He cautions that there may be a future rise in incidence “if we abandon our vigilance and fail to use preventive facilities fully” (1985, 1090). What he meant by this will be made clear below. However, it is worth pausing to note that we are not talking about a disease like polio. Lorber’s “vanishing nightmare” does not refer to an infectious agent, it refers to *people*.

The sharp decline in the numbers of children born with spina bifida in the UK (something reflected across the Global North) is a phenomenon relevant to the work reported in this thesis and is worthy of comment. The reduction can be in large part explained – though by no means entirely – by two things: prenatal screening and folic acid supplementation.

Prenatal screening

Brock and Sutcliffe (1972) reported that increased levels of alpha-fetoprotein (AFP) (derived from the growing embryo) in maternal amniotic fluid seemed to be associated with the presence of a neural tube defect (NTD) (mainly spina bifida). By 1974, there were several confirmatory reports of this finding, and it was noted that this could open up the possibility of a screening programme. This led to the establishment, in 1975, of a larger-scale multi-centre UK study (Wald and Cuckle 1977) which concluded that AFP testing of maternal blood would be an effective screening method for NTDs but follow-up amniocentesis testing would be required for a firm diagnosis.

Gagen and Bishop (2007) analysed the literature around this development of prenatal screening for spina bifida, using this as a model for the development of medical ethics. They noted the near absence of any ethical discussion and the implicit – and often explicit – assumption that prevention of the birth of children with spina bifida was a social good. In other words, the purpose of screening was prevention of birth and that a positive result would result in termination of the pregnancy. This was true from the initial Brock and Sutcliffe (1972, 199) paper, which concluded that its results suggested that "spina bifida may be detectable in utero early enough to allow termination of pregnancy," right through to the 1977 study, which states that screening was "the only means available for reducing the number of live infants born with these congenital defects" (Wald and Cuckle 1977, 1332). It is worth pausing to note that the link between detection and termination is accepted as so obvious as to be beyond question. It should come as no surprise, given the preceding account of his work, that Lorber was an enthusiast: "…so that at least we can prevent the birth of such infants" (Lorber 1974, 307).

It had literally not occurred to the authors above that this might not be a choice for medical professionals to make at all and that their role might be simply to provide the choice in the first place, not to make the decision. As Gagen and Bishop (2007, 502) note, this was perhaps an instance of medicine "crossing the brink into social engineering." If so, it was – as with Lorber's policy of selection - doing so with government support.

A Department for Health and Social Security (DHSS) consultation paper was quoted by Roberts *et al*. (1983, 1315): “The introduction of a routine screening service is clearly desirable on humanitarian and social grounds and can be expected to achieve significant results in the prevention of handicap.” The same document was also quoted by Gagen and Bishop, in the context of an “ethical” issue that it raises – that the medical position might be challenged by the “patient” (ie the mother). Parental choice was actually seen as a potential problem.

This association between detection and termination of pregnancy was also central to the economic case made for funding a screening programme (see for example Henderson 1982). The underlying premise was that there was an economic benefit from preventing the birth of disabled children, and that this made the cost of a screening programme worthwhile. Unfortunately, from the consensus medical viewpoint, people will insist on acting in a way that upsets such calculations. They may choose not to take part in screening at all or, in the event of a positive result, may not choose to terminate the pregnancy. As Chamberlain (1978, 1295) puts it, it is “disappointing” that “so many pregnancies are likely to escape early detection and termination.”

Today, a screening programme is firmly in place and the blood test for spina bifida (and Down’s Syndrome) is a routine and largely unremarked on part of prenatal care – unless, of course, the result comes back as positive. In that case, there is some

evidence that the attitudes and assumptions prevalent in the development of screening are still in place, if expressed more subtly.

Hart *et al.* (2022) report on the language used around prenatal testing and the pressure put on women to opt for a termination in the event of spina bifida being detected. A striking example is the use of the phrase “Most parents in your position end their pregnancy” (2022, 570). While ostensibly objective, it will be familiar to users of online retailers such as Amazon as a marketing technique. It facilitates a particular choice. Stretching the analogy further, the emphasis on worst-case scenarios, also identified by Hart *et al*.’s report, is comparable to only showing customers the one-star reviews of competing products. Against this background, it is perhaps not surprising that up to 80% of parents presented with prenatal diagnosis of spina bifida opt to terminate the pregnancy (Mansfield *et al*. 1999, Olde Scholtenhuis *et al*. 2003, Ghi *et al*. 2006).

Neville-Jan (2005) provides a rare example of the voice of someone born with spina bifida in the academic literature. In her autoethnographic account, Neville-Jan challenges the narrative that spina bifida is “a disaster and a tragedy”. Starting from a pro-choice position, she argues that an informed choice on termination of a pregnancy depends on changing the overly pessimistic public view of spina bifida. She is not alone in that view.

There are those within the medical profession who also dissent from the predominant narrative. Bruner and Tulipan (2004) in a paper entitled *Tell the Truth about Spina Bifida* argue that parents who have probably never heard of spina bifida prior to diagnosis, are reliant on medical professionals to provide them with reliable information. Yet those professionals may well be ignorant of the current prognosis for affected children, with the result that "much of the information initially provided to couples with a newly diagnosed foetus is biased and misleading."(2004, 959) and that "Physicians who routinely tell pregnant women that their foetus with spina bifida will be mentally retarded, never walk, and suffer bladder and bowel incontinence are ignoring a wealth of recent literature that contradicts this stereotype. Most of these children are intelligent, adaptable and able to function well in society" (2004, 595). They conclude: "We urge all those involved in prenatal care to learn the facts, and tell the truth about spina bifida" (2004, 596). In other words, there is no one single objective answer as to whether a pregnancy should be ended. Parents should be able to make their own subjective choice, on the basis of accurate information about the condition. This does not seem like an unreasonable thing to expect of medical professionals. Pruitt (2012, 183) argues that the misrepresentation of the reality of the lived experience of those with spina bifida has "cost countless born and unborn lives and sometimes negatively shaped the experiences of those who live with spina bifida." Again, it is possible that the negative and outdated view of spina bifida held by medical professionals is to some extent a legacy of the sustained and vociferous case made by Lorber in defence of his policy of selection.

Hubbard (2013, 84) draws a direct connection between prenatal screening and the eugenics of the past: "No one these days openly suggests that certain kinds of

people be killed; they just should not be born. Yet that involves a process of selection and a decision about what kinds of people should and should not inhabit the world." Arguing from a pro-choice perspective, Hubbard warns of the dangers inherent in this approach: "a woman must have the right to terminate a pregnancy, whatever her reasons, but she must also feel empowered not to terminate it, confident that the society will do what it can to enable her and her child to live fulfilling lives. To the extent that prenatal interventions implement social prejudices against people with disabilities they do not expand our reproductive rights. They constrict them." (Hubbard 2013, 85)

This argument is supported by Saxton (2013, 88) writing from both a feminist and disability rights (as a woman born with spina bifida) perspective: "…selective abortion or eugenic abortion, as some disability activists have called it, not only oppresses people with disabilities but also hurts all women". Arguing that there can be no real freedom of choice, where that "…choice is so constrained by oppressive values and attitudes" (Saxton 2013, 94). She concludes that the message that selective abortion sends to those with disabilities such as spina bifida is that we are unworthy of being born. While individual families have a right to make their own decisions for their own reasons, the overall result is clear – in most cases, the detection of spina bifida is enough to turn a wanted baby into an unwanted foetus. The misleading picture of spina bifida is a significant contributor to this outcome.

Folic acid supplements

The second known cause of the reduction in incidence of spina bifida is less problematic. It had been hypothesised that folic acid deficiency might have a role in

congenital conditions as early as 1964. Hibbard (1964) argued that the demands of the growing embryo meant that folic acid deficiency during pregnancy was common and argued that a possible association with congenital malformations was worthy of further investigation. Further work seemed to confirm that was the case (Hibbard and Smithells 1965, Smithells *et al*. 1980, Laurence *et al*. 1981), leading to the launch of a large-scale randomised trial in 1983, aimed at coming to a definitive view on effects of folic acid supplements. The trial continued until 1991, when it was considered that enough data had been gathered to give a statistically significant result (MRC Vitamin Study Research Group 1991). It concluded that folic acid supplements reduced the number of children born with a Neural Tube Defect (NTD) (primarily spina bifida) by 72% and recommended them for all women who had a previous pregnancy resulting in an NTD. Indeed it went further, suggesting that the fortification of food with folic acid should be considered.

Folic acid supplements have, therefore, been able to have a significant effect on the reduction of pregnancies with spina bifida; however, this could be improved on. This is because the uptake of folic acid supplements is poor, is not being communicated well to people from ethnic minorities and, by its nature, is aimed at planned pregnancies only (Peake *et al*. 2013). Morris *et al.* (2016) point out that uptake of folic acid supplements is only 27.8%. They calculate that the failure to fortify food eg by adding folic acid to flour, has resulted in an additional 150 pregnancies affected by an NTD each year, about half of which would be spina bifida. Spina bifida organisations worldwide continue to campaign for the fortification of food (eg flour for bread) with folic acid (see, for example IFSBH 2023), with success in several

countries. In 2022 the UK Government launched a consultation on proposals to do the same in the UK (Defra 2022)

There is an interesting contrast here between the strong support that spina bifida patient organisations give to folic acid supplementation and the, at best ambiguous, attitude to termination of pregnancy following prenatal testing. At one level, the intention and effect of these two approaches is the same – a reduction in the number of people born with spina bifida. Yet to many people – including myself - they feel very different. I think, in my own case at least, it comes down to a sense of discrimination. Folic acid supplementation helps avoid impairments – and none of us would choose mobility problems, pain etc. if we could avoid it. There's no judgement on our worth as people with spina bifida contained in that, just a judgement on the symptoms of spina bifida. And one with which the spina bifida community agrees.

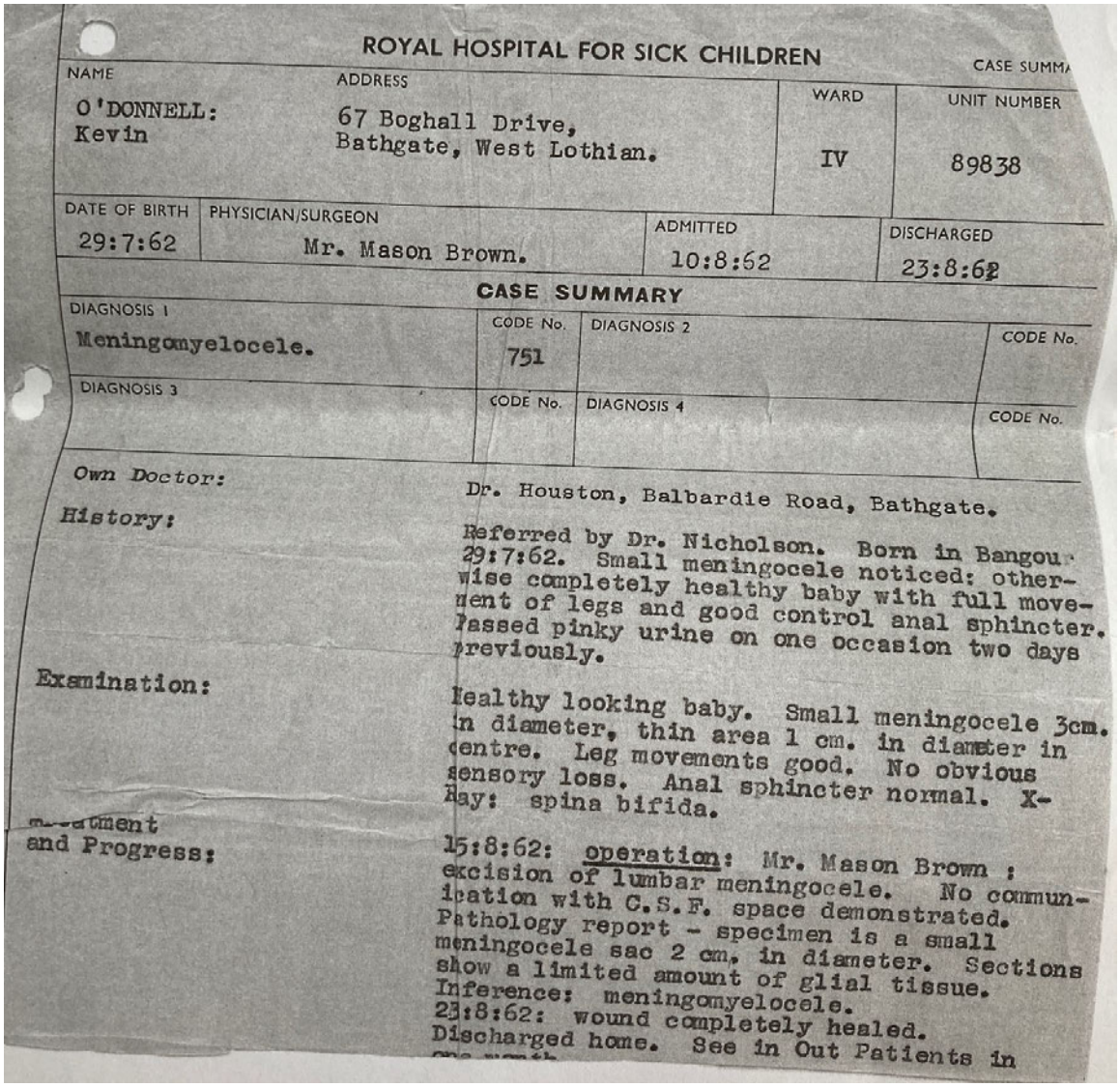
However, selective termination, and particularly the assumption that selective termination is the obvious and correct choice, does seem to carry a judgement on our worth as people. And that judgement is that our worth as people is less than those who do not have spina bifida.

I would argue that there is a continuous thread connecting bogus still births, selection for treatment and assumption of termination, all manifesting the same underlying attitude of the medical profession (and, by extension, society as a whole): spina bifida is such a dreadful thing that it would be best if people with spina bifida

did not live. I find myself asking, what effect might growing up with this pervasive background narrative have had on the research participants – and indeed myself? How might our own personal narratives – and those of our parents - have been influenced by it? This will be discussed further in the analysis of the interviews with research participants.

A personal narrative

I feel I should try to make transparent the way the developments and debates I have described have intertwined with my own life and the reflections and emotions that this has prompted. I cannot pretend that I can set aside (bracket) that experience in the writing of this thesis and in particular in the analysis of the interview transcripts that follows. I was born with spina bifida in 1962 and my own surgery was performed at the Royal Hospital for Sick Children in Edinburgh, 2 weeks after I was born (figure 5). Myelomeningocele was confirmed following lab analysis – I was fortunate that there was no major spinal cord protrusion.



ROYAL HOSPITAL FOR SICK CHILDREN

CASE SUMMA

NAME	ADDRESS	WARD	UNIT NUMBER
O'DONNELL: Kevin	67 Boghall Drive, Bathgate, West Lothian.	IV	89838

DATE OF BIRTH	PHYSICIAN/SURGEON	ADMITTED	DISCHARGED
29:7:62	Mr. Mason Brown.	10:8:62	23:8:62

CASE SUMMARY

DIAGNOSIS 1	CODE No.	DIAGNOSIS 2	CODE No.
Meningomyelocele.	751		
DIAGNOSIS 3	CODE No.	DIAGNOSIS 4	CODE No.

Own Doctor: Dr. Houston, Balbardie Road, Bathgate.

History: Referred by Dr. Nicholson. Born in Bangou· 29:7:62. Small meningocele noticed: otherwise completely healthy baby with full movement of legs and good control anal sphincter. Passed pinky urine on one occasion two days previously.

Examination: Healthy looking baby. Small meningocele 3cm. in diameter, thin area 1 cm. in diameter in centre. Leg movements good. No obvious sensory loss. Anal sphincter normal. X-Ray: spina bifida.

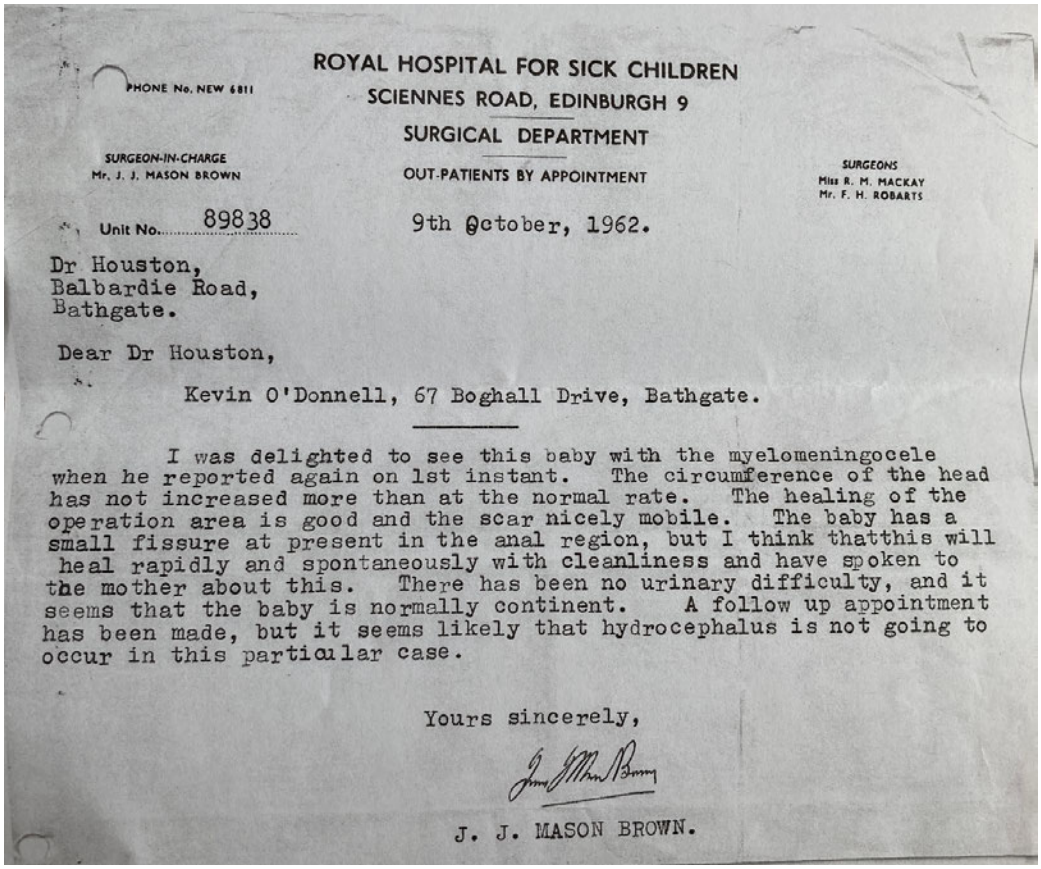
Treatment and Progress: 15:8:62: operation: Mr. Mason Brown : excision of lumbar meningocele. No communication with C.S.F. space demonstrated. Pathology report - specimen is a small meningocele sac 2 cm. in diameter. Sections show a limited amount of glial tissue. Inference: meningomyelocele. 23:8:62: wound completely healed. Discharged home. See in Out Patients in one month.

Figure 5 Medical record of initial diagnosis and treatment

Throughout my childhood, my parents mentioned the person who carried out my surgery, James Mason Brown, with reverence, almost awe. He died in 1965 but their memories of him are clear – perhaps because he provided some certainty and assurance during a traumatic time. He explained spina bifida to them with a sketch drawn, quite literally, on the back of a cigarette packet, which my parents kept for many years. Given the negative impact of communication by medical professions described elsewhere in this thesis, I can appreciate why they held him in such high

regard. My own feelings towards him have become more complex. I find myself wondering about that 2 week delay before my lesion closure. Was its purpose to make sure that I was likely to survive, before proceeding to surgery? It is quite possible that the delay was intended to allow any early symptoms of hydrocephalus to become apparent. Certainly, the examination section in figure 5 takes on a different hue when it is considered as an assessment for selection. While I am glad to have, literally, made the cut, I find myself thinking of those who did not.

I also find myself reflecting on how comparatively little I have said about hydrocephalus. The explanation for this is simple – it has not been part of my own lived experience, so I have not had direct cause to think about it (figure 6).



ROYAL HOSPITAL FOR SICK CHILDREN
SCIENNES ROAD, EDINBURGH 9
SURGICAL DEPARTMENT

PHONE No. NEW 6811

SURGEON-IN-CHARGE
Mr. J. J. MASON BROWN

OUT-PATIENTS BY APPOINTMENT

SURGEONS
Miss R. M. MACKAY
Mr. F. H. ROBARTS

Unit No. 89838

9th October, 1962.

Dr Houston,
Balbardie Road,
Bathgate.

Dear Dr Houston,

Kevin O'Donnell, 67 Boghall Drive, Bathgate.

I was delighted to see this baby with the myelomeningocele when he reported again on 1st instant. The circumference of the head has not increased more than at the normal rate. The healing of the operation area is good and the scar nicely mobile. The baby has a small fissure at present in the anal region, but I think thatthis will heal rapidly and spontaneously with cleanliness and have spoken to the mother about this. There has been no urinary difficulty, and it seems that the baby is normally continent. A follow up appointment has been made, but it seems likely that hydrocephalus is not going to occur in this particular case.

Yours sincerely,

J. J. MASON BROWN.

Figure 6 Medical record - "likely that hydrocephalus is not going to occur."

Before researching this chapter, I had never fully appreciated how unusual it was that I was unaffected by hydrocephalus. Not just unusual, but fortunate; the early days of shunt technology entailed a risk of failure. Even today, the risk of shunt blockage is a constant fear for those who depend on them.

That was not my only misunderstanding. When I set out to write this part of my thesis I had not anticipated that the narrative of the development of treatments for spina bifida would be the one that I have written here. I had always thought of myself as a child of science, a direct beneficiary of the medical progress of the early 1960s. I suspect that this played a large part in my choice of science as a field of study and eventual career. I had anticipated that I would be writing a story of steady and uncomplicated medical progress; the medical and scientific professions working tirelessly to help people like me because they were on our side. Instead, I am left with a feeling of having unwittingly navigated a minefield. I found Lorber's 1978 Nursing Mirror article particularly disturbing. The use of bodies that were different to make a case that others like them should not be allowed to live, made me think of the differences between my own body and the 'norm' and how that might be perceived and judged by others. That feeling was compounded by the openness of the Lorber and Salfield (1981) paper regarding how the lives of those considered to be too different were ended. Not just because of the content but because it brought home to me that this establishment view of the worth of the lives of children with spina bifida was something that carried on well into my lifetime. I remember 1978 very clearly – I sat my O Grade exams (I failed French; it still stings), I went to my first rock festival (Genesis at Knebworth; reader, my tastes have changed). By 1981,

I was in my second year at university and I was in love for the first time. My life was taking off. This was not something that happened in the dim and distant past; my memories are sharp. I made friends then that I still see regularly today; in a sense, that time is still my *now*. And yet, all the while, doctors were still deciding whether or not people like me should be allowed to live. In a way, I am glad I was unaware of it at the time – I think the knowledge would have crushed the fragile sense of self-esteem that I was beginning to put together. Having become aware of it now, I feel a deep sense of anger – how could such things have happened? In what sort of world were they permitted? Yet this was the world in which I and the 1960s cohort of research participants grew up. How much of this, I wonder, did we absorb, from our interactions with hospitals and from the anxieties of our parents? The history set out here provides the context to the childhood narratives of the research participants – and of myself. I do not believe they can be properly understood without it.

Chapter 5: Analysis and Discussion

Introduction

I will outline the three themes that were generated by the analysis, before going into each one in more detail. The subsequent sections describe the findings that led to the development of the themes and also include discussion of them, including my own personal accounts.

1. "I was baptised in hospital"

This is a theme that emerged from the finding that most of the 1960s cohort (and indeed myself) had 'emergency baptisms' at home or in hospital. The narrative that we grew up with was that we were not expected to live – but we did. In an environment where medical authority was unchallenged, we nevertheless grew up with the story that we had proven the doctors wrong. What might the effect of this narrative be, for both the research participants and their parents? For several of the research participants, this theme was associated in their adult lives with a sense of determination or 'beating the odds'. A different lens considered here is that of the quest narrative – how do the research participants incorporate their origin story into a narrative that shows them asserting control over their illness? Lastly, this story is considered from a counselling perspective, for example, in terms of conditions of worth.

2. Things have got better (up to a point)

There were many contrasts between the lives of the 1960s cohort and the 1990s. Obviously, the 1960s cohort have done more living, however the contrast between the descriptions of childhood, school etc. for both cohorts is quite stark and represents, perhaps, the effects of the emergence of the social model and the changes associated with it. Two main aspects of childhood were identified in this theme – changes in the way that parents talk to children about spina bifida and changes in the experience of school, including bullying. The difference in quality of life is such that it allows us to conclude that the childhood experience of people with spina bifida has got better and that hopefully it will continue to do so. However, the process of applying for disability-related benefits was a strongly negative experience for people in both cohorts.

3. The transformative power of love

Although the 1960s cohort have had some harsh early experiences, it is striking how lives were improved – transformed - by meeting a life partner, for those who did so. This aspect spoke to me strongly because it is also the story of my own life. There was something quite moving in seeing a variation of the same experience being described by some of the research participants, which led me to reflect on the difference meeting the woman who became my wife made to me, the importance of love and the implications of that for counsellors.

Theme 1: "I was baptised in hospital"

The first question asked of each research participant was "What are the family stories about your birth?" I was surprised to find that this question elicited a similar response from most of the 1960s research participants.

> Joan: *And everybody thought I would die... So I was baptised in the hospital chapel the day, the morning after I was born*
>
> James: *They said to my mum and dad at the time I was in [overseas military base], if you want to christen him, do it now, because I wouldn't see out the day.*
>
> Mary: *I know I was definitely baptized that night.*
>
> Maureen: *And when my mum gave birth to me, they thought I was going to die, and called the priest – as you do! - and the priest came, and I was baptized then.*

It is also my own story. One of the things that renewed my interest in spina bifida was being sent a short piece of video by one of my cousins, entitled "Kevin's baptism". The thing of relevant interest in this video, a copy of an old cine film, is that it is not my baptism at all. I had actually already been baptised in hospital immediately prior to my perinatal surgery, as is made clear on the note written on the back of my birth certificate, shown in figure 7. My suspicion is that this hurriedly organised ceremony in the video was intended to reclaim me for Catholicism, the hospital chaplain who baptised me having been a Church of Scotland minister.

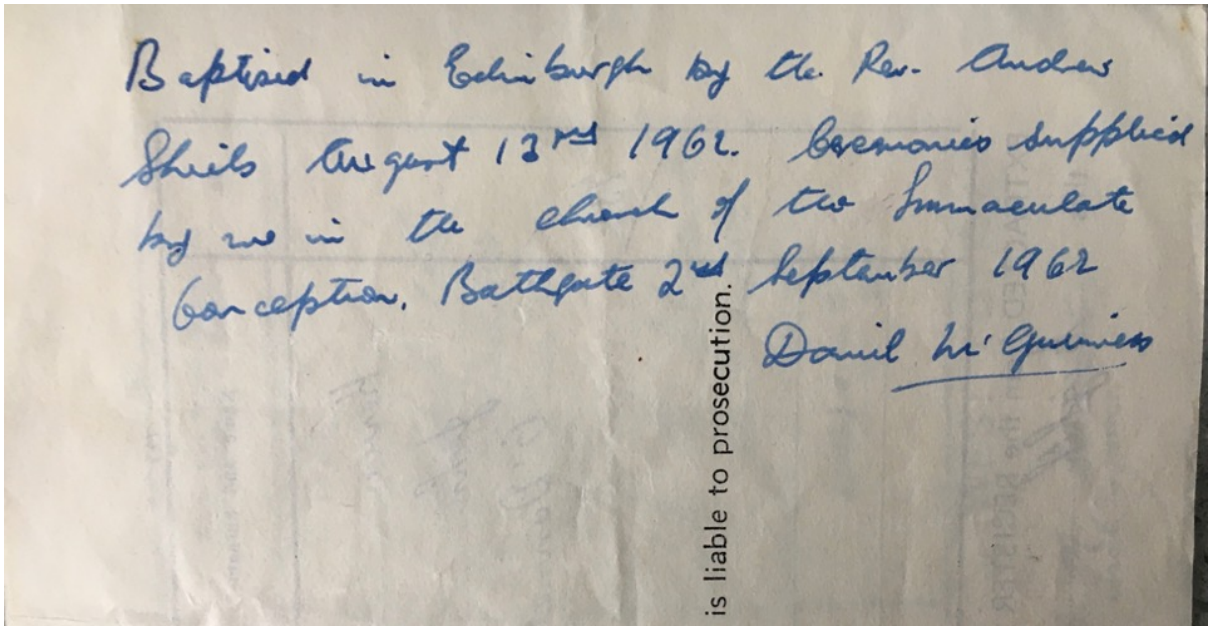


Figure 7 Note on back of birth certificate, referencing hospital baptism

The implication of these ‘emergency baptisms’ may not be obvious to those unfamiliar with the western Christian tradition – or indeed to those whose experience of that tradition is more recent. 1960s Scotland was a predominantly Christian country and this is reflected in the family background of the research participants. Baptism is the ceremony whereby an infant (in most variants of Christianity) is inducted into the Christian faith. The baby is named and the ‘original sin’ of Adam and Eve is symbolically washed away. It is generally an occasion for family celebration.

For the observant Christian, this was therefore an important occasion – to an extent, a parental obligation. From a Catholic viewpoint in particular, baptism was also a necessity as it was thought necessary for entry to heaven, even for infants, though

this position has relaxed in recent years (International Theological Commission 2007).

Other Christian denominations have broadly similar attitudes to baptism. A joint study by the Roman Catholic Church and Church of Scotland concludes that "…in terms of intention, it was the same sacrament of baptism that was being celebrated in the Roman Catholic Church and the Church of Scotland" and even goes on to raise "the possibility of a common baptismal text for our respective baptismal liturgies." (Joint Commission on Doctrine 2007, 8). However, the Church of Scotland, while recognising the importance of baptism, does not share the view that unbaptised children cannot enter heaven: "We believe fervently that God loves us and calls us into greater closeness whether baptised or not." (Rev. Iain Torrance, personal communication, 2023).

Baptism was therefore taken seriously. Aside from the high mortality rate associated with spina bifida at that time, I wonder whether a fear of infant death might have reflected a 'folk memory' of higher infant mortality rates. McKeown *et al*. (1975) describe a huge improvement in infant mortality rates throughout the 20th century, with a 90% reduction between 1901 and 1971. This reflected fairly recent medical advances - for example, penicillin had only become available for clinical use in 1943, less than 20 years before (Hutchings *et al*. 2019). For my parents' generation, infant death was therefore a greater fear – a more realistic fear – than it is now. Hence, perhaps, the hospital baptisms.

Hospital chaplaincy can be seen as an important resource for parents, particularly as critical illness of a child can lead to a heightened concern for spiritual matters and can be considered as part of the treatment team (Gibbons and Miller 1989). Baptisms can be carried out as a result of that. Caulfield *et al.* (2019) in a study of 'emergency baptisms' carried out in a neonatal unit in Ireland over a 15 year period concluded that, despite a decline in religious belief over that period "Emergency baptism remains an important element in the spiritual care of the critically ill infants admitted to neonatal units" (2019, 611). Campbell and Campbell (2005) note that many parents consider this to be of such importance that in an emergency situation, medical staff may be called upon to baptise an infant, in the absence of a chaplain.

The ceremony of baptism was therefore an important one. A hospital baptism – hastily organised and very far from being the usual family celebration – was unusual. The fact that they took place implies the recognition of the significant possibility of infant death. Mary, born (and baptised) at home, had a stark addendum that reinforces this:

> Mary: *The doctor said he'd be back the next day to sign … the death certificate.*

As a result, the local priest came to their house and baptised her that night.

Joan's narrative also makes it clear that the context was fear of death:

> Joan: *I remember them telling me that there was a boy born with spinal bifida that same day and he died.*

There is a shared narrative in that the parents of all of those participants were confronted with the shocking possibility that their new baby might die and were asked to act on that possibility so that they would not die unbaptised; that is what a hospital or other 'emergency' baptism means. One can only imagine that this must have been a traumatic time for them and wonder what affect this might have had on their experience of parenthood.

In my parents' recollection, my hospital baptism took place without them, just before I went into the operating theatre. They were simply told "We think you had better have him baptised. What name have you given him?" If my parents were not worried already, they certainly were after that. I was their first child and they had never heard of spina bifida before. It must have been a difficult time for them and the surgery going well, i.e. my survival, would have been a huge relief.

My conversation with my parents about this time left me struck by two things. Firstly, that this had clearly been a traumatic time for them. Even now, 60 years later, they talked about it in hushed tones. Secondly, that this was the first time that I had really seen my birth from their perspective. I had always seen being born with a disability as something that *I* had to contend with, something that affected *me*. That it affected my parents too, in quite profound ways, wasn't something that I had really considered. Yet this was something that played a significant part in Lorber's policy of selection described earlier – that a disabled child was a burden on both the family

and on society at large. The effect of the birth of a disabled child on parents is something that will be discussed under Theme 2.

The actual experience of perinatal surgery and hospitalisation is one that must have been significant for those of us that it happened to, even if we have no conscious memory of it. A review of research on the psychological and social impact of serious illness (i.e. that involved time in the ICU) on children (Manning *et al*. 2013) noted that the impact on 'survivors' was not well understood and attempted to address this through a review of the literature. Despite the fact that they would have been old enough to remember the illness experience themselves (the review included research with children up to 18 years old), children were often reluctant to talk about it and that this reluctance "appeared to emanate from feelings of anxiety or embarrassment relating to a lack of understanding of their critical illness" (2013, 148). There are similarities here with the way that the 1960s cohort did not have an understanding of spina bifida. Furthermore, "Parental narratives appeared to be most significant in forming and influencing participants' perspectives and views of their critical illness experience and the life events that surrounded it" (2013, 150). This use of the narratives of others was obviously even more pronounced in the research participants here, who had no conscious memory of the events surrounding their birth. A limitation of the above review noted by the authors, was that it concentrated on research with children who were old enough to verbalise their experience. This meant that they had a 'before' as well as an 'after', which the research participants in this thesis did not, aside perhaps from a notional lost 'normality'. The narratives the children constructed helped them address the 'psychosocial adversity' they faced

(Manning 2013). In this sense, the ‘emergency baptism’ narratives of the research participants had a similar origin and purpose.

It is perhaps not surprising that for the research participants (and for myself) the hospital baptism would be a family story that was told and retold. After all, many of the ingredients of a good story are present - there was not only drama and danger, there was also a happy ending. We all survived to, literally, tell the tale. However, what does it mean to grow up with such a story? What significance would it have for both the tellers – the parents and other family members old enough to remember – and the subjects? It is a story of tragedy avoided, certainly, but what purpose does it serve?

In one sense, it is a story that fits firmly within the medical model. The people suggesting baptism are the medical profession, either directly as in my own case and that of James, or indirectly, as in the case of Mary; the doctor’s statement that he would return the next day to sign the death certificate left her parents in no doubt as to how they should act. In each case, baptism took place as a result of the medical prognosis, which was, essentially, that we might not live. Certainly, in Mary’s case, as she was born before the introduction of shunts as a surgical intervention for hydrocephalus, the prognosis was not good. For James and Joan, they would have been born at a time when the high mortality rate for spina bifida was only just beginning to decrease and had not yet been fully reported - the paper urging that the closure of the spina bifida lesion be “treated as a medical emergency” would not be published for another year (Sherrold *et al*. 1963).

While this story is situated inside the medical model and bears witness to the acceptance of the authority of the doctor – particularly the Consultant – it also subverts it. This is because the outcome was not the one that the parents had been warned of. We did not die; we lived. While it could be argued that this is a testament to the skills of the surgeons involved (and objectively, it is) it is interesting that the story is never told with that moral in mind. In each case, the moral is more along the lines of 'The doctors said you might die – but you proved them wrong!"

This is reinforced by family recollection of other aspects of the medical prognosis given at the time. For example, James' parents were told that even if he survived he might be "*badly mentally handicapped and never able to look after myself*." Maureen's parents were told that "*I would never walk and that I would be in a wheelchair all my life*." My own parents were told similar things. However, the medical profession was again shown to be wrong. In what other ways, it is implied, might we continue to prove them wrong?

Interestingly. Michael's parents had a similar experience in the 1990s:

> Kevin: Do you know what sort of things they were told?
>
> Michael: *Em, wouldn't talk, wouldn't walk, wouldn't sit up, possibly couldn't feed myself. Basically the sort of bleakest picture possible.*

There is certainly a tendency amongst the medical profession, to this day, to give the worst-case scenario. This is reflected in the advice given following detection of spina bifida during routine screening, as described in the previous chapter.

However, by the 1990s medical authority was not what it was. It is worth noting that Michael's parents added another element to the story, that they were also told that they would never be able to go on holiday – unless it was to the North of France.

> Michael: *You would never be able to go on holiday. The only place you would be able to go would be the north of France because that was the only place that they had specialists...*
>
> [laughter]
>
> *Don't quite know how that works!*

This was related by Michael - presumably reflecting how he had heard it told by his parents - in a way that made it clear that the family regarded it as a somewhat bizarre touch. One that in turn, perhaps affected how seriously everything else the doctors said should be taken. It is difficult to imagine anyone in the early 1960s laughing at consultants. I have to say, it feels like progress.

However, if laughing at consultants was unthinkable in the 1960s, the hospital baptism narrative offers a more indirect way of subverting medical authority. There is quite a subtle contradiction at work amongst the parents of the 1960s cohort; on the one hand, the authority of doctors is unquestioned – but on the other hand, the doctors were wrong about *their* child. In the face of a "worst-case scenario" prognosis, living with these contradictory views could have been a way of keeping hope alive. The hope that having proven the doctors wrong once, their child might do it again. Hope is important for both parents and children. Kirpalani *et al*. (2000)

found that parental hope was a more important indicator of children's health-related quality of life than physical limitations themselves.

It is interesting that although the research participants were aware of their origin stories, they often had no recollection of their parents otherwise discussing spina bifida at all. Maureen's experience was typical of that generation:

> Maureen: *They never talked about spina bifida and how, you know it was just treated, as as, you know, ignored almost*.

This will be discussed more fully under theme 2. The thing that was talked about, the origin story, therefore assumed a greater significance. The narrative of "The doctors expected you to die - but you proved them wrong." is, in many respects, a powerful narrative to have about oneself. What might it mean, for that narrative to form part of someone's sense of self? There are several lenses we might apply.

Beating the odds

Several participants referred to a sense of determination. That if they set their mind to do something, they would manage to do it, despite obstacles.

James spoke of this in terms of 'beating the odds:'

> *And then they gave me until the age of 7, 14, 21… and I'm still here. So, I've beaten the odds!*

It was something that he returned to throughout the interview, in relation to difficult times in his life. For example, he had a shunt fitted for hydrocephalus and when he was 5 or 6, this failed and had to be replaced:

So they said I was a quarter of an hour from death – again!

On going to a mainstream secondary school, that entailed walking up a steep hill:

And they says , I wouldn't manage it. I proved them wrong again.

I asked James specifically whether that was something that he'd found useful in life.

Kevin: *… is that something that stayed with you do you think?*

James: *I, yes I think right yeah certainly – I beat the odds*

Kevin: *and can you think of times in life that's been useful?*

James: *Never give up. Like getting failed, or whatever.*

James saw his ability to 'beat the odds', rooted in his survival of surgery, as something that had been useful in life. He talked about it almost like a resource, that he could draw on in difficult times, that made him able to continue. This was true of a range of experiences including school bullying, finding employment and an alcohol problem. It is clear then that in James's case, this narrative, expressed by him as 'beating the odds' was one that had served a useful purpose in his life.

Something similar emerged in the interview with Joan, expressed as 'determination' rather than 'beating the odds'. She made the point about determination early on in the interview, in relation to her chosen introductory object, which was a Brownie

photo. She recalled that there had been resistance to her – a disabled woman – becoming a Brown Owl, the adult leader of a Brownie group.

> Joan: *But I was absolutely determined*. *And when I'm determined to do something, you haven't got a hope.*
>
> *And there was no way they were going to say "no, you can't."*
>
> *Because "can't", "can't" is not a word in my English Dictionary.*

As with James, this was a theme that Joan returned to throughout the interview, in relation to obstacles in her life. It was also reflected in her choice of television viewing:

> Joan: *But I love watching these these sort of programmes on the TV. About*
>
> *children who have been told the same sort of thing. And they, they've been told that they … about [being] different …about what they, what they can't do. And they go on and they prove that they can.*

Clearly, the narrative being told on the TV was one that she identified with. She went on to add, towards the end of the interview, referring again to her battle to become a Brown Owl:

> Joan: *I love proving folk wrong.*

I asked her if that story of her birth was something that had continued to have an effect on her in her adult life:

Joan: *Oh, definitely. Em, I think that's, that's, em, that's had a huge impact on the way I See things.*

Kevin: Really?

Joan: *Because it's made me, I think that's made me such a determined person.*

Kevin: Mmhmm

Joan: *Yeah, I don't give in to anything, I think there's got to be a way round such and such*

So for Joan, the narrative had a similar function to James – she was someone whose determination could overcome obstacles and confound the expectations held by others of what she was capable of.

Mary had a similar story of determination.

Mary: *I'm very strong willed. Very very determined.*

If you tell me I can't do it, then just wait, I'll show you I can. You know, it might not be the way that you want me to do it, but I will do it.

While she did not volunteer a connection with her origin story, she definitely saw it as being a trait rooted in her childhood.

Kevin: What have you brought from childhood to now?

Mary: Probably still got a positive outlook, a positive attitude. A 'can do', a 'can do' attitude.

What is clear from Mary's story is that her positive attitude is self-generated. She did not find her parents supportive – her father died when she was still at school and she describes her mother as "a cold woman". Nor was school a happy environment for her. I asked where she thought this positive outlook had come from, given her unsupportive environment?

> Mary*: I suppose I've just watched my brothers and sisters doing things. I've thought I'll just try that as well.*

The urge to belong is of course a strong one and it is possible that Mary's determination to do things was driven by an urge to simply be the same as everyone else.

There was a sense from the 1960s research participants that this was how they saw their lives – a series of obstacles that they got through despite difficulty, including physical pain. They had an expectation that life would be difficult but that they would endure it. I find something noble about this and at the same time it leaves me with a certain sadness. A life limited by disability but perhaps also self-limited. This narrative could therefore be seen as one that is helpful but only up to a point: "I am someone who overcomes difficulties. And I see my life as a series of difficulties for me to overcome." It is both life enhancing (in a sense) and yet, at the same time, limiting; to be fully lived, a life should perhaps be about more than being endured. This individualistic approach is one that is reflected in in the medical model of disability.

It is a measure of how deeply rooted the medical model remained that many of the 1960s research participants were drawn to that area of work. For example, Joan found work as a medical secretary, and regarded the attraction as self-apparent:

Joan: *I've always been hospital daft for obvious reasons.*

While alive to the shortcomings of the system, Maureen and Ailsa both pursued careers in the NHS. Mary, while critical of some aspects of her care, was also attracted to medicine:

Mary: *I really would have liked to be a doctor. A doctor or a nurse.*

Mary struck me as a bright, perceptive person and could well have had the capacity to follow such a path. Unfortunately, she was denied the educational opportunities that would have allowed her to demonstrate this. I was reminded of Robert Zachary's words about the capabilities of the children with spina bifida he treated and how they were not given the opportunity to develop them: "Simple clerical and mechanical work is well within the capacity of most of these young people, but there must be many who are potentially great authors, artists, linguists, musicians, scientists and philosophers, and yet they may have no opportunity to advance themselves in this way because of the lack of educational opportunities" Zachary 1968, 276).

Manning *et al*. (2017) looked at the narratives a group of children who had survived critical illness had around death and dying. They identified "fear and anxiety" in the

children's stories "…anxieties about their death and the potential of dying in the future" (2017, 245). Such anxieties appear to be absent in the narratives of the research participants, perhaps because they have no conscious memory of the time. However, Manning *et al.* (2017, 249) concluded that: "Hope and quests to be normal were posed, even in traumatic accounts, which constructed resilient survivor identities." There was therefore a similarity in the way that the narratives were used, in that they contributed to resilience.

An example of this narrative outside of this thesis is the Paralympian Jean Driscoll's account of growing up with spina bifida and becoming a successful athlete (Driscoll, 2000). The first line is "I am the baby who lived." As the title – *Determined to win* – suggests, determination is a recurring theme in the book. Outside of spina bifida, Richards (2008, 1721), commenting on a serious hospitalisation when she was 8 months of age states: "I feel as if I am 'the girl who lived.' You cannot be the same after something like that."

There is a sense in which the baptism narrative also demonstrates determination to others. It shows the person with spina bifida fighting their condition. Pollock (1993) argues, in an echo of Parson's sick role theory (Parsons 1975), that if the sufferer can demonstrate making an effort to improve their situation, this can make them more socially acceptable. As Radley notes (1993, 110) "they are doing their best and are therefore free from moral condemnation by others."

Conditions of Worth

As a counsellor working primarily in the person-centred tradition, I have reflected on the ways in which person-centred theory is a useful lens through which to examine this theme. In particular, the extent to which the experiences described have led to conditions of worth that have in turn led to divergence from an authentic sense of self (Brown 2014). By 'conditions of worth' I mean the idea put forward by Carl Rogers that we absorb the belief that our parents' love is conditional on us behaving in certain ways – behaviours that might not be what we would recognise as our authentic self (Rogers 1990/1959). Rogers' belief was that while conditions of worth were inevitable, if they lead to too great a divergence from an authentic self, that could result in tensions that affect our mental health. I therefore looked at the transcripts through that lens – was there anything there that could be understood better through that concept?

It is possible that the determination that many of the research participants described could be seen as a condition of worth. They will have absorbed through their origin story that they not only could, for example, 'beat the odds' but that this was something that was expected of them. In fact, that their parents' love was conditional on them behaving in a particular way.

I reflected on my own history of disability and surgery. I think I absorbed the belief that enduring without complaint was a 'good thing.' I recall being in hospital in my early teens and overhearing myself described as being 'a model patient.' I was delighted at this and felt that it was high praise indeed. It was what I aspired to be: a

good boy who never complained and did what his parents and the doctors told him. Unfortunately, people who never complain seldom manage to change anything. It is interesting that, even now, my anger over discrimination is not for myself but for the spina bifida community as a whole. It is as if the involvement of others is needed to validate my own feelings and give them worth. I think this is because the remnants of the stigma of disability, that I am somehow unworthy, and the ingrained belief that enduring in silence is somehow a virtue, is still a powerful combination that has a strong effect on my instinctive reaction in any situation related to spina bifida.

I remember an incident during the Counselling Diploma, at a time when I was a wheelchair user following spinal cord surgery. Our seminar class had been moved to a different building due to the lifts being serviced and I arrived at the new building to find that, ironically, the lift there was out of order. I briefly considered dragging myself up a flight of stairs, before observing that the accessible toilet, visible from the bottom of the stairs, was also 'out of order'. My immediate reaction was one of shame, mixed with a feeling of anxiety that this was my fault and I would, in some way, get in trouble. I felt crushed and took a taxi back home. I immediately felt better on learning of my classmates' reaction. They were angry on my behalf, to the point of sending a delegation to the University Vice-Principal to complain. I was touched by this supportive action. However, I also reflected on the reasons for it not being my own reaction. Why hadn't I felt angry at the lack of access? Why hadn't I wheeled myself up to the VP's office and made my views known? At the root of it was a feeling that I somehow did not deserve an accessible building. Part of that feeling was down to the individualist approach of the medical model; accessibility was my problem, not anyone else's. However, I do wonder if the shame part of it is due, at

least in part, to the attitudes to spina bifida in the society I grew up in. After all, if it was debateable whether we should be allowed to live, what right would we have to expect an accessible building? It is striking too that despite all the progress in my life, that incident was enough to bring back the feelings of childhood. This is a measure of how deeply our childhood experiences mark us and of the enduring power of conditions of worth. It can also be seen, I think, as an example of the power of shame. Gilbert (1998, 6) notes that "Episodes of shame have an almost panic-like quality to them, where the capacity for rational thinking steps aside." And that "Most aroused shame is via fast-track, involuntary processes that are difficult to control" (1998, 30). Childhood stigma and shaming, as will be discussed further under theme 2, casts a long shadow.

The Special Child

One other lens for looking at this theme, is that of specialness. Did this origin story leave the people telling it with a sense of specialness or importance? Did it confer any special status within the family?

I can see nothing from the point of view of the research participants that indicates that their origin stories had left them with a feeling of 'specialness' in the sense that they were somehow better than others. All of the 1960s cohort describe their childhood as being a difficult time, one in which they were discriminated against, rather than favoured in any way (this discrimination will be dealt with in more detail in the discussion of the *Things have got better* theme). However, there is some

indication that others – siblings in particular – perceived a specialness and resented it.

Mary spoke about this and how, for her, it persisted in her siblings' attitudes to her in adulthood.

> Mary: *…they're going on because you're getting the attention, they thought they should be getting and even now it kind of cast up and I think 'Guess what? you actually probably got the attention more than me although you didn't realize it'*

She realised that her siblings' perception of that time was different from her own. Things that she experienced as difficult – having to go to a different school, hospitalisation for surgery – were a source of resentment by her siblings.

> Mary: *I didn't feel that I ever grew up with my family. Because if I wasn't at hospital, I was at school and the only time I really saw them was when we were home from school or holidays. So I don't see why they had to have the sibling rivalry. I was more often there than not. I mean I was more often away than not.*
>
> Kevin: It sounds like you were the one that was missing out.
>
> Mary: *Yeah but they can't see it.*

Mary's siblings may have, even unconsciously, resented the fact that Mary was the only one with a story about her birth – a story that they would have heard being told

and re-told. However, this will have been compounded by what they may have seen as other examples of Mary's specialness. The different school that entailed transport, the hospital stays. Bad experiences for Mary but ones that her siblings perhaps saw in terms of parental attention.

Maureen talked about similarly difficult experiences with siblings:

> Maureen: *You know one of the huge things that always upset me growing up was my two older sisters. Yes, sixty-seven and sixty-six, em, and these used to always walk away ahead of me. They didn't see the need to, to you know, do anything different, because it was never spoken about.*
>
> Kevin: Do you think it's possible your sisters may have resented that you got more attention?
>
> Maureen: *Of course there would have been issues like that as well. But you know that there was obviously bits of resentment, and they still don't understand it to this day.*
>
> *You know, I have brought it up a couple of times. But I just get defence, you know, defensiveness and they've never understood it, and never wanted, I suppose, to accept any responsibility for leaving me behind all the time, you know.*

In a sense this is a story as old as the Old Testament account of Joseph and the jealousy of his brothers towards him. However, the 'favouritism' that sparked

resentment seems to have been illusory – neither Mary nor Maureen felt like they received any favoured status from their respective parents – or if they did, it was not perceived as such. This is an example of how a narrative can mean different things to different people, perhaps without any of them being consciously aware of it.

There is evidence that 'well' siblings of chronically ill or disabled children can find the family situation difficult. A review of the research on sibling experiences by Havill *et al*. (2019, 334) states that "Well siblings of chronically ill children experience family disruption that can profoundly affect them for the rest of their lives." This could take the form of anxiety about a situation that they did not understand, or resentment about lack of parental attention or family activities, holidays etc. In some cases this led to responses like fear, anger sadness and embarrassment towards disabled siblings. Similar responses were also found in a survey of siblings specifically relating to spina bifida (Bellin *et al*. 2008). In a further review of research on the perspective of well siblings, Deavin *et al*. (2018, 6) note that "They often felt jealous and resentful of the time, protection and 'special treatment' parents bestowed on their siblings, especially when their sibling appeared to be 'doing well'." Something that improved the situation was parental explanation and information about their sibling's condition: "Understanding sometimes helped them to cope with the imbalance of attention between themselves and their sibling." However, as we shall see in the later section on parental communication, this was unlikely in the cases of Mary and Maureen, which may go some way to explaining the siblings' behaviour.

Attitudes to disability also had an effect on sibling behaviour. In a study of siblings of children with spina bifida, Bellin *et al*. (2009, 3) note that "…more negative attitudes about the condition were associated with worse adjustment outcomes." A general conclusion in the work cited above is that families need support, not just affected individuals. It is probably fair to say that, based on the accounts of the research participants and of my own experience, such support was thin on the ground in the 1960s.

There is another sense in which there could have been an unconscious, pervasive sense of specialness. I noted earlier that I hadn't really thought about things from my parents' point of view. Nor, interestingly, does the parental perspective feature in many of the interview accounts. On reflection this seems to me to be a significant omission. Is there something about this narrative that is essentially self-centred? In making ourselves the centre of our narrative of endurance, the heroic overcomer of a relentless series of obstacles, is there any room for a supporting cast? Or perhaps there is simply a universal tendency to take our parents for granted, to see them entirely in their parental role and not as individuals with their own agency, thoughts and feelings?

Quest narratives

Arthur Frank (2013) describes different sorts of illness narratives. One – the restitution narrative - is essentially an immersion in the medical model. The narrative is controlled by the medical profession and the person reduced to a kind of bit-part in their own story – the recipient of expert care. Is the 'hospital baptism' story a

restitution narrative (2013, 72)? There are certainly aspects of the 1960s childhood narratives that fit into that category. It is possible to frame it as: “I was ill but the surgery made me, to an extent, better?” As Frank notes, (2013, 92) in the restitution narrative we “… bear witness not to the struggles of the self but to the expertise of others.” However, the origin story as told by the research participants subverts this narrative – “the doctors were *wrong*.” It reclaims the narrative from the medical history and centres it on the individual’s lived experience. More than that, by becoming part of lived experience, it reclaims the narrative from a positivist paradigm that would negate that lived experience, simply because it cannot describe it. In their different ways the research participants all transcend the restitution narrative and the medical model. They see a larger role for themselves and use their experience of spina bifida – of disability – to make a difference.

I found this perspective particularly relevant because it brought two incidents that had happened to Joan into focus. The first was when she herself had been a Brownie.

> Joan: *And even to this day I remember, em. We went for a, sausage sizzle.*
>
> Kevin: yes.
>
> Joan: *One day at the bottom of a steep bank.*
>
> Kevin: *Uh-huh*
>
> Joan: *And all the other brownies ran down the hill to the bonfire. But I but I was left thinking how am I gonna get there? I can't remember how, em, how it ended.*

It is interesting that Joan did not remember the ending of this story but did remember how it had made her feel. Perhaps this is not surprising because the ending was not the point of the story, the point was the feeling of being different and excluded. That feeling of exclusion was so powerful that the memory of it had lasted half a century. It was amplified by a similar incident in the workplace, where colleagues chose a route to a training session that was not accessible.

> Joan: *And so I just followed all the other secretaries and they went towards the steps. And I just stood at the top of the steps. I didn't say a word purposely. I just stood at the top of the steps. And they said. "Joan, are you not coming with us?" And I was using a walking frame at the time.*
>
> Kevin: uh-huh
>
> Joan: *So I just threw my … right, so I just went gradually forwards as though I was just about to fall down the steps. And then one of the secretaries who used to do… was nurse trained …She realized what was happening, so she came back. She came back with me out the level access. But I just… I purposely didn't say a word just to see if they realized their mistake.*

It is interesting that these two stories are similar. However, in the second one, Joan, while still feeling excluded, demonstrates some agency. She acts in a way that resolves the situation – and presumably in a way that encouraged her colleagues to be more mindful in the future. It is interesting too that the colleague who helps her – the hero of the story - is the one who was medically qualified.

However, Joan went on to tell me something that transformed her narrative into a quest. She herself trained to become a Brown Owl, a Brownie leader, in charge of her own pack. It was a photo of this group that Joan had brought as her introductory object. Joan talked about her role as a Brown Owl and how she made sure that a girl who used a wheelchair was able to join in, despite the reservations of the area managers of the organisation.

> Joan: *but from past experience I knew how much it would mean to that girl to be a Brownie.*
>
> Kevin: yeah.
>
> Joan: *So I did and it meant a lot of adapting. But I was perfectly prepared to do all that, just so that she could join in the games.*

Joan went on to describe a specific incident.

> Joan: *And they were just two seconds into the game when I shouted "stop!" "Have you forgotten something?" And they then realized themselves that they had forgotten to take [the Brownie with a wheelchair].*

Joan's role as a Brownie leader illustrates the development of her narrative into a quest. She intervened to make sure that a disabled child felt included, in a way that she herself had not been. In so doing, she takes control of her story and gives it a purpose of her own; she is no longer someone to whom bad things have simply

happened. Joan's story illustrates the point made by Frank (2013, 131): "'Whatever has happened to me or will happen' the storyteller hero implicitly claims 'The purpose remains mine to determine'."

Joan goes on to say:

> Joan: *And I find myself, em more and more, em, trying to help people to overcome things.*

This then is an outcome of everything that Joan has been through. She is not someone who has been overwhelmed by her lived experience of disability; she is someone who uses that experience to help others.

Other research participants explicitly include helping others as part of their narrative. For example, Mary described her involvement as a voluntary youth worker and also as an organist at her church. Both of these gave her a way to contribute, to give to others as well as being a recipient of help.

For Maureen, her sense of having been excluded resulted in her being driven to help others:

> Maureen: *and whether it was a patient, a carer or a staff member, you know, I, I am tenacious fighting for other people.*

Part of Maureen's story was her initial reluctance to admit that she needed help, in the form of disability benefits (explored further under Theme 2) or a Blue Badge and her negative experience of seeking help. However, Maureen's story did not end there. Her story was not that she was simply someone who bad things had happened to. She saw herself as part of a wider political story:

> Maureen: *Which is what they're depending on, that people are are going to be so scared, em, that you know that they'll be punished in some way. And that is your whole Tory government, you know, disabled people are to be punished for being disabled.*

> Maureen: *The Tory government don't want to provide anybody with services, and we probably come way down their list of priorities, but I think it's really important.*

So again, Maureen was someone who had taken control of her narrative. She was not simply someone whose medical condition meant that she needed help. She was someone who saw that help as an important function of society and wanted to make sure that it was available for others who needed it and in doing so specifically located herself as part of a political struggle. While she did not mention the social model, these ideas are consistent with it.

Ailsa told of her experience of the medical profession, which she characterised as negative:

Ailsa: *… growing up, I went two years to the general surgeon, and then I was put on to orthopedics and twelve years of hideous appointments at the old, em, Princess Margaret Royal in Edinburgh*

Kevin: Oh yes, I knew it well.

Ailsa: *Oh, awful, yeah, and then discharged and told to be normal!* [laughs]

So that was my childhood, really. Just constantly being told to be normal, but not, but knowing that something was not right. And nobody else with this great big scar on their back.

Kevin: So, do you, do you know what was said to your parents at the time about your prospects?

Ailsa: *They were told… every time they said, 'Oh, her toes are curling', or 'she doesn't walk the same as anybody else', they were told 'Be thankful she can walk.' That was all they were told, So they were just … left. I don't think they knew much about it, to be honest. They just stumbled along. Didn't tell anybody at school, you know, because you didn't want to admit you had anything wrong with you. So, yeah, I had a really strange situation. But they never spoke about it much.*

This sets the scene for Ailsa's childhood experiences of feeling different and excluded and not really understanding why. That lack of understanding, by school, parents and herself, is seen as being rooted in the actions, or inactions of the medical profession. However, her story does not end there. The conclusion of her narrative reframes her childhood experience as not merely something that happened

to her but something that put her in a position to help others. It was a major contributor to her decision to pursue a career in the NHS, working with children:

> Ailsa: *I think I was attracted to that because of spina bifida and you can make things so much better for kids, and I think that's probably what pulled me in there at the time. Well, I said that in the job interview, I felt I wanted to make a difference, and didn't want kids to feel the same way as I'd felt. And they don't nowadays, they're not treated like that.*

Ailsa has taken her negative childhood experiences and made them part of a narrative that ends with her helping others to avoid those same negative experiences.

An application to counselling

As I became aware of this phenomenon of 'hospital baptism' amongst my research participants, I noticed that it also arose in the narratives of my counselling clients with spina bifida. I didn't initiate the subject, as I thought the boundary between my role as a counsellor and as a researcher was an important one and that it was not ethical to pursue my research interests through my clients. However, applying the knowledge gained from my research to my role as a counsellor presents no ethical problems – indeed it is one of the objectives of the Professional Doctorate in Counselling and Psychotherapy.

When clients mention this – that they had not been expected to live – I now have a wider context in which to place it. I wonder with them what has prompted them to

mention it and what the story means to them. One client in particular introduced the subject in a striking way and I reproduce her words here with her permission. Claire (a pseudonym) said to me: *"The thing is Kevin, I'm not even supposed to be here."* That was Claire's way of introducing her origin story narrative i.e. that she had not been expected to survive. This story immediately struck me as very different in purpose from the ones told by the research participants. In Claire's case, it served as an explanation for the sense of isolation and detachment from the rest of her family she had felt when growing up with spina bifida. In a way, it served to confirm her difference and sense of dislocation from the world around her; she didn't belong because she wasn't supposed to have survived. This contrasted with the way that the research participants' narratives were, to some extent, helpful to them. It is, perhaps, significant that Claire was telling me her story as a counselling client, rather than as a research participant. However, my experience of the research interviews helped me to discuss with Claire the ways in which her own narrative might be reframed. This was a fruitful thread within our sessions. A year later, Claire said, in reference to the same story (again, repeated with permission) "*Well if I can come through that, I can come through anything!*" The story of her birth now had a very different meaning for her. A good illustration of therapeutic progress reflected in narrative change.

Summary of Theme 1

My analysis of this theme leaves me with the feeling that, overall, the narrative of surviving, beating the odds etc. is one that has been useful for the research participants. It is one that they have used to make sense of their lives and has, broadly, been a resource that has helped them to overcome obstacles. As Garro

argues (2000, 71) “Narrative accounts … make sense of the past from the perspective of the present.” In other words, they are not just a record of the past but a resource in everyday life.

It is worth noting that by the 1970s, the ‘hospital baptism’ seems to have become less prevalent as a phenomenon in the UK, for spina bifida births at least. Ailsa, born in 1971, has no recollection of any such story for her. The 1990s cohort thought the question itself was slightly bizarre – they grew up in a much more secular society. The interview with Eileen summarises the societal change quite well:

> Kevin: Were you baptized when you were a baby?
>
> Eileen: *No. No I’m not, my family's not religious at all. And neither am I.*

The body language indicated that Eileen found the question somewhat ‘random’, as her generation might put it. A statement about being non-religious is an unremarkable response now but would have been quite an unusual one in early 1960s Scotland. The phenomenon of the ‘hospital baptism’ narrative is therefore one largely confined to the ageing spina bifida population. As noted previously, there is for the first time a growing community of people born with spina bifida who are now in their late 50s and early 60s. This population show a decline in both physical and mental health, which has resulted in pressure on patient organisations to provide mental health support. The narrative discussed here is therefore relevant to those involved in providing counselling to that ageing community.

Theme 2: Things have got better (up to a point)

Introduction

There is much in the interview transcripts and in the background literature on spina bifida that might be described as difficult. Indeed there are parts that are indisputably dark – for example infant mortality and the policy of selection. However, one of the themes that emerged for me was an optimistic one: *Things have got better*. This theme emerged from the contrast between the narratives told by the 1960s and 1990s cohorts.

However, at a societal level too, things have improved in terms of how disability is treated and that improvement is reflected in the interview transcripts and in the literature around spina bifida. Some of that is due to scientific progress – the prognosis for children born with spina bifida has steadily improved and advances such as in-utero surgery generate the hope that this will continue (Crombag et al. 2021). Most importantly, attitudes to spina bifida – and to disability in general – have improved. It could be argued that this reflects a general acceptance of the social model of disability and a greater openness and acceptance of disability.

A small illustration of this is that in 1974, the musician Robert Wyatt, a wheelchair user following an accident, had a hit single that, in those days, meant an appearance on the BBC TV programme *Top of the Pops*. The producer of the programme tried to insist that Wyatt appear sitting on a wicker chair, on the grounds that the sight of a

wheelchair was “not suitable for family viewing.” Wyatt insisted on staying in his wheelchair, precipitating a day-long argument which Wyatt eventually won (O’Dair 2015, 220). In 2002, the BBC started using an ident of wheelchair dancers in between programmes, putting people in wheelchairs up front, on primetime TV, every day. A very visible measure of changed attitudes to disability.

There is a sense, of course, in which that greater visibility of disabled people in the media is part of a positive cycle. It becomes included as part of what people consider normal. We might also note here the increasing prominence given to the Paralympics that occur alongside the Olympic Games.

In terms of people with spina bifida, perhaps the biggest indicator of this societal change has been that, bluntly, doctors are no longer trying to kill us at birth. It is hard to imagine that Lorber’s policy of selection would be acceptable at all today, let alone the more extreme components such as withholding of antibiotics or high doses of sedatives. The absence of a debate over whether babies born with spina bifida should be allowed to live – and of a background where such a debate was considered acceptable – has, I believe, meant a substantial lifting of the stigma that many of us felt. This change is expressed in several different ways in the research interviews, two of which are explored here in detail.

Parental communication has got better

There is a marked difference in the description of parental attitudes to spina bifida between the two cohorts. The childhoods of the 1960s cohorts were characterised by silence about their spina bifida. Aside from the baptism stories discussed in the earlier chapter, spina bifida was not discussed much by parents at all:

> Kevin: *So is it something that your mum and dad talked much about?*
>
> James: *No, not really no,*
>
> Joan: *I never questioned her. She must have been so... I can't, I can't even begin to think how she must have felt.*

It is worth noting here that Joan has filled the gap left by silence with the conclusion that it was too terrible an experience for her parents to talk about. Therefore, she too should be silent. In fact, Joan described sending away for information leaflets about spina bifida on her own initiative.

Mary told a similar story (with an interesting slip):

> Mary: *I don't actually know anything greatly other than when I was born the GP came and said he would be back in the morning, to sign the birth, sign the death certificate.*

This silence was sometimes part of a difficult relationship with parents. Mary described her mother as being quite a distant figure:

> Mary: *a mother that wasn't very loving in the first place…*

Mary: *but my mum was one of these… she was a very cold person.*

There could be any number of factors at play here that made the relationship between Mary and her mother a difficult one. However, the sense of being different from others, of being somehow less, is something that started for Mary in childhood. It is possible that the societal view of spina bifida as something unwanted, something shameful, made an impression on Mary's mother and through her, on Mary.

This was echoed by other research participants:

Maureen: *You know from wee things that you're told, because you know it was never talked about, you know*

Maureen: *But it was never talked about in the family, you know, and you know I I I used to when I was younger was convinced that I was some sort of changeling. You know, that, you know, I didn't really belong and that they had, you know, they found me or something.*

It is interesting to note that Maureen filled the gap left by parental silence with her own fantasy explaining her difference and feelings of not belonging. This had such a profound effect on her that it was something she dealt with through counselling later in life:

Maureen: *I mean a lot of the counselling was around my mum and dad and how they never talked about spina bifida and how, you know it was just treated, as as, you know, ignored almost*

Maureen: … *that you know the effects of these things on children, em, you've always been left behind, of knowing you're different, but never really understanding it. Em, you know. And you you look back at yourself as a child and think 'Gosh!' you know*

That experience of feeling different from others but not understanding why was something that coloured Maureen's childhood and later life, something that she was only able to process and come to terms with through counselling in adulthood.

Maureen: *you know [counsellor] had a real thing around that, you know "Yes, your your parents loved you, but they didn't really didn't do what they should really have done" kind of thing. Not that they did anything that they shouldn't have done, but they they didn't deal with it in a way that for me as a child would have made it better. And because of that I ended up with a lot of issues around stuff, you know.*

Silence does not mean that that nothing is communicated. Clearly Maureen inferred a great deal from the fact that her parents never said anything about her spina bifida.

Ailsa told a similar story of spina bifida not being talked about:

Ailsa: *They don't talk about it a lot. I come from quite a guarded family*

She made specific mention of the practice of not allowing parents to be with their children in hospital and the negative effects of this:

> Ailsa: *my mum describes me as being in an incubator for a month at the Western in Edinburgh. And they were and they were allowed to visit once a week. So, I don't think I ever truly bonded with my mum – and I don't think she ever truly bonded with me either, I just get that feeling*.

Again, the vacuum left by silence has been filled. It is perhaps not surprising that when people are left with low self-esteem, that the silence is filled with things that reflect that.

As with Maureen, Ailsa was left with feelings of being different, which were never explained:

> Ailsa: *So that was my childhood, really. Just constantly being told to be normal, but not, but knowing that something was not right*

> Ailsa: *I don't think they knew much about it, to be honest. They just stumbled along. Didn't tell anybody at school, you know, because you didn't want to admit you had anything wrong with you. So, yeah, I had a really strange situation. But they never spoke about it much.*

Interestingly, just as Maureen had filled in the unspoken topic of spina bifida with her fantasy explanation, Ailsa's parents did something similar, with their own fantasy of what it meant to be someone with a disability:

Ailsa: *Em my mum and dad were always very much. "You'll never manage that." " You'll never manage that to the… you know. You'll never manage it if you go for an upgrade, you'll never manage to be the boss. You'll never get married, you'll never have kids, you'll just…". I've done all that. So it's, you know, I feel great, happy about that. But sometimes I think they more they said that they wouldn't want it to get more, you know, be better.*

Kevin: So you think they were saying that to be protective?

Ailsa: *Yeah. Probably just, you know, you might don't set yourself up to fail. Whereas I quite like doing that now? I think I'm more like that now, as I get older. You know, "I'm going to try that!" because you couldn't as a kid. Yeah definitely.*

Ailsa's parents' fantasy of what life would be like as someone with a disability had a negative effect on her, contributing to a sense of low self-esteem. While it is tempting to criticise their ignorance, it is worth noting that their comments echo those of John Lorber, someone held to be an expert on spina bifida. As shown earlier, Lorber's statements about on people with spina bifida having low employment prospects and likelihood of never meeting a partner were part of his justification for his policy of selection. Perhaps his beliefs helped form those of Ailsa's parents, consciously or unconsciously. They certainly contributed to the establishment view of spina bifida in the 1970s. So what we can say is that Ailsa's parents were by no means unusual in their beliefs – they were, at the time of Ailsa's birth, so prevalent that they were being used as the basis for selecting children with spina bifida for treatment or for death.

This was reflected in something that Ailsa's mother said to her:

> Ailsa: *My mum actually told me if there had been twenty weeks scans when I was around, I wouldn't be here.*

The telling thing here is perhaps that it indicates that while spina bifida was not being talked about by Ailsa's parents, it was certainly being *thought* about. Her mother's view on termination of a pregnancy affected by spina bifida – regardless of whether we might think it would have been better left unexpressed in this specific instance – again reflected that of Lorber and the medical establishment. As detailed earlier, it is a view that formed the rationale for the development of the pre-natal screening programme for spina bifida; that the purpose of the screening was so that pregnancies affected by spina bifida could be – indeed, *should* be - terminated.

I see strong similarities between the experiences of the 1960s cohort with regards to their parents' attitudes to spina bifida. The fact that spina bifida was not discussed – other than in terms of their origin stories – seems significant. It perhaps indicates a sense of stigma about disability – spina bifida was a skeleton in the family cupboard that should not be discussed. It is not difficult to imagine that this would have been reinforced by the dominant view of the medical (and political) establishment that there were too many children born with spina bifida, to the extent that two thirds should not be allowed to survive.

This has made me reflect on my own experience. In many respects, it was similar to that of the research participants; spina bifida was not really discussed. When mentioned, it was along the lines of 'there was something wrong with you when you were born but it was fixed, so you're fine now'. Like Ailsa, I found this confusing – because I did not feel fine, I felt different. I felt different because of problems with mobility and problems with continence – and the reaction of others to these problems. I was aware early on – by which I mean that I cannot recall a time when I was unaware – that my parents did not like to talk about it, that the subject was difficult for them. I was left with a feeling that this was my fault, that I had somehow done something wrong. This developed into feelings of shame about my spina bifida, feelings that would last well into my adult life. I wonder too about the extent to which the issues around selection formed a background that I absorbed unconsciously. However, there are other emotions in the mix here. When my parents said "you're fine now" I have no doubt that they desperately wanted that to be true. In any event, I think it is fair to conclude that not discussing spina bifida made life more difficult for both parents and children. It is therefore heartening to note that the experience of the 1990s cohort was completely different.

For example, Michael described an open discussion with his parents about spina bifida:

> Michael: *I wouldn't be able to pinpoint an age sort of when I understood the complexities of it and stuff but it was very much that never hidden from me and so very openly discuss when I was growing up.*

And this was something that he came back to and I asked him what sort of feelings were associated with his parents talking about spina bifida:

> Michael: *I wouldn't say there's any been particular pattern or anything like that it's just been an open dialogue. so I would say that it's been noted at a particular juncture. It's just been an open conversation, I think.*
>
> Kevin: How does it feel when they talk about that?
>
> Michael: *Is it ok to say sort of neutrality? I don't necessarily have any positive or negative it's just sort of more 'it happened' so. I think it's because it's what, it's what I've always known. I've not known any different so , I don't necessarily have any particular positive or negative connotations with that, if that makes sense?*

I was immediately struck by how the difference in openness about spina bifida was accompanied by a difference in attitude to it. The absence of secrecy and stigma meant that Michael did not seem to experience those things either.

It may also be relevant that Michael's parents were able to stay with him in hospital following his surgery, so there was none of the parental separation described by the 1960s research participants.

> Kevin: Have your mum and dad ever said anything about how long you were in hospital after surgery, and it was for them?

Michael: *They have but just trying to think. Probably six weeks, at least, I think. Em. one of them was with me at all times so that was very much mentally draining for them just running up and down to hospitals and stuff.*

Kevin: yeah.

Michael: *I'm pretty sure it would've been around that sort of timeframe.*

Kevin: Do you know, do you know if they were able to stay in the hospital with you?

Michael: *yeah yeah they definitely were. It's, it's a slight divergence, I always remember my dad telling me that one of his friends came up to visit and the hospital chair was similar to one that we had in the house and he was like 'can you bring your own furniture in?' ' yes I brought it in over my shoulder...' So, so they were definitely allowed to stay in that sense.*

I was struck here by how much Michael knew about his birth, in comparison with the 1960s research participants, and also by the richness of his description. He was aware of not only what his parents did but how they felt. I'm struck too by the tone, of how this story has a lightness of touch; there is nothing to be afraid of here.

Eileen also described an ongoing dialogue with her parents:

Eileen*: So as I was saying, I knew about my disability but I didn't fully understand things. But obviously, as I'm older, if I want to know something I can ask a question so like if there's something that I am unsure about I just ask.*

Again, she was aware of the stories around her birth and was aware that she had not been on her own in hospital

> Eileen: *I know that from times I've stayed you're only usually allowed one parent like to stay with you but they always used to have a side bed that you could stay on but you were only allowed one parent I'm sure.*

In fact, Eileen had discussed this period with her mother, in relation to her preference to sleep with a light on.

> Eileen: *… and that's me in my twenties and I still do that. And I used to get embarrassed about it, but now I don't because I actually think back to, and I think it maybe stems back to see when I was a baby and I was in the hospital. There was lots of lights about me … And she's thinking is that like maybe a psychological thing, I've maybe grew up with and that's why it's like a comfort thing.*

For me, the interesting thing here is not whether this is indeed why Eileen likes to sleep with a light on. What is interesting is that it is an indication of the ease and depth of discussion between parent and child about that time. Her birth with spina bifida is by no means a subject that is avoided.

I reflected on the contrast between the narratives of Eileen and Michael, compared with those of the research participants. A source of confusion, hurt and shame – of stigma - has been brought out into the daylight and made part of the everyday, being stripped of its power in the process. It is clear, I think, that this made a difference to

the lived experiences of Eileen and Michael, as compared with those of the research participants. However, it may also have made a difference to the parents too, in terms of their experience of spina bifida and of their relationship with their child. I thought of the hushed tones in which my own parents talked about their experience of my birth, the traumatic experience that was still difficult for them to put into words. In interviewing people with spina bifida about their own experiences, that of their parents has been communicated only indirectly. However, I wondered if the clear differences in how children with spina bifida experienced their parents, around the issues surrounding spina bifida at least, was reflected in the experiences of the parents themselves regarding spina bifida. There is an extensive research literature that examines the parental experience of having a child with a disability. This can be used to help shed light on the accounts of the research participants.

There is consistent evidence that parents find the initial diagnosis a difficult time (see for example Hare *et al*. 1966, Walker *et al*. 1971, Hedderly *et al*. 2003, Bingham *et al*. 2010, Green *et al*. 2013, Kisler 2014). They experience emotional distress, anxiety and worry about the future. There is also a loss of an imagined future, replaced by a new, uncertain one. This has led some researchers to suggest that grieving process for the lost 'ideal' child is necessary before they can come to terms with their new reality (Parks 1977). The comparison with the grieving process is in keeping with the idea of disability as a 'personal tragedy' for parents and child, a perception rooted in the medical model. This would certainly have been the case in the 1960s, prior to the development of the social model. As Kisler (2014, 333) notes, such comparisons while intended to help "have only negative connotations"; there has not, after all, actually been a death.

There is also evidence that the position of parents was made worse by poor communication from medical professionals – in the 1960s, at a time when it was not yet dreamt of that information on anything at all could be found from a handheld device, medical professionals were the only source of information for parents. The importance of this cannot be understated. As Hedderly *et al*. (2003, 30) note: "All parents remember the moment when they first learned that their child had a disability and tend to suggest that how well they subsequently coped depended on how they were told." In the case of spina bifida, the sometimes relentless focus on the worst case scenario will not have helped. Chaplin *et al*. (2005) interviewed parents who had received a prenatal diagnosis of spina bifida and chose to continue with the pregnancy. One parent describes being given their diagnosis as follows: "And he turned to me and the words that came out of his mouth were, 'This fetus has spina bifida. If I were you I'd terminate because it's going to be crippled.' And then he just got up and walked out…" (2005, 155). The example of the research participant Mary is another striking example of this phenomenon, with the doctor saying he'd be back in the morning to sign the death certificate. The conclusion of Chaplin *et al*. (2005, 158) seems somewhat understated in the light of these examples: "Professionals, whether in brief or long-term contact with parents, need to be aware of their potential to have a major impact on parents' pregnancy experiences." Bingham *et al*. (2012, 373) argue that medical professionals need to provide both information and emotional support, finding that the experience of parents following their child's diagnosis was "less traumatic if professionals were sympathetic, direct, communicated well and provided sufficient information and opportunity to ask questions." Sadly, as the examples above show, this has not always been the case,

however there are continued efforts to improve. Hedderly *et al*. (2003, 31) state that the medical school curriculum now includes “Breaking bad news” and that this often includes role play. Hedderly *et al*. (2003, 32) go on to state that “it is vital that professionals see the child first and the condition or disability second” – the very point made in relation to children with spina bifida by Robert Zachary a quarter of a century earlier (Zachary 1977). It is encouraging to note that there is an increasing literature aimed at improving communication by medical professionals. For example, Joseph (2023) specifically looks at the needs of parents with spina bifida and how health workers can help meet them. While a work in progress, it is a positive development that there are examples of best practice in the literature and a seeming consensus on how things should be done.

As described earlier, the social stigma associated with disability would have applied to both parents and children. For parents this would have been two-fold. As courtesy stigma, through being related to a child with a disability (Goffman 1963, 43) and also direct stigma, as parents who had brought a disabled child into the world. Some conditions attract more stigma than others and, as I argue here, that was the case with spina bifida. The policy of selection emphasised the undesirability of babies with spina bifida, to the point that most were not allowed to live. The development of pre-natal screening was done with the express intention of termination of pregnancies where spina bifida was detected. Again, Goffman’s (1963, 15) words ring particularly true here: “By definition, of course, we believe the person with a stigma is not quite human.” Parents of a child with spina bifida therefore faced the stigma of having brought, in the eyes of society, an unwanted child into the world. It is perhaps not

surprising then that so many reacted by pretending that everything was normal, by never speaking of it, in the hope of ‘passing’ (Green *et al*. 2013).

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It was held as self-evident that the birth of a disabled child would put unbearable strains on a marriage. Indeed, this was one of the arguments used by Lorber in favour of selection (Lorber 1973). Tew *et al*. (1977) stated that marriages of parents who had a child with spina bifida were nine times as likely to end in divorce as other marriages. In fact, this finding was quickly revealed to be wrong – the result of a series of what can only be called ‘’schoolboy errors” (Stevenson *et al*. 1978). It is tempting to conclude that these errors passed the editorial process simply because it was what people believed must be true. In fact, there is no convincing evidence that the marriages of parents who have a disabled child are more likely to end in divorce (Risdal and Singer 2004).

The birth of a disabled child can certainly cause a strain; however, the evidence is that couples adapt. This, I would argue, is what marriage is about, weathering life together, as a team. Furthermore, there is evidence that the longer-term health effects observed on parents are not due to the disabled child per se but due to lack of societal support. At higher rates of income (twice the US Federal Poverty level), there is no association between maternal health effects and having a disabled child. The effects on health are due to poverty, not anything intrinsic to disability (Bixby 2023).

We can see then that the silence of 1960s parents about spina bifida described by the research participants is not necessarily surprising. Their experience of stigma perhaps led them to pretend that everything was normal, despite the research participants' own experience that they were different from other children. It is also possible that parents simply did not feel well-informed enough to talk about it with their children. However, there is evidence that things have changed in terms of parental experience.

Green *et al*. (2013, 2016) carried out a meta-analysis of qualitative research on parents of children with disabilities over a period of 50 years (from 1960 onwards). They note that while some experiences have remained constant over the decades – the initial reaction to diagnosis, the variable quality of communication by medical professionals - there has also been significant progress. That progress has been in the form of parents taking a more positive attitude to disability, with parents moving from a desire for 'normalisation' in the 1960s, to an increasing questioning of the concept of 'normal'. Green *et al*. (2013, 2016) argue that this is a result of the increasing influence of the social model. While parents might not mention the social model directly (though an increasing number do) they are familiar with the ideas associated with it. Parents increasingly challenge the concept of 'normal' and the narrative that disability is a 'tragedy'. Thomas (2021) interviewed parents of children with Down's syndrome and shows how parents resist the tragedy narrative by describing the joy of parenting: "…a perfectly normal, happy life as you would have planned anyway" (2021, 456). Niedbalski (2023) interviewed parents of children with an intellectual disability and notes how they construct narratives out of their positive experiences, rejecting the idea that disability had affected their sense of self. In both

cases parents defined their own ‘normal’. Carroll and Carroll (2023) present a joint paper giving their moving perspectives of spina bifida, as mother and son. This seems like a good positive example with which to end this section on parental communication.

We can see then that this change is reflected in the experiences of the 1990s research participants. Spina bifida was no longer a stigma, best not to be spoken about but simply a fact of life to be dealt with.

School has got better

Another striking difference between the 1960s and 1990s groups is how the research participants talked about school. The 1960s cohort had a uniformly negative experience.

Mary describes being separated out from her siblings and neighbours and made to go to a ‘special’ school. She spoke with some feeling about the events of half a century ago:

> Mary: *And of course, my whole childhood was… I wasn’t able to get mainstream education at all. Which is also really bad. The local school was possibly just five minutes walk from our house. And all the others went to there and I had to go in the school bus to [town] and into school there. For obviously this was the special school as they liked to call it then. I didn’t feel that I ever grew up with my family.*

That childhood feeling of separation and difference from her family would last for the rest of Mary's life. I asked her what had made it such a negative experience.

> Kevin: What was it like being at the school, you know I always think that "special school", is a kind of broad term?
>
> Mary: *Yeah. It probably was alright being at the school because I wasn't a great academic. I mean, I think I could have been better had I been tutored better. But it was more the stigma. The stigma of the wheelchair, the stigma of going on the grey bus, as it was known. Em and everything. 'Oh, that grey bus is for special people'. I thought, I'm not special, I just couldn't get up the steps at the school that was on the doorstep.*

Although Mary did not put it in these terms, this is a clear instance of a situation that looks different when seen through the lens of the social model of disability. Mary's impairment meant that that her local school was inaccessible. That the solution was to make it accessible is not one that seems to have occurred to anyone then but certainly would do so now. Instead, Mary was taken out of mainstream schooling altogether, an experience that that cast a shadow over her life. Mary came back to this experience again when I asked her about feeling different.

> Kevin: Can you remember maybe the first time you felt different?
>
> Mary: *Yeah. When I went to school. Because in my head I'm not different, even now. I was 'I don't know what you're talking about because I'm just the same as everyone else' but the day that I was handed over, by a mother that*

wasn't very loving in the first place and said "just watch her, she's not a very good girl" Think 'Oh what have I done?' But it wasn't only that, it's when I got plonked on a hard seat on this wee funny bus and I looked all around me and I thought what's wrong with these young wee boys and girls, because there was callipers and all sorts of different things and I think well what can be wrong with them because … why are we all on this bus?

From childhood then, Mary was left in no doubt that she was different. The mention of stigma indicates that she was also left with the feeling that to be *different* was to be *less*. That was the lesson that she remembered from school.

I personally went to a mainstream school, however I was conscious of the stigma attached to a 'special school'. I remember clearly an occasion when I was, I think, aged 9 (in my memory it is in my primary 5 classroom). A girl stood up in class, pointed at me and said "My mum says that people like you should be in a *special* school!" I've no idea what provoked this and I have no memory of what happened afterwards (did the teacher intervene? I would like to think so.) However, I can remember how it felt – like the ground had opened up beneath me. I was shocked that an adult was implicated in her bullying and it added to my feeling that school was not a safe place to be. I can also remember thinking that distressing though this was, I would not show it. A conscious turning inward. In retrospect, I wonder if the mother concerned was reacting to the association of her daughter with a stigmatised condition – a kind of courtesy stigma.

Mary did not find her school a welcoming environment either:

> Mary: *I've really… I would say… now I look back it's actually bullying that I got at school and…*
>
> Kevin: yes.
>
> Mary: *… at home and outside as well. The ones who wouldn't play with me in the street.*

Bullying was, unfortunately, a consistent theme in the interviews with the 1960s research participants. For example, James went to a mainstream school

> James: *Yes, and and of course I was bullied at school of course, the usual - I think a soft target, you know.*
>
> James: *But yeah I just took it so much then I bit back and they got a shock, you know. Bullying stopped.*

James was to return to this subject in more depth, in a way that made it plain that it had a bigger effect on him than is implied here. This was perhaps indicative of a developing rapport during the interview.

> Kevin: Can you remember the first time that you were made to feel different?
>
> James: *Just when they started laughing and pointing and calling me names like frog legs and this. And I just laughed it off. Yeah I just said "sticks and stones…"*

Kevin: And was that just in primary school?

James: *No academy as well, I was surprised that, well, it was actually worse at the academy. They were bigger you see. More or less adults you know?*

James: *So that was that. Then, as I said before, I got my own back, I just bit back. Of course, I told the teacher and everything what was happening. They were looking out for me as well. But this bully was sly he never did it with any of the teachers were about*

Kevin: mhmm.

James: *See he was fly. But ever since then I cottoned on to what he was thinking and I stayed around the teachers. So that was it*.

It is clear from James's account that he was not, in fact, describing a one-off incident of bullying, as he initially implied, but a repeated experience over the school years that led to changes in his behaviour. It had an isolating effect.

Kevin: Just, just thinking about school again - would you say you were quite solitary, you know, kept yourself to yourself?

James : *Yes, yeah I did. To me that that the best way of staying out of trouble.*

Kevin: Keeping out of trouble in the sense of… people causing you trouble?

James: *Exactly yeah.*

Kevin: Keeping your head down, sort of thing?

James: *yeah just yeah*.

This sense of isolation was to have a profound effect on James's life and one that could have ended badly. I will deal with this in more detail, and how his life was turned around, in a later section. However, towards the end of the interview, I asked a question that once again led to an indication of the importance of the experience of bullying.

> Kevin: If you could go back in time and speak to the young you, still at school. What advice would you give, do you think? What would be the one thing you'd tell yourself?
>
> James: *Eh Keep your head down, if you get bullied tell your teacher.*
>
> Kevin: mm-hmm
>
> James: *That's what I did, just keep your head down.*

I was left with the impression that for James, school had been an experience to be endured. At the final part of the interview, using the emotional touchpoints, the list of negative words elicited this response:

> Kevin: Any of those words trigger any particular memories, for you?
>
> James: *Not really no. No. Well I am thinking of being bullied. Away with them! Picking on someone less fortunate than them. And that's about it.*

Clearly, bullying had a profound effect on James; it is his main recollection of school. As it is mine. Sadly, our experience was not unusual. Bullying can be defined as aggressive treatment from peers, whether physical, verbal or behavioural, that is carried out repeatedly and involves an imbalance of power. The imbalance of physical power is inherent in a condition like spina bifida. As Flynt and Morton (2004, 3321) note, when children have a physical impairment, they "…may move slower, have less stamina, have an unsteady gait…these conditions may be viewed by bullies as a sign of weakness and precipitate verbal or physical abuse." Those descriptors certainly apply to ambulant children with spina bifida.

There is a consistent body of evidence that children with physical disabilities are between 2 and 4 times more likely to experience bullying than children without a disability (Dawkins 1996, Flynt and Morton 2004, Wolke and Lereya 2015, Rose *et al*. 2015) and that this can continue for years (Rose and Gage 2017). The effects are significant. Children who are bullied "…have low self-esteem, a negative view of themselves and feel stupid ashamed and unattractive." (Dawkins 1996, 603). That is a description that feels all too familiar. Nor do those feelings end when we leave school, as James' story illustrates. Wolke and Lereya (2015), in a review of the literature on bullying, conclude that victims of childhood bullying continue to be at higher risk of anxiety and depression up to 50 years of age (this does not preclude the effects going beyond that age). It is not surprising then that such experiences feature in the accounts of the research participants.

On a more positive note, Rose *et al.* (2015, 427) conclude that such bullying is not inevitable: “By providing appropriate educational accommodations, social skills instruction and peer models, an inclusive setting may afford students with disabilities a buffer against victimisation and bullying.” I think this can be seen in terms of the reduction and removal of stigma. Schools can act in a way that normalises diversity. As we shall see in the further accounts below, in 1960s and 1970s Scotland, schools did not do this. In fact, they acted in ways that emphasised difference in a negative way.

In contrast to Mary’s story, Joan’s parents resisted the idea of her going to a ‘special school’, which would have entailed a long journey to the nearest city.

> Joan: *But my my mum and dad put their foot down and said “no way. she's going to [local school]”. So Mum spoke to the, the School secretary, who we knew quite well.*

Aided perhaps by the personal connection, Joan went to the local school and some adjustments were made to help her.

> Joan: *Bit at that, but when I was at school I was let out of class 5 minutes before the end of the lesson.So that I could get downstairs before the, before the Stampede started.*
>
> Joan: *And then the teachers told me in confidence when the fire alarm was going to go.*

Kevin: Right. Inside information!

Joan: *Yeah. So that I could get ready for, if I was in the swimming pool for instance.*

I could get ready before I had to evacuate the building with all the others.

Joan's memories of her schooldays seem better than those of James and Mary and perhaps part of that was down to these adjustments to her impairments.

It seems that her parents' attitude, aided by a personal connection, made a difference in terms of choice of school and the adjustments that made life easier. It also extended to Joan's experience of bullying.

Joan: My mum was so supportive. *When I came home from school and, and told her about it. She must have gone to the, gone in to school and spoke to the secretary. Because em the bullying suddenly stopped.*

It is perhaps relevant here that Joan came from a farming family and the associated culture of resilience and the experience of running their own business might have left her mother better equipped than most to take a strong stand where necessary.

Maureen's school narrative is closer to my own.

Maureen: *I remember going into primary school, and even feeling very aware that I was different and treated… I mean, I was bullied a lot, you know, and nobody ever wanted me on the sports team! [laughter]*

Kevin: Oh, listen, I can still remember that feeling. I don't know if they did it with netball or whatever…

Maureen: *throughout school! I know, I was always last picked!*

Kevin: Well, I mean, really, what a horrible thing to do…

Maureen: *I was good at hitting the ball, I just couldn't do the running!*

Kevin: Same here! And if I ever actually kicked the ball, you know it was uh kind of random which direction it would then go off in?

We are referring here to the then common practice of choosing teams by getting the two best players to take turns at choosing someone for their team. Obviously, the worst players would be picked last – and the children with a disability last of all. It was a public foregrounding of impairment that had a profound effect on me, Maureen and also Ailsa (see her account below). This shaming experience formed a constant drumbeat throughout my early years: "You are different, you are *less*." Gilbert (1998, 17) says that shame "… is related to the belief that we cannot create positive images in the eyes of others; we will not be chosen, will be found lacking in talent, ability, appearance and so forth; we will be passed over, ignored or actively rejected." It would be difficult to design a system better suited to eliciting shame than this public exhibition of negative difference. It was as bad as bullying – but this was a system imposed by teachers. It was not done with the intention to be cruel, I'm sure. It was simply lazy and ignorant.

In Maureen's case it contributed to a sense of feeling different.

> Maureen: *I I did have some, probably mental health issues, maybe even at that point, because I do remember, because, like walking down to school, you know, would take me ages, and if I left a bit too late, I would be late, and I always... from a very young age I hated having to walk into a class full of people. Hated it. Because I was so aware of my limp and you know, people would look, and and even from that sort of five, six age, you know, and if I did end up late I used to just go into the cloakroom and hide behind the coats.[laughter]*

This feeling of being exposed and stared at was something that happened repeatedly throughout Maureen's time at school.

> Maureen: *Yeah. I wanted to run and, you know, not be last all the time! You know, and usually I wouldn't, I just sort of dawdle back, you know, if it was like running I mean [school] used to make you run round the wall. And again I hated that, because you you know, cars were passing, and I hated people looking at me, trying to run. I hate to this day, because I still can't run to save myself. So you know, as you know, these things do do leave a lot of scars, and I think a lot of people don't understand that, you know*

I found myself identifying with the experiences that Maureen found difficult. I too hated being stared at because I walked differently and strongly disliked being put into situations where that happened. Lewis (1998, 131) in discussing stigma and

shame, describes a similar situation: “A woman who limps when she walks notices others looking at her. At home, she anticipates walking in public and being observed by others. Stigmatisation is a public mark.” One result of this was that school never felt like a safe place, partly due to bullying but also, as here, because of the situations created by staff. This reminded me of another experience of my own.

This was in my first year at school, in Primary 1. The teacher had a cupboard in which she kept, amongst other bits of classroom equipment, a box of musical instruments. These ranged from little xylophones, drums, tambourines etc. down to triangles and finally single bells. The problem was that we were a large class and there were not enough instruments to go round. The teacher explained that everyone would get a turn and that those who didn’t get an instrument this week would get one next week. I did not get an instrument that week. Or the next. In fact, for the entire year, I did not get so much as a shake of a bell. I remember this because I *longed* to get an instrument to play and I slowly realised that I was never going to get one. Worse, I came to believe that this meant that I somehow did not deserve to get one (I refer back to Gilbert’s description of shame above: “we will be passed over, ignored or actively rejected.”)

It seems like an extraordinary way for a teacher to behave and I can only guess as to what was going on. One of the effects of spina bifida is incontinence and I struggled with this for some years. Perhaps she felt I was ‘dirty’ and shouldn’t be allowed to touch her instruments? As with my previous example, I wonder now if this related to the stigmatisation of spina bifida and whether she felt that, at some level, that stigma

would extend to her and so acted to distance herself from it. You may also ask, regardless of stigma, does the distribution of cheap instruments in a class for 5-year-olds really matter? It mattered to the five-year-old me. So much so that I can remember how bad it made me feel over half a century later. Such is the power of shame. No child should ever be made to feel like that.

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Despite academic ability, the experience of difference overshadowed Maureen's time at school.

> Maureen: *Just things like I hated PE [Physical Education]. Hated PE with a passion. And it was like, it was like. It was almost the highlighting of your issues and problems, every week, you know.*
>
> *Maureen: I mean, I was always in the top classes. But I just… I, I think probably always a huge chip in my shoulder, and just felt, you know, I wasn't worthy. I wasn't, you know. But you know, I think my self-worth in primary school was shocking, and I don't know if that really particularly improved and I think it probably did a wee bit, but not not so much through school but afterwards. But you know em primary and secondary, both were nightmares…*

Again, I identified strongly with Maureen's experience of school. I too did well academically but had a very low sense of self-worth. Maureen saw a counsellor in adulthood, which helped her come to terms with her experiences and also develop an awareness of how they had impacted on her life. How much better it would have been to have had an inclusive school environment that welcomed diversity.

Ailsa, the remaining research participant from the 1960s group, told a similar story. Again, we shared the experience of PE:

> Kevin: So was that how you became aware you were a wee bit different because you were walking differently?
>
> Ailsa: *Yeah, I knew that … people would say, 'What's that scar on your back?', you know, and I would say … I knew I had spina bifida but I don't know what it was. … And you know you were treated as a sort of… left, always left at the back at PE. You know that was my, I don't know about you, but it was my worst nightmare. And, yeah, something's not right here, but my parents were like 'Well, we were told just to treat you as normal.' So, I'm just rubbish at that then!*
>
> Kevin: You know, if somebody had just said to me 'Look, don't bother with PE. Just go to the library for an hour.'…
>
> Ailsa: *That would have made such a difference. Yeah, primary one to S5, being subjected to PE and asked why you couldn't do it. Well, I don't know about you, but that's like my overriding memory of school.*
>
> Kevin: I remember saying to a PE teacher, you know, 'Well, I've got Spina Bifida', and not wishing to get into prejudices about PE teachers, but that did not compute.
>
> Ailsa: *No, no, they're just wicked. And in [region], if you didn't play hockey, you were nobody.*

Kevin: Did , em, I know this was a thing with the boys, I don't know if it was with the girls as well, but the teacher would pick two boys and tell them to pick teams.

Ailsa: *Oh! Yes.*

Kevin: And they would pick one each and...

Ailsa: *You were always the last one. Yep. Oh, you're just standing there waiting for the ground to open up.*

Kevin: I don't think they do that now.

Ailsa: *No, I don't think so. No, my kids like PE!*

It is interesting to note that during this part of the interview, we were finishing each other's sentences, such was the intensity of the shared experience. It was somehow validating for us both – I think the same was true with Maureen - to find that what had been an awful experience for ourselves had also been the same for someone else (I have quoted extensively in order to illustrate that).

It is worth noting again that this destruction of self-esteem was something done to us by teachers, not other children. It obviously had an effect on relationships with peers though, even if, in Ailsa's case, bullying was not a major factor.

Kevin: What was it like with the other children?

Ailsa: *I was very, very shy, I think, conscious of being yeah, I didn't really fit in. I used to… my mum says I used to walk around the playground to look at other kids and just prefer to watch them play than interact with them. So I think that was probably deliberate because you don't get yourself into a situation then.*

Kevin: A bit of self--protection?

Ailsa: *Yeah. You're not going to trip over a skipping rope if you don't do it. So yes, definitely preserved myself that way.*

So we can see once again, school as an isolating experience. There's a sense too in which we both enjoyed this part of the interview. It felt as though we were swapping war stories.

Kevin: anything else you'd like to say about school?

Ailsa: *No school was just... I hated it to be honest. Just put in among … yeah, absolutely hated it. I don't ever consider it to be the best days of my life. So absolutely. And I think…Yeah, it's just… I, I've no happy memories of school whatsoever… Once I got a job, life looked up. Yeah, definitely.*

Kevin: Yeah, it's a completely different environment.

Ailsa: *Yeah, completely different. I probably should have gone to university, but I think I just wanted away from that whole situation of being in amongst lots of people your age and … yeah, So, not great.*

Kevin: Just when you say there ‘not the happiest days of your life’ I remember saying to my dad ‘I hate school’. He said “It’s the happiest days of your life!” and I thought oh my God…

Ailsa: *If this is the happiest!* [laughter]

Kevin: He was completely wrong, Thank goodness.

Ailsa had a fear – as did I – that things might not improve on leaving school. But they did – and the sense of relief is palpable.

Kevin: So when you, when you, started work, that was a different environment from the school environment?

Ailsa: *Definitely. And you were just… nobody judging you. I think. Yeah. Brilliant*

Kevin: Do you feel that you were seen as you, for the first time maybe?

Ailsa: *Yeah really just seen as a normal person coming in to learn a job and not as somebody that you don’t want to be picking in PE. And yeah, absolutely, it was really good. And and because I was obviously more academic than I was anything else, like. that was a good thing to be, and people were pleased with you. You got respected and included. Aye, included would be the … It would be that yeah.*

Interestingly, and prefiguring the analysis of the 1990s research participant interviews, we both had a different look at schools, through the lens of our own children:

> Ailsa: *yeah definitely. I just remember… Awful. But it's nice to see that the kids don't mind going to school. It's quite strange*.
>
> Kevin: Yeah, I mean, I remember when mine went to school, I was just… I mean, I guess, that intellectually, I knew rationally knew that schools were better, you know, just going in with them in their classroom and seeing how they liked it was just, I remember being surprised at just how nice it was.
>
> Ailsa: *Yeah. It's not this big, scary place anymore. It's just inclusive,*
>
> Kevin: yeah.
>
> Ailsa: *and everybody's different, everybody. You know they've all got friends who've got like a disability, or you know nobody bothers nowadays, and I think that's brilliant! Step forward. That's nice.*
>
> Kevin: Oh, definitely.
>
> Ailsa: *it's good.*
>
> Kevin: The world has become kinder
>
> Ailsa: *definitely has!. That's.. yeah.*

There was a sense for us both of how our children's positive of experience of school had helped us to move forward. The scary place of our memories no longer existed.

However, there is evidence that the experiences related above regarding PE were not uncommon. Blinde and McCallister (1998) interviewed 20 US school students with a range of health conditions, including spina bifida, about their experience of PE. They identified a problem with negative reactions and bullying from other children, when impairments were emphasised by the activity. One child is quoted as saying that the other children "…think that I'm a pity, no good … and, they just don't want me on their team" (1998, 67). An experience that echoes those of the research participants and myself above.

In a review of research giving the perspective of children with impairments towards PE, Coates and Vickerman (2008) note that children's' experiences of PE were "…somewhat restricted by the behaviour of others, leading to self-image and emotional distress" (2008, 170). They go on to comment that "…some PE teachers expect pupils to adapt to existing programmes, rather than them needing to adapt the curricula to the children" (2008, 171) - an echo of the medical model. Writing from a US context, a review by Haegele and Sutherland (2015) noted that PE can lead to students with an impairment being exposed to bullying. They state: "…being forced to participate in physical education, particularly when activities are not modified to meet the needs of students with disabilities may have similar detrimental effects [to forced exclusion]." An update of this review (Holland and Haegele 2021) noted research describing positive social interactions related to inclusive PE classes, as well as negative ones related to exclusion and bullying. They conclude that despite the positive experiences, progress has been slow.

Hughes *et al*. (2017) identified the need for PE teachers to improve their awareness of medical conditions, including spina bifida, with a view to improving inclusiveness. In order for PE to become truly inclusive, there needs to be a move away from a concentration on a small set of competitive team sports and a move towards individual achievements. Clearly, this is a work in progress.

Nevertheless, as Ailsa and I both observed from our children's experiences, schools have improved. Part of that is because schools have become more inclusive places and more aware of diversity. This even extends to PE teachers. Coates (2012) notes that the Labour government (elected in 1997) had placed inclusion at the forefront of its educational agenda and goes on to identify the social model as driving inclusiveness in education, including PE. In other words, it was recognised that schools needed to adapt to the needs of children with impairments, rather than individual children with impairments having the problem of fitting in with their school. However, Coates also identified that many PE teachers did not feel well-equipped for inclusiveness and suggests ensuring that student teachers are "prepared and confident to teach from a diverse range of activities, rather than just traditional competitive games activities" (2012, 362).

Even at some 50 years distance, it felt validating to hear about experiences of PE similar to my own from the research participants; it wasn't just me after all. The same was true of the experiences reported in the literature and it was encouraging to read of the efforts to make PE truly inclusive. And that leads us to the school experiences of the 1990s research participants.

Michael certainly did not have any negative feelings around sport. The introductory object he chose to bring to the interview was a photo of him in a wheelchair basketball team. In retrospect, this immediately set the scene for a more inclusive experience. Indeed, unlike all of the 1960s research participants, Michael could not recall being made to feel different.

> Kevin: Can you remember a time when you felt different, maybe the first time, from other children or were made to feel different?
>
> Michael: *I was thinking about this the other day and honestly not really. Which is maybe a bit surprising but I don't ever really remember feeling different or left out …*
>
> *I obviously remember, at nursery or early school, people walking about and I wasn't. But I don't remember that making me feel different or othered or anything like that, if that makes sense.*

My immediate thought was 'oh how lucky!' But of course, luck doesn't come into it – this is what the experience of a proper school environment should be like.

Michael told a story about being involved that seems quite significant.

> *Michael: One night I remember being told about – it must have been nursery – it was a magic show, they were asking for volunteers, obviously muggins stands up... "do you want to come up to the stage?" and I think I crawled to the front of the stage. I think they were a bit "what's going on here?" so even*

from that age I don't really remember feeling different in the sense that, I couldn't have just crawled up and been involved type thing.

I don't think it changed from earliest feeling until now to be honest.

The significance of this for me is that Michael's impairment was not turned into a disability – it did not prevent him from taking part in the magic show. This is partly his own personality coming through, however it also reflects the attitude of his parents and his school.

Michael associated school with encouragement, particularly from his parents. This exchange resulted from the emotional touchpoints section of the interview, where 'encouraged' was one of the list of positive words.

Michael: *With my parents, Was never pushed into anything but always encouraged of you wanted to do something… tried sort of various things that , I think maybe four or five of us went to drama classes which probably helped in terms of self-confidence, shall we put it. Again, that was sort of in the [theatre] again with all able-bodied sort of flung in there.*

Kevin: Did you go to just an ordinary High School?

Michael: *[name of school] yeah, all the way through. In that was something that mum and dad were quite keen to push for early on as well a wee bit in the sense that don't use sort of physical disability interchangeably with other disabilities or inability to go mainstream, I suppose.*

Eileen's story was not quite as positive as that of Michael, however it still reflected an experience very different from those of the 1960s research participants. I have quoted more fully here, to honour Eileen's style and give her the space to express herself in her own way.

Kevin: What was it like for you, being at school?

Eileen: *So em, I was more thinking about when I was younger., when I was like primary school yeah that was maybe a time, I felt different and it wasn't because other people are making me feel different or, you know they were wanting to make me feel different. They weren't doing it, you know, on purpose or anything like that, but it was more like I remember sitting like, see when they're in the playground and they're playing and things like that, and you're out and you're in the playground, and I was just watching and like you just watch people playing and that.*

… I remember looking at other people and I used to get upset because I used to think how can I not do that you know, like can't run the same as them and you know so I did feel feel different because they're all playing round about me and I'm the only one that's standing …that's sitting in the middle of the playground not doing anything

Hospital appointments also led to a sense of difference.

Also when I was younger I was always at hospital appointments like all the time.

So I would like go in the morning and come back at lunchtime and go back to school like once I was finished. And that used to make me feel different as well, because I used to always come back and I'd be like why am I the only one, you know going out to appointments and coming back.

And so I would say, they were the main things that made me feel different. As I've got older I've not really felt that which is good.

So unlike Michael, Eileen did feel different. However, unlike the 1960s research participants she has been able to come to terms with this. Eileen puts it into a perspective where she did not necessarily like it but has not allowed it to blight her life.

Kevin: How was school generally, do you think of it as a happy time?

Eileen: *Em. I don't miss if I'm honest with you. I don't. I would say probably yeah I was gonna say high school was better than primary but not really because because I didn't necessarily like high school either to be fair. No I wasn't really… I didn't really like it.*

However, Eileen has been able to put that into perspective.

I'm more a person, like see because I'm very chatty, like I'll chat to anybody. So I found that kind of difficult because I didn't have a certain friend group. Which… see as I get older, I see that as a good thing, because I'll just chat to anyone, so I can have friends from anywhere. You know.

Eileen's account struck me as a reasonable and proportionate response to her experience of school – an experience that I suspect would be familiar to anyone who feels a bit outside the mainstream, not just someone with spina bifida or another disability. I asked Eileen specifically about bullying, which had featured so prominently in the stories of the 1960s research participants.

Kevin: at Secondary did other people make you feel different?

Eileen*: Uhhuh. But they weren't like doing it consciously if you know I mean like they weren't leaving me out consciously. It was just, as you say, it was like an observation thing it was just the way I was feeling inside, it wasn't necessarily what people were doing. It was just how I was feeling.*

Kevin: Did it ever take the form of bullying by people being verbally or physically abusive to you?

Eileen: *No, I wouldn't say so. Em it was just more, I think it was more just the loneliness feeling like, because obviously you're watching other people and you're like why can I not join in?.*

Kevin: You didn't come out with it, with em with it denting your confidence?

Eileen: *yeah. I would say if anything my confidence has got better. it's not got worse. I did used to be very, very shy when I was younger… I never used to want to talk to anybody I used to be very, very shy but as I've got older that's definitely changed, and you know definitely since I've left school you know my confidence has been so much better. Like within myself as well you know coz I'm not … I used to be quite an insecure person I still could be sometimes and I still can be but I'm definitely more self-confident than what I used to be.*

Once again, I was left with a sense of Eileen having examined her life and put her experiences in their proper place; she had not been particularly happy at school, however it had not been traumatic either and she had gone on to better things. It had certainly not cast the long shadow that it had for many of the 1960s research participants and myself. I was impressed by her degree of self-awareness that enabled her to do this, far beyond anything I had been capable of at her age. This was, in part, because I had been overwhelmed by my school experiences. I was desperate to leave it all behind and start my life again – though of course, I took my baggage with me.

Society has got better … up to a point

There was one experience that featured in the stories of both sets of research participants that, while not strictly to do with childhood, overshadows the progress described here. That experience was applying for Personal Independence Payment (PIP) and other benefits associated with disability.

I will change the order I have previously used in this chapter and begin with an account from a 1990s research participant. The interview with Michael was in fact the first that I carried out. As discussed earlier he was positive about many aspects of his life, which were different from my own experiences and, as the later interviews were to show, from the 1960s research participants. At the end of the interview, I

used the emotional touchpoints technique to prompt any further memories that might be relevant to the study. This is how Michael reacted to the list of negative words.

Michael: *The latter half of that list, I would say the only time has been PIP [Personal Independence Payment] assessment.*

Kevin: Really?

Michael*: yeah I would say that's probably the only… but never in a social or an educational context.*

Kevin: Just that. What are the ... that's very interesting…. Is there anything, in particular in that list that you'd associate with doing your PIP?

Michael: *A probably the last two maybe? Actually, to be fair, probably quite a few of them. I think Because you probably spend so much of your life just getting on with it. Finding ways round things I think it's probably more when you're forced to write down. Where you can't do things or where you need help, I think that was probably the only time that I've felt particularly angry about it. Only because I had to prove that my life-long condition was in fact still life-long!*

Kevin: Yeah, yeah and the PIP game, if you like, is that you have to write down the things you can't do.

Michael: *And that's it, it's a game, you have to know how to play it with that's not… I mean I don't want to politicise it but if you have to sort of play the game to get support get support or… Because I think we all know that it does cost more to be disabled and the hidden costs of disability are…*

Kevin: Yeah.

Michael: *Aye, I would say that's probably the only experience that's impacted me negatively.*

Michael: *I thought it was a bit degrading to be honest.*

I was quite struck by this and I resolved to ask other research participants about their own experiences, should the opportunity arise in the course of the discussion. There was a balance to be maintained. The interviews were about people's stories about their childhood experiences and the role those stories played in their adult lives. Having decided on a semi-structured interview, I did not want to start adding specific questions that reflected my personal interests. I wanted to hear what mattered to them. Nevertheless, I was now primed to look out for the issue of applying for benefits should it arise. And it did.

Maureen spoke about her interactions with the DWP (Department of Work and Pensions) and she too had not found it a happy experience:

Maureen: *You know what a bloody nightmare you know it was horrendous, … I mean there is nothing worse for a disabled person to have to sit and go through all their failings and all their, you know, all the things you can't do, and that you need to help to do. You know there is nothing more humiliating and more self-destroying than having to kind of. "Well, yeah, yeah, I I I can't do that" …*

The experience had such a negative effect on Maureen that although her condition has deteriorated to the extent that she has given up work, she is reluctant to apply for the higher level of PIP.

> Maureen: *But I've just been so terrified because you hear all the stories about them taking off. I mean you hear of people in wheelchairs having it taken off, you know. So, you're like Oh, well, I'm not going to try and rock the boat. Which is what they're depending on, that people are are going to be so scared, em, that you know that they'll be punished in some way. And that is your whole Tory government, you know, disabled people are to be punished for being disabled.*
>
> *Nightmare… because there's been so much bad press about benefits scroungers, and all the rest of it, that you feel, you feel targeted every day. That is not a way to treat people, you know, in in in a civilized society, supposedly.*

Maureen's language here is quite vivid – "nightmare", "punished", "terrified" – and leaves us in no doubt as to how she found the process of applying for a benefit to which she was entitled. It is particularly concerning that it has had the effect of discouraging her for applying for further help to which she may be entitled. It is worth noting at this point that Maureen is an articulate, intelligent woman with significant experience of dealing with difficult situations. If she found dealing with the DWP so

bad an experience that she has been put off applying for benefits, what is the likely effect on someone with less mental and emotional resources to draw on?

Ailsa also found the experience difficult.

> Kevin: How did you find the … the process of applying for PIP, having to put forward your 'worst self', if you like?
>
> Ailsa: *Hideous. Because you don't want to. You're used to going through life trying not to be different, and then you have to put yourself in the situation of being different, and filling in the form I was like No, no, I'm fine with that, no. When you look at it and think actually, I'm not fine with that.*
>
> *But the actual interview! Oh! Oh my god, it was incredible. From the woman hiding under the desk when we went in, to see how you walked in, and then she popped up from under the desk, went "Hi!" and then followed out by this guy going to fill his kettle along the street, to see where you went. You know it was just … and my dad used to work for the DSS, so he was saying "I can't believe that they're doing this"*
>
> *I was like… that was quite a demeaning process, but it had to be done, so…. It was really traumatic.*

So Ailsa had also found the process difficult – "demeaning", "traumatic". It had left her with a feeling that it might be taken away from her, even though, as Michael noted, spina bifida is a life-long condition from which you do not suddenly recover.

> Ailsa: *You worry about it being moved*.

There is a growing body of evidence that suggests that the difficult experiences described above by Michael, Maureen and Ailsa are actually fairly common. PIP was introduced in 2013, replacing Disability Living Allowance. One feature was that assessment was contracted out to private companies.

The process of applying and being assessed for disability benefits, including PIP, has been found to have a detrimental effect on mental health of applicants (Shefer *et al*. 2016, Saffer *et al.* 2018, Wright and Patrick 2019, Webb and Albert 2022, Machin and McCormack 2023). Echoing Ailsa's comment above, Roberts *et al.* (2022, 13) conclude that PIP assessments "were found to be re-traumatising and to have an adverse effect on claimants' mental health."

The experiences of the research participants are in line with the finding of Saffer *et al*. (2018), who interviewed people with physical disabilities in the UK on their experience of the benefits system. They report that "a deep distrust in the process was described by participants who found themselves trying to navigate a system experienced as unclear, unpredictable and unreliable, and over which they had no sense of control." (2018, 1563) As with Maureen and Ailsa above, they identified a fear that benefits could be taken away and, as with Maureen "Some avoided reporting changes in their conditions or attempting to appeal to receive a higher rate of benefit for fear of losing all of their benefits" (2018, 1563). In terms of how they were treated, their research participants described "being treated unfairly, rudely, disrespectfully, patronisingly and even threateningly, and they often felt distressed and frustrated as a consequence". (2018, 1566) They were left with a feeling of not

being an equal member of society. Not surprisingly perhaps, their experiences " negatively affected their physical and mental health, leading to increases in psychological distress, including anxiety and low mood.' (2018, 1567) Furthermore, the necessity of presenting the worst-case scenario for their impairments also took a toll' This unusual public display of disability caused participants to focus on their limitations rather than their abilities, which had a detrimental impact on both mood and identity" (2018, 1568) – as illustrated by the research participants' comments above.

It has been argued that the negative experiences of applicants are not the signs of a broken system but in fact the system working as it was intended to by government, in order to reduce benefits expenditure (Shefer *et al*. 2016, Saffer *et al*. 2018, Wright *et al*. 2020). Wright *et al*. (2020, 278) go so far as to describe it as "state-perpetrated harm." Porter *et al*. (2023) make the point that decisions on whether to award disability benefits allows the government to administer the dividing line between where someone is expected to work and where they are entitled to support. They point out that this is not an objective decision but a political one: "Where these boundaries are drawn, and the ease by which claimants pass through, are political choices and do not reflect of any essential aspect of impairment or disability." (2023, 1165).

Porter *et al*. (2023) describe the application and assessment process in terms of "epistemic sabotage" – the systematic downgrading and disqualification of evidence given by disabled people and their medical professionals and in favour of that from the private-sector assessors. The effect of this is that the award of PIP can be

based not on the opinion of a medical expert who is familiar with the claimant but on the sort of farcical subterfuges described by Ailsa above. Porter *at al*. (2023, 1183) conclude that the ultimate purpose of this "…is not to support disabled people but to police the boundary of disability's administrative category."

Webb and Albert (2022), arguing for recording and analysis of PIP assessments, point out that the effect of this private sector surveillance is that 67% of assessment decisions are overturned on appeal, in the applicant's favour. Porter *et al*. (2023, 1168) argue that this entails a "deeply disempowering cycle of assessment, rejection and appeal that leaves claimants feeling disempowered and demoralised." Once again, this is not a bug; this is a design feature.

The moving of responsibility disability benefits to the Scottish Government has resulted in a new scheme, Adult Disability Payment, which is in large part a rebranding of PIP. One important difference is that life-long conditions such as spina bifida will no longer be subject to regular review. While a welcome change, this leaves the basic principles of initial assessment intact. In my view, this was a lost opportunity to do something radically different that did not have the same negative effects on applicants' mental health. So much of my work as a counsellor is aimed at building up people's resilience, in the face of declining physical health. The system for awarding disability benefits relies on testing that resilience to breaking point – and beyond. If the research participants quoted here – articulate, intelligent professionals, with a well-documented life-long condition – found it such a difficult and punishing experience, what hope for those less able to give a good account of themselves?

Summary of Theme 2

Two sets of stories about childhood experiences are described here. The first was around the way that parents dealt with the subject of spina bifida and the second was experience of school. I believe that the differences are striking and to some extent at least, reflect changes in society's attitudes towards disability. The social model had grown in importance and formed the basis for policy around accessibility, for example. By the 1990s, the policy of selection had disappeared from view – there was no longer any question about whether a baby born with spina bifida should be allowed to live. As a result of that, it was perhaps easier for parents to talk about it. I found it heartening that in neither of the 1990s accounts is there a trace of the stigma about spina bifida that I felt so strongly and which distorted my sense of self. Michael and Eileen simply accept it as a fact that means they have to do some things differently. So in that sense, things have indeed got better. However, there is still a way to go.

It is clear from Michael's narrative in particular, that implementation of the wrong policy can undo the positive gains accrued through changes elsewhere. This is something that I think bears further investigation. For example, I think it would be worth looking at the ways in which a benefits system could be constructed that had a positive effect on the mental health of people with disabilities, rather than a negative one. In the Scottish case, this would require a government motivated to use its devolved powers in a different and creative way.

Theme 3: The transformative power of love

One final theme spoke to me from the research transcripts: the difference it made finding a life partner. Although it applies to a minority of the research participants, it is one that resonated strongly with my own experience. For reasons of age perhaps, it applies only to the 1960s research participants – it was not something mentioned by the 1990s participants.

As I took part in the research interviews, I found myself reflecting on my own life experiences, some of which were discussed in the preceding text. I reflected on how difficult things had been – the low self-esteem and self-confidence, the sense of stigma surrounding spina bifida. I could see the effects of those early experiences still. However, I could also see that despite those early difficulties, my life had moved on and had become happy and fulfilled in a way that I would not have dared dream of then. I asked myself, what had made the difference? And when I realised the answer, I also found it looking back at me from the research transcripts.

James, having given an account of a difficult time at school, described beginning to struggle once he had left, particularly with loneliness.

> James: *I did, I did I used to have a half bottle of vodka now and again because I was getting really down, you know?*
>
> Kevin: yeah?

James: *but I shoved that off as well and carried on again. it was just a mistake. A blip.*

Kevin: What do you think… Do you think was,was driving the vodka?

James: *Ah, feeling lonely I think it was. Maybe. A few times I've gotten depressed*.

I found that I could identify with James's account. I reflected that I too had been desperate to leave school, yet found that life was not immediately better, not least because I brought all my inner baggage with me. I can certainly remember, even at university, a feeling of loneliness. I wondered what had helped James leave his past and turn his life around. More text is quoted here because I wanted to give a flavour of the changing tone of the interview.

Kevin: So, would you say your, your self-confidence built up after you left school? and this wee blip with the alcohol?

James: *definitely yeah yeah.*

Kevin: What do you think what do you think changed it for you.?

James: *Well, meeting my wife for a start.*

Kevin: aha.

James: *yes, that's it and getting married, got a house* .

This answer resonated strongly with me and I wanted to know more.

Kevin: By the way, feel free to tell me if I'm being too nosey at any point...

James: *no, no*

Kevin: When, when did you meet your wife?

James: *Oh well we've been married for 36 year, so that's about 40 year ago.*

Kevin: And … was it … this might sound like a strange question, you might not even remember it but can you remember telling her about spina bifida?

James: *Yes, oh yes. Uh huh. It didn't move her at all just "you are what you are". "You can't be what you're not", you know what I mean?*

Kevin: yeah yeah yeah.

James: *She was ok.*

Kevin: So, Something she knew about from the start?

James: *yeah I told her straight off. No she's still with me 40 years later on*

Kevin: Didn't put her off!

James: *No, no, some days, she wishes she could kill me like but...*

[laughter]

It was clear that meeting his wife had been a pivotal moment in James's life. His periods of loneliness that had been a trigger for depression were ended, as was the associated heavy alcohol use. I noticed the fact that the tone of the interview had

completely changed. James was no longer cautiously feeding me bits of a difficult past. He sounded happy and positive.

Kevin: So meeting your wife was a big thing for you big change in your life?

James: *Oh yeah definitely. I had someone to talk to and everything like tha*t

Kevin: And somebody that accepted you as you are?

James: *Yes exactly. Like I said I am what I am.*

Kevin: We've been lucky in the same way as well - that's quite nice.

James: *Yes it is*

I identified strongly with what James said. Meeting Elaine, the woman who became my wife, had had a similarly transformative effect on me. James returned to the subject again when we used the emotional touchpoints in the final part of the interview. Just as the negative ones elicited memories of bullying, the positive ones made him think of being married.

Kevin: anything popping into your head with those words?

James: *eh just being married and being thankful for getting the jobs that I had.*

A life characterised by low self-confidence and loneliness was transformed by meeting his partner. By love.

I knew that the same thing had been true for Mary. Her story of how she met and married her husband is a marvellous one, however as she told it to me outside of the research interview, it would not be appropriate to relate it here. Nevertheless, there is a point in the interview where we get a sense of what that relationship meant to her, from her experience of being widowed. During the interview she mentioned a kind of nervous breakdown that occurred when she was 14 and of which she has little memory.

> Kevin: Quite a dark time then when you were 14.
>
> Mary: *Yes.*
>
> Kevin: And the rest your life, you have kind of rebounded from that, would that be fair to say?
>
> Mary: *yeah.*
>
> Kevin: Nothing, nothing like that's happened to you again has it?
>
> Mary: *No. Well maybe, as you know, maybe after my husband died yeah. But that was totally different thing altogether. But eventually I came back from that as well. But I was still, I still was going out and about and the usual things but I wasn't doing it, I was just on automatic pilot for a long long time but I'm alright now. Different thing really. yeah. but I'm all right.*

In Mary's description of loss, of going through life on automatic pilot, we get a sense of what her life had been before her husband's death. Mary's own comparator for her loss was with the worst time of her childhood, so we get an idea perhaps of the difference he made.

Maureen's story is different again, in that her marriage ended in divorce. However, she found relationships liberating. Talking of her reluctance to go swimming with female workmates, she said:

> Maureen: *I don't want anyone to see my back, I don't anyone to see my leg, and you know, and that was a obviously a huge issue through my life, you know, of never wanting anyone to see these things, you know. Em, obviously, when you start dating, you know. Probably at that time it didn't seem such a huge issue, because you know, I felt…I wasn't…dead off normal, you know. But you know I, I couldn't, maybe, you know… Obviously I walked with a limp. It was a, an ex-boyfriend just used to say 'Oh, it's just a gallus gait.' [laughs]*

Given how self-conscious she had been made to feel about her walk when she was at school, I could sense even now the feeling of relief that came with her ex-boyfriend's empowering comment. As with Mary though, I think we get a sense of what was lost when Maureen's marriage ended, in the way that she describes things afterwards. Whatever eventually went wrong with Maureen's marriage it had clearly given her a period of not feeling self-conscious about her body, something that was lost after her divorce.

> Maureen: *But then, obviously as you got older, and then, when the marriage ended, and you were going back out into that dating field, it definitely got a lot worse. You know. I got a lot more self-conscious about it. I became a lot more, you know, I'd be saying, you know, if I met somebody, I'd say I fell over*

the cat this morning, you know. At least initially, you know, to, you know… I kind of feel there's an element of, even for dating now, you know, of well it's not anybody's business.

But then there's another side of it. Is that being dishonest? You know. You know there's a a kind of, you know, I think probably if I was meeting somebody I would still give the 'fell over the cat' just to cover the initial of having, you know,

Kevin: See if they're going to be worth telling more?

Maureen: *Uh-huh. And then you know. So em so I mean obviously huge impact on your relationships throughout your life, and and probably one of the reasons that, you know, em I mean that's when… When did I split up - thirty-four? And I've not had a proper long long relationship since then, and a lot of it is to do with my back, because I've kind of it, especially now because I'm older, because it's got worse now. I kind of think you know people will look at you as a burden. You're a disabled person. You can't walk this distance, you know. You can't walk up the Munros, or, you know, or, or swim miles, or em, you know. And that's such a negative way to look at yourself but it's the reality, you know, it is, it's how it is.*

As with Mary, we get a sense of what her marriage brought to her from the description of the gap that it has left. Maureen had a sense of acceptance and now that has been taken away, leaving her self-conscious and seeing herself as a burden to any potential new partner. I was also struck by her explanation of her walk by "I

fell over the cat". I recalled doing something similar myself when I went to university, explaining my gait by saying that I'd been in an accident – specifically that I'd cut my foot with a cleaver while working in a slaughterhouse. A somewhat bizarre and transparently false story (though I had indeed worked in a slaughterhouse that summer; it was every bit as horrific as you imagine) but one that probably successfully communicated that I didn't want to talk about it. Why not just tell the truth? Because I was ashamed of it and afraid of being judged for it – afraid of a repeat of the same reaction as at school. This is a phenomenon described by Goffman (1990/1963) in his work on Stigma. Goffman describes the phenomenon of stigmatised individuals 'passing' as "normal", by attempting to control information about themselves. In one pertinent example: "… while a lame boy may seem always to present himself as such, strangers can momentarily assume that he has been in a temporarily incapacitating accident." (Goffman 1990/1963, 94). He points out the increased significance of 'passing' when it involves people with whom we might have an ongoing relationship and who will eventually discover the truth: "…he who passes can find himself called to a showdown by persons who have learned of his secret and are about to confront him with his having been false." (Goffman 1990/1963, 84). Similarly, Nario-Redmond *et al*. (2013, 471) note that "…passing or intentionally concealing a non-visible disability, with the acceptance of disability stigma that this strategy implies, has been associated with fear of being "found out", reduced well-being and anxiety." There is a price to be paid for 'passing'. The fear of self-disclosure is something that would come up again in the interviews.

Ailsa told a similar story to that of James.

Ailsa: *I didn't think I'd ever meet anybody. But I did meet [husband] at school – at school! - at work*

Kevin: Did it make a big difference to you, meeting your husband?

Ailsa: *Yeah, I feel like I got out my mum and dad's clutches…They would want to know what you were doing with money and jobs, and then meeting my husband was like 'oh she's going to have to go away and live her own life now'. And so yeah, I think that did make a difference. Yeah.*

I had been thinking about meeting Elaine and the feelings about myself that I was forced to confront. There was something here that crystallised for me in my discussion with Ailsa.

Kevin: And do you remember telling them that you had spina bifida?

Ailsa: *yeah, I remember. And that was quite a thing. I built myself up to that for a couple of weeks before I told him because I thought oh how do we … because any boyfriend you had, how did you tell him that you've got great big scar on your back, you know. Yeah, that's but he was like, he was like "And?" He didn't bother.*

Kevin: That was exactly like my wife. I built up to tell her, I said look I've got this thing to tell you about me. She just laughed. She said "I thought you were going to tell me you were a criminal!"

Ailsa: *I know! You build it up into this huge thing… Yeah, that was fine. He's fine about it... It's a massive thing isn't it to tell somebody?*

Kevin: I was kind of ashamed of it.

Ailsa: *Yeah, yeah, it's totally ashamed. I'd go with that, and and no need to be. But*.

Kevin: I mean you, you, you can't be ashamed of what you are. You know it's just corrosive.

Ailsa: *Yeah, it's just how you are and once you get over that it's fine. Although I must admit, where I work now … My, my line manager there doesn't know, the girls at work I might have said I've got spina bifida but they don't know much about it. I've only been there seven years, but still… I'm not quite close enough to any of you to let you in there. So I suppose I am still a little bit ashamed of it, which is stupid.*

Kevin: Because I'm actually doing a project on it, I've got to, I've kind of outed myself. [laughter]

I thought about how that had been, telling Elaine. I had dreaded it, thinking perhaps that all the negative feelings that I had about myself would now also be shared by her. And why would she want to stick around with someone she felt so negatively about? I had actually ended a previous relationship rather than self-disclose, so strong was my anxiety around it. I remember being dumfounded that Elaine was so bemused by it when I told her. It was a real turning point for me – 'Hold on, maybe this spina bifida thing isn't as big a deal as I've made it inside my head'. That was a moment when I felt a weight lifted, of possibilities opening up.

The experience of self-disclosure described above is in broad agreement with the research of Heller *et al*. (2016). This looked at the experience of young people revealing their spina bifida to prospective partners. They found that their research participants were reluctant to do so out of a fear of rejection. However, when they did so, it could lead to increased self-confidence and increased confidence in the relationship. A wider review of young adults with long-term physical health conditions also concluded that “Overall young people felt inhibited, reluctant, or worried about disclosing their condition and sharing personal thoughts/feelings with others and communicating its impacts to their partner.” (Jordan *et al.* 2021).

At some point, a relationship requires openness – it is a big step. In a sense, falling in love is always a leap of faith. We let go of the flying trapeze and hope that the other person will catch us safely. Low self-esteem makes it more difficult to let go the trapeze.

Lim and Yi (2021) show the power of a qualitative approach in furthering the understanding of this lived experience. In a thoughtful paper, they set out to understand the lived experience of adults with spina bifida, interviewing 16 South Korean adults, aged 21-45. They describe the complex interaction between the urge for self-protection and the need for self-disclosure in the lives of their research participants. They note that self-concealment is a psychological burden, describing a journey in self-awareness where “they realised that it was wise for them to live with their SB like a friend, a lifelong companion…” (2021, 71). They conclude by noting that their research participants achieved a balance between self-concealment and

self-disclosure : “the participants showed psychological maturity and could coexist with others, armed with self-defence strategies based on appropriate levels of self-disclosure.” (2021, 73).

Heller *et al.* (2016) is also one of the few publications that actually features the lived experience of adults with spina bifida. Despite that, it says relatively little on relationships other than in a sexual context. In this, it is typical of the sizeable literature on relationships of adults with spina bifida that concentrates almost entirely on sex and sexuality (see for example Verhoef *et al.* 2005, Arke *et al*. 2015, Lee *et al*. 2015, Hensel *et al*. 2022) This leads in some cases to the medicalisation of sex – it becomes simply one of a number of symptoms associated with spina bifida that require professional intervention (Webb 2010, Patel *et al*. 2019). It is possible that this concentration on sex is partly due to the fact that it is quantifiable in a way that love is not.

Sex is certainly an important part of life and of relationships. Shared pleasure and shared intimacy are life-enhancing, bringing joy, as well as improved self-esteem and self-confidence. It is a subject that deserves attention. However, there is a reason that this chapter is not titled *The transformative power of sex*. Sex is simply not transformative in the way that love is.

In my case, the reality of being loved by another, despite all the experiences that made me wary of rejection, despite years of having been made to feel *less*, despite

all the things about myself that I found shameful and the self-loathing that accompanied that – and for that love to come from someone that I in turn loved above all others – that was truly transformative. I speak of my own experience here however I believe it was also true of the research participants discussed above. It is also true of one of the rare accounts of love and spina bifida in the literature. Singh and Chopra (2021) give an account of the life story of Ashima, a young woman from Dehli, India. Her account of childhood othering is similar to that of myself and many of the research participants. However, when she met the person who became her husband, described as a 'turning point' in her life, he "…made her believe that she could also be loved." In Ashima's own words: "…when I met Rohit, the kind of confidence he gave, I thought let's give it a chance and it was the best decision. It made me strong and when you have a partner who is psychologically supporting so that matters … and I have one such." (2021, 91)

To be loved in that way – and to love in return – affects every single facet of life. It means never being fully alone again. The things about my body that I thought were unacceptable, turned out to be acceptable to the one I loved and therefore, eventually, to me too. I learned to love myself.

It would be wrong to say – and I'm sure this is true of the research participants too – that life became wonderful overnight. However, there is something marvellous at work here. Years – two decades in my case – of bullying, of rejection, of being made to feel less, of shame, had built a shell around me. A shell that was broken by love and that allowed me to grow and to become myself. To be accepted as yourself, and

not what others say you are, is a remarkable gift to be given. Truly, love is stronger than hate.

That leads me to the question of what place this has in a therapeutic settling. I have a number of spina bifida clients, particularly men, who describe a life of isolation and loneliness. They long for a relationship but are crushed by low self-esteem. In them, I cannot help but see the person I could have been, had my life taken a different turn. What hope for them of the transformative power of love?

There is a sense, of course, in which the therapeutic relationship is one in which the client experiences a kind of unconditional love. In the person-centred tradition, unconditional positive regard could be said to fulfil that role, to a certain extent (Rogers 1990/1959). This idea is developed further by Keys (2017). While working in a university environment, Keys (2017, 34) nevertheless describes her clients attitude to love in a way that I immediately recognised from my own work with spina bifida clients: ” … people who come to us in distress because they feel unlovable or they realise they have never been loved, and who also yearn to know themselves as capable of loving.” Keys goes on to argue that the love offered (and received) in the counselling relationship is a crucial part of the therapeutical process for such clients. In a discussion of different types of love, Keys identifies the Judeo-Christian concept of ‘agape’ or selfless love to be equivalent to the person-centred counselling concept of unconditional positive regard (Mearns and Thorne 2013b). However, she identifies 3 other types of love as also being important – ‘storge’ or parental love, associated with contact and being perceived, ‘philia’ or friendly love, associated with empathy

(Mearns and Thorne 2013a) and ‘eros’ or desire, associated with congruence (Mearns and Thorne 2013c). Thus, Keys argues that the different types of love are associated with the different essential parts of the person-centred counselling relationship.

Other schools of counselling thought recognise the importance of love in the therapeutic relationship. The issue of love in counselling has been the subject of long debate in the psychodynamic school of thought. Bodeheimer (2011) reviewed the historical perception of the role of love in psychotherapy. Again, the lack of love in the lives of clients is recognised “… many of our clients have gone most of their lives deprived of love.” (2011, 40). Bodenheimer argues that the disagreement between Freud and Ferenczi over whether therapists should feel love for clients, is one that has cast a long shadow over psychodynamic therapy but that the positive role of such feelings is beginning to be recognised and discussed. Fromm (1958) described the disagreement between Freud and Ferenczi as a personal one, but one which had its roots in Freud’s attitude to love. He quotes him as follows: “Why should I love my neighbour? He doesn’t deserve it. I love my family; that is fine. But to love my neighbour is just plain nonsense. It is against human nature and it is utterly irrational.” We might deduce from this that Freud saw no role for agape in therapy. However, the debate continued. Shaw (2003, 253) recognised the safeguarding element in Freud’s stance but argued that it had gone too far: “…suspicions against tenderness in our work have gone beyond their proper safeguarding function and have led instead to the inhibition of the growth and development of our thinking about analytic love.”

Writing from the psychodynamic perspective, Gerrard (1996, 163) echoes Keys' view on clients: "… most patients who present for analysis or psychotherapy feel themselves quite unlovable at some very deep level." Going onto to argue that "until and unless there can be felt moments of love for the patient by the therapist, the patient is not able to develop fully. I think it is only when a patient can arouse our deepest loving feelings (not empathy) that we can really hope for a truly positive outcome from our work." Gerrard concludes that while love is not itself enough, therapy will not be effective without it.

Glucksman (2010) poses the question "Is love curative?" in the context of the psychodynamic approach, with a review of thinking from Freud onwards, beginning with a quote from Freud "Essentially, one might say, the cure is effected by love" (2010, 159). However, Glucksman argues that Freud saw this in terms of transferential love – the feelings of the client for the therapist and was suspicious of the counter-transferential feelings of the therapist. Later thinkers argued that counter-transferential feelings were an important part of the therapeutic relationship, indeed that "the analyst's dedication to the growth and safety of the analysand is itself an act of love and respect" (2010, 164). Glucksman argues that the therapeutic relationship is a kind of boundaried friendship and that "The caring, respectful, loving elements of this friendship are thought to facilitate the patient's growth and change" (2010, 165). Interestingly, and bringing us back to Keys, Glucksman argues that 'agape' is a good description of the curative love in therapy. He concludes that the therapeutic relationship "… serves as a laboratory for the patient to experience and

communicate mature love, which if not curative, promotes the capacity for intimacy and love in other relationships" (2010, 176). While Glucksman's lens of transferential relationships may not be one that a person-centred counsellor would bring to bear, the perception of the client would, arguably be the same.

Sleeth (2013) also argues for the importance of love in the recovery of clients from traumatic experiences. This contribution resonated strongly with me because many spina bifida clients experienced their childhoods as traumatic. Sleeth argues that there is a cycle of love, beginning with awareness – if someone believes they are loved, they will feel loveable; if not they may conclude that they are not loveable. In an insightful passage that reminded me of many counselling clients, Sleeth says of this feeling of being unloveable (2013, 17): "You might even give up any hope of being loved and opt for self-coping strategies such as indulgence, exploitation or indifference to others, never mind how self-defeating this might be for any prospects of being loved." I immediately recognised this as a description of a hole that many people dig themselves into. Indeed, I recognised it as a situation that I could have ended up in myself, had my life taken a different direction, had I not felt loved. The therapeutic relationship is one that can help break that self-destructive cycle.

Summary of Theme 3

While I am in agreement with the arguments above that love is an important part of how counselling works, the therapeutic relationship is not in itself a basis for living. It is an important relationship but not the one that clients need. In cases of such clients, I think the most important task of the therapeutic relationship, is to help the

client love themselves, to realise that they are both deserving of love and love-able. In doing so, other things fall into place that make a relationship more likely. If they are not as self-conscious about their bodies, this will be more likely to become true of anyone they speak to.

This is not, however, short-term work. For some, it is a long, slow process of peeling away layers of rejection and of becoming what they recognise as their authentic self. In the case of my spina bifida clients – and I think this may be true of others with a life-long disability – there have often been decades of othering, of stigma, of being made to feel *less*. All against a background of the societal belief described earlier, that it would be better if people with spina bifida did not live. To get to a point where people see themselves as loved and loveable, takes a long time. Keys (2006) describes the progress made with a client with cerebral palsy over three years – a therapeutic relationship that only ended when the client left the educational establishment where Keys was employed. This long-term nature of the work has implications for organisations like SBH Scotland, which provides a counselling service to the spina bifida community. Resources are limited – is it better to concentrate them on a few long-term clients, or to limit the number of counselling sessions provided to ensure wider access to the service? This is a difficult question, however given that the need for long-term work is established, it could perhaps be reframed as ‘Is it better to help some people or none at all?’.

Chapter 6: A story about what this research has contributed

Introduction

The preceding chapters have presented the three intertwined strands that make up this research: the historical investigation, the interviews with research participants and my personal story. Returning to my research question – **What are the childhood narratives of adults with spina bifida? -** I discuss in this chapter how the exploration of the narratives described in this thesis has improved our understanding of the lived experience of adults with spina bifida. I then go on to consider the implications of this for counselling practice, for those counsellors and psychotherapists serving the spina bifida community.

The impact of state-sponsored stigma

To a far greater degree than I had anticipated, the lives of people born with spina bifida in the 1960s and beyond were affected by stigma – stigma that derived from the medical establishment and the state. As Chapter 4 makes clear, for the first decades of the lives of the 1960s cohort, babies born with spina bifida were treated as less than human, even to the extent of their lives being ended with impunity. This overlapped with the establishment of a state scheme for the detection of spina bifida during pregnancy, with the assumption of termination of such pregnancies. This adds an essential context to our narratives. Spina bifida was not just a “spoilt identity” but a potentially fatal one. Those of us born with spina bifida may not have been consciously aware of this stigmatisation, however we will still have felt the

effects. It was, in a sense, the very air that we breathed; spina bifida was such an undesirable thing that it would be better if we did not exist.

The interviews with the research participants highlighted the impact of stigmatisation on their lived experience. For the 1960s research participants (and myself), this manifested itself in our narratives around school experiences. Those narratives were of being made to feel different and also *less*. The effects lasted beyond our school years, into adulthood. It is striking how fresh the recollections are, not just of what happened but of how it made the research participants feel, even decades later.

The other manifestation of the effects of stigma that I identified from the interviews was around parental communication. Parental reluctance to talk about spina bifida, to instead pretend that there wasn't a problem, perhaps reflected their own experience of being stigmatised for having brought a child into the world with a condition so disapproved of by society. It could be argued that this, in turn, compounded the effect of stigma on the 1960s research participants, reinforcing the impression that spina bifida was shameful and therefore not to be spoken of.

As described under the *Things have got better* theme, society's attitudes to disability have changed. It is encouraging to see the improvements in the experiences of the 1990s research participants, compared with those of the 1960s. It seems that those positive changes took place alongside the growth in influence of the social model of disability and the reduction in the power of hospital consultants to decide who was

worthy of life (though see section below on unfinished business). It feels safe to conclude that, in many ways, the world is a kinder place for people born with spina bifida in the 1990s, than it was for those born in the 1960s. However, while one source of stigma has receded, another has taken its place, in the form of the treatment of those applying for disability benefits, as revealed by the comments around PIP.

It appears that our government has constructed a process for the assessment of disability benefits that is itself damaging to mental health – something that has a general relevance outside of spina bifida, of course. Scambler (2018) has characterised this as the weaponisation of stigma, in the service of government policy. It seems that as one source of state-sponsored stigma has been dealt with, another has taken its place, rather like the fairground 'whack-a-mole' game.

Relevance to counselling practice

The research reported here indicates issues that counsellors should be aware of as potentially relevant to their clients with spina bifida, in particular the effects of stigmatisation. The early experiences discussed by the research participants have a long reach. I think that there is a sense in which the opportunity to talk about these things during the research interviews had a therapeutic value for the participants. The possibility of the need to explore such experiences is one that counsellors for this community should be aware of. I certainly took the opportunity to discuss the memories that arose for me with my own counsellor. Counsellors and psychotherapists should also be aware that the shame and silence around spina

bifida means that parent/child relationships could be an issue, whether their clients are people with spina bifida or their parents. Both have had experiences that might benefit from being dealt with in therapy. I have certainly become more aware of what my own parents went through and what a traumatic experience it was for them.

The research has also illustrated the importance of love and its capacity to transform lives. Having seen this in the research participants, I now see it in my clients. However, while the interviews with research participants show the difference made by love's presence, in many of my clients, I see the effect of its absence. For some people, the internalising of stigma as shame has resulted in feelings of being unloved and unlovable, leading to social isolation and loneliness. For older counselling clients, unpeeling the effect of decades of being made to feel like this, is not short-term work. It is a slow process to help them to first begin to love themselves and their bodies, and to help them build the self-esteem they need to develop the relationships they long for. There is a sense in which the therapeutic relationship itself is an opportunity for such clients to experience love in the form of unconditional positive regard (Rogers 1990). The effect of this is something I will continue to observe and reflect upon. The relative absence of love in the academic literature, despite its importance, is perhaps an indication of the inability of the predominant quantitative approach to capture lived experience; love can only be lived, not measured on a scale.

The research also revealed a potentially useful tool for counsellors. The "emergency baptism" narrative held by the 1960s research participants came as something of a

surprise to me. I was aware of it as part of my own story, however I had not considered that it might have been a more general experience or what its impact might have been. I suspect that this story will have been a shared experience for many of the spina bifida community born in the 1960s – but not for those born afterwards, due to both improvements in mortality and the decline in religious belief. It is perhaps an unusual thing to have as part of a personal narrative, however I think that, overall, it has had a positive effect on those who tell it. Many of the research participants spoke of a determination, a belief that they could overcome obstacles and related this to their origin story. I also think the subversive nature of the story is important – the subtle undermining of the medical model; "the doctors were *wrong*".

This prevalent origin story is something that those providing counselling and psychotherapy services to this community should be aware of. Both for their understanding of the lived experiences of their clients and for the opportunities to use it in positive framing. It is a narrative that people have used as a resource, a contributor to resilience – and those who do not use it in this way might perhaps benefit from being enabled to do so.

Selection is still unfinished business

The differences between the experiences of the two cohorts illustrates the importance of societal change. There is a sense in which those changes relating to the policy of selection are still unfinished business. Some four decades on, it is perhaps not surprising that selection is not widely known about today. In my experience, even medical professionals are unaware; it is not how things are done

today. Should it then be left in the past and forgotten? I am of the view that it should not because there are lessons to be learned from it. I am also mindful of those babies born with spina bifida who were selected for death; the empty spaces alongside me. I believe there must be a reckoning, one that would help lift any sense of stigma perhaps still felt by those who grew up in that era (and their parents).

There should be an acknowledgement that selection happened, that it was unacceptable and that nothing like it should happen again. Unfortunately, I do not think that those things currently apply. That there has been no reckoning with what Lorber did, may be judged from the fact that The Royal College of Paediatrics and Child Health ("Leading the way in children's health") confers a biannual Lorber Award, in his memory. I wrote to the RCPCH asking whether, given what he had done to babies with spina bifida, it was appropriate for them to continue to confer an award in Lorber's name. At the time of writing, I have been assured that this will receive a thorough review "at the highest levels", followed by a decision by their executive committee, of which I will be informed. That decision will tell us something about the current attitude of medical professionals to people with disabilities. If the decision is that Lorber's work remains deserving of being honoured by the RCPCH, then clearly there will be work to be done in challenging that view.

A personal journey

The reflexive nature of the research reported here has meant that it has been a personal journey. Prior to starting my research, I had not fully appreciated the extent to which there is a spina bifida community. There are, relatively speaking, a lot of us.

Nearly 6,000 babies were born with spina bifida in Europe, between 1991 and 2011 (Oakeshott *et al*. 2019, 1202) and spina bifida is therefore a model for other conditions. At the present time, for example, the issues surrounding a significant older population are emerging. The improvements in mortality seen in the early 60s have now resulted in a growing population of people living with spina bifida in their 60s. Given the drop in incidence over the decades after 1970, spina bifida will eventually be a condition predominantly associated with older people – in the UK, many more people with spina bifida will celebrate their 60th birthdays this year, than will be born with the condition. At the time of writing, I chair the Working Group on Ageing of the International Federation for Spina Bifida and Hydrocephalus. So there is a sense in which, through this research, I have become part of the international spina bifida community and that represents a significant change in my own story. As noted in the literature review, one antidote to shame and its effects on mental health is to have a more positive concept of disability and disabled identity. Being a part of a community of others with the same condition can be an important part of that and certainly has been the case for me. I have found my tribe.

Limitations and future work

An obvious limitation of the research described here is that it relates to a relatively small group of people from a limited geographic and cultural area. It is therefore reasonable to ask whether the same findings would apply to people born in other parts of the UK, let alone other parts of the world. It would be interesting to see whether the “hospital baptism” narrative had any analogous expression in non-Christian cultures, for example. I hope that the research will be added to by further

investigations of the lived experience of the ageing spina bifida community in other parts of the world.

Another limitation is that in interviewing people born with spina bifida, I have elicited a different set of narratives than those which would have come from their parents. It would be interesting to capture parental experiences in the same way, particularly as we might expect them to have been more aware of societal attitudes to spina bifida.

The work reported in this thesis is part of an emerging picture. Further work on the lived experience of the aging spina bifida is required in order to improve the clarity of that picture. It is also worth noting that it is a picture that will change, as that population continues to age.

"And in the end…"

Lastly, one effect of my discussion of the importance of love is that I have emerged with a renewed appreciation of the part that my wife Elaine played in my life. Elaine died in 2014 and my decision to become a counsellor happened after that, perhaps as a result of that loss. Just as my life was transformed by meeting Elaine, it was also transformed by the loss of her. In a sense, she has inspired my work as a counsellor and as a researcher. And not the least of her gifts to me was that I would know love again, when I found it. My life has, once again, been changed by the transformative power of love.

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Appendices

Appendix 1 Participant Information Sheet

How do childhood experiences influence the narratives of adults with spina bifida?

Participant Information Sheet

Introduction

You are invited to take part in a research study that explores how childhood experiences might affect adults with Spina Bifida. The purpose of this is to improve our understanding of life with spina bifida. To help you decide whether to take part in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact me if there is anything that is not clear, or if you would like more information.

Background

My name is Kevin O'Donnell and my interest in spina bifida arises because I too was born with it, in 1962. A few years ago, during my counsellor training, I had surgery to de-tether my spinal cord. This prompted me to think about the surgery I had soon after birth, my childhood experience of being "different" and how this influenced my adult life. This is my 'story' and such stories form a narrative that both reflect and influence my lived experience. We all have a narrative like that – and I am interested in hearing those of others. Once I have gathered these stories, I will analyse them to look for patterns that might help improve our understanding of how adults with Spina Bifida experience life.

One of the stories we all tell is our "origin story". This is a story that we have been told by family members. For example, my "origin story" is that I was diagnosed with spina bifida immediately after I was born. My parents had never heard of it before. They were warned that I might not survive surgery and if I did, I might not walk or might have a mental disability. This is a story that I heard many times in similar forms when I was growing up. You may see different elements in it – shock and anxiety, luck, perhaps determination. It's a story that I absorbed and included in my life narrative. What effects might that have had?

I share this personal story to give you an idea of what the research is about and to demonstrate how I will go about conducting it. My intimate knowledge of the subject means I cannot be a detached, objective observer. Instead, I want to be transparent about my own involvement, in a way that allows co-creation of the research material with participants.

Who is invited to take part?

I am looking for 12 participants, 6 born in the 1960s (or before) and 6 born in the 1990s. In order to take part you need to: 1) have been born with spina bifida 2) be resident in the UK 3) speak English 4) Have online access of sufficient quality to allow Zoom sessions.

As far as possible, there will be a balance in terms of gender and mobility in each group, so not everyone who is interested may be able to participate.

Recruitment will be left open until all the places are filled.

Do I have to take part?

No. This is simply an invitation for those that are interested in doing so. If you do decide to take part, you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect you in any way.

What will happen if I take part?

If you are interested in taking part, we will have an initial discussion so that you can decide whether it is something you would like to do. If you decide that you would like to continue, I will send you a consent form that you can complete and return to me by email.

Participants will be asked to take part in a one hour interview with me. This will take place online via the Zoom video conferencing platform and will be arranged at a time and date to suit those taking part.

The online interview will deal with early life (including “origin story”), childhood and adulthood.

There is the possibility for a further interview, if we both think it would be useful. There is no obligation to take part in the further interview if you do not want to.

The interviews will be semi-structured in that there will be some common questions but the path for each one will be determined by what you choose to talk about. Participants will be encouraged to bring objects (photos, toys etc.) of particular significance to them and to talk about them.

The research will involve two sets of people with spina bifida, those of around my own age, born in the 1960s (or before), and those from a younger generation, born in the 1990s. The reason for this is that there may be some differences in the experience of the two groups. For example, the availability of prenatal testing and a more enlightened approach to the treatment of babies in hospital.

With your consent, the interview will be recorded and transcribed into text, though your name will be replaced with a pseudonym. A transcription of your own interviews will be made available to you if you would like to have it.

I will then analyse the different transcripts, looking for common themes and patterns. You can opt to be sent a summary of the findings and any copies of publications that arise from the research.

What are the possible benefits of taking part?

Some people find a benefit in the opportunity to talk about their experiences. More generally, you will be contributing to a project that might improve the understanding of living with spina bifida.

What are the possible disadvantages of taking part?

There is a risk that participation in the interviews may cause distress, for example by bringing back unwanted memories. You should therefore consider carefully whether you want to take part. It is also important to bear in mind that you are under no obligation to complete the interviews and are

free to stop the interview at any time, if you choose to do so. If do feel distressed, speak to a family member or friend, or one of the support services listed in the information that will be supplied at the end of the interview.

Will my taking part be kept confidential?

All the information collected during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

How will we use information about you?

We will need to collect the following personal identifiable information from you for this research project:

- Your name,
- Your contact details
- Your date of birth
- Your gender
- Health information eg whether you use a wheelchair

This identifiable data will be stored for 5 years after the study has finished. For routine use,

any information that contains your name and personal identifiers will be removed so that you cannot be identified. All information will be coded and de-identified. The information we have collected in paper copies will be stored at:

Counselling, Psychotherapy and Applied Social Sciences,
School of Health in Social Science

University of Edinburgh

Doorway 6,

Medical School at Teviot Place,

Edinburgh, EH8 9AG

under lock and key cabinet, while the electronic data will be stored in a secured computer which can only be accessed with a secure password. Only the researcher will have access to the data.

The interview recordings will be transcribed by the Researcher and given a unique code to de-identify them. If any unwanted personal information is revealed accidentally during the interviews, it will be removed from the transcripts to maintain your confidentiality. Once transcribed, the recordings will be deleted.

De-identified data may be deposited to the University of Edinburgh School of Health in Social Science repository for a minimum of 5 years for knowledge sharing, future research and future learning, but none of your personal identifiable information will be stored there.

The results of this study will be published in a peer-reviewed journal and shared with other researchers but you will not be identified in any publication or presentation of results.

If you have any concerns about how we will use your information, please contact:

- The University of Edinburgh Data Protection Officer: dpo@ed.ac.uk
- Contact the researcher, Kevin O'Donnell: s1682944@sms.ed.ac.uk

What will happen to the results of the study?

The study will be used to improve the understanding of spina bifida. This will be done through publications, including a doctoral thesis, and presentations. You will not be identifiable in any of these publications.

Who has reviewed the study?

The study proposal has been reviewed by the HiSS research ethics committee and has received its approval**.**

Who is organising and funding the research?

The research is being carried out as part of my Professional Doctorate in Counselling and Psychotherapy degree, at the University of Edinburgh. The University of Edinburgh is the sponsor for this study.

Researcher Contact Details

If you would like to take part in this research, or would like more information, please contact

Kevin O'Donnell,

Researcher, Counselling and Psychotherapy

School of Health in Social Science, University of Edinburgh

E-mail: s1682944@sms.ed.ac.uk

Telephone:

If you have questions about your rights in this research, or you have any other questions, concerns, suggestions, that you do not feel can be addressed by the researcher, please contact: Professor Heather Wilkinson
e-mail:

If you would like to discuss this study with someone independent of the study please contact the Convener of the Counselling, Psychotherapy and Applied Social Science Research Ethics committee: CPASS.ethics@ed.ac.uk

If you wish to make a complaint about the study, please contact:

the Research Governance Team at cahss.res.ethics@ed.ac.uk

Data Protection
For general information about how we use your data please go to:
https://www.ed.ac.uk/records-management/privacy-notice-research

Alternatively, please contact the University of Edinburgh Data Protection Officer:
dpo@ed.ac.uk

Appendix 2 Sponsorship Agreement

University of
Edinburgh College of Arts,
Humanities and Social Sciences
Research Governance Office

55 George Square

Edinburgh EH8 9JU

29th July 2021

Kevin O'Donnell
c/o Health in Social Science
University of Edinburgh

Dear Kevin

Study Title: How do childhood experiences influence the narratives and lived experience of adults with spina bifida?

Sponsor number: CAHSS2103/08

Under the requirements of the UK policy framework for health and social care research, the University of Edinburgh agrees in principle to act as Sponsor for this project. Sponsorship is subject to you obtaining institutional ethics for the project.

As Chief Investigator, you must ensure that the study does not commence until all applicable approvals have been obtained. Following receipt of all relevant approvals, you should ensure that any amendments to the project are notified to the Sponsor.

Yours sincerely

Charlotte Smith

Research Governance Manager

Appendix 3 Participant Consent Form

PARTICIPANT CONSENT FORM

Study Title: How do childhood experiences influence the narratives and lived experience of adults with spina bifida?

Researcher name and contact details:

Kevin O'Donnell,

Researcher, Counselling and Psychotherapy

School of Health in Social Science, University of Edinburgh

E-mail: s1682944@sms.ed.ac.uk

Telephone:

Participant ID:

Please initial box

1. I confirm that I have read and understood the Participant Information Sheet (Version 2.4, 13APR2021) for the above study. ☐

2. I have been given the opportunity to consider the information provided, ask questions and have had these questions answered to my satisfaction. ☐

3. I understand that my participation is voluntary and that I can ask to withdraw from the interview at any time without giving a reason and without my medical care or legal rights being affected. ☐

4. I understand that I will not be personally named in connection with the data I create or in any report, or anything to do with the research and that anything I contribute will be treated in confidence unless I give express consent for this to be otherwise. ☐

5. I understand that my anonymised data may be stored in a research repository for a minimum of 5 years and may be used in future ethically approved research. ☐

6. I agree to my interview being recorded, for the purpose of preparing a transcript for analysis. ☐

7. I understand that relevant sections of my data collected during the study may be looked at by individuals from the Sponsor (University of Edinburgh), where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data ☐

8. I agree to take part in the above study. ☐

Name of person giving consent	Date	Signature
_____	_____	_____

Name of person taking consent	Date	Signature
_____	_____	_____

Appendix 4 Schedule of interviews

Date/Time	Code	Pseudonym	Consent received Y/N?	Interview took place Y/N?
21/10/21, 10:30	KODRP001	Michael	Y	Y
11/11/21, 15:00	KODRP003	James	Y	Y
18/11, 15:00	KODRP002	Joan	Y	Y
31/3/22, 11:00	KODRP004	n/a	Y	N
19/5/22, 13:00	KODRP005	Eileen	Y	Y
20/5/22, 14:00	KODRP006	Mary	Y	Y
7/10/22, 13:30	KODRP007	Maureen	Y	Y
28/10/22, 13:30	KODRP008	Ailsa	Y	Y

Appendix 5 Words used as emotional touchpoints

Positive words	Negative words
Fortunate	Angry
Relieved	Anxious
Supported	Misunderstood
Calm	Scared
Respected	Frustrated
Hopeful	Let Down
Pleased	Lonely
Strong	Ashamed
Happy	Confused
Thankful	Awkward
Encouraged	Awful
Trusted	Sad
Heard	Unsupported
Included	Worried
Safe	Powerless
Valued	Vulnerable

Appendix 6 Contribution of nodes to themes

Node	Number of coded texts	Theme contributed to
Accessibility	30	1, 2
Achievements	23	1, 2
Ageing decline	41	2
Attitude to disability	33	1, 2
Attitude to hospitals, medics	26	2
Beating the odds	5	1
Benefits	19	2
Bullying	23	2
Childhood stories from parents	15	1, 2
Children	21	2
Choice of school	11	2
Continence	2	2
Describing body	13	2
Determination	55	1, 2, 3

Employment	44	1, 2, 3
Feeling different	39	1, 2, 3
Friends	16	2
Further education	15	2
Hospital baptism	8	1
How spina bifida discussed with participant	33	1, 2
Impact on adulthood	24	1,2,3
Introductory object	15	1,2
Isolation	2	2
Medical model	5	2
Mental health	12	2, 3
Missing school time	11	2
Mobility	36	2, 3
Negative emotional touchpoints	23	1, 2
Neuropathy	7	2
Other people’s attitudes to disability	46	1, 2, 3

Pain	20	2
Parental origin	3	1
Parental reaction to spina bifida diagnosis	13	1, 2
Partner	4	3
PE	15	2
Perinatal surgery	10	1
Positive emotional touchpoints	30	1, 2, 3
Prognosis at birth	28	1, 2
Relationships	28	3
School experiences	74	2
Siblings	20	2
Social contribution	24	1, 2
Social model	3	2
Surgery/hospital	15	2
Transition	3	2