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Quality of life in older people with mental health difficulties

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Introduction: The proportion of individuals aged 65 and over is increasing and mental health services need to recognise the resources of these individuals and meet their needs. Quality of life is a widely used outcome variable in mental health policy and clinical research. Subjective factors are consistently found to be more significant than objective factors in determining quality of life. This gives clinicians areas to consider when working to improve an individual's quality of life. The current research looks at the relationship between successful psychosocial development and quality of life in older people with mental health difficulties. A secondary aim is to consider the impact of chronic mental health difficulties on quality of life. **Method:** Twenty-four older people (mean age 72) who were living in the community and supported by Community Mental Health Teams opted in to the study. Questionnaires, which included the WHOQOL-Old and MEPSI, were administered by the researcher. **Results:** Strong and significant correlations were found between quality of life and successful psychosocial development. A regression analysis found that successful resolution of the final stage of psychosocial development was the most significant predictor of quality of life over other psychological and demographic variables. No impact of chronicity was found. **Discussion:** The results of the study suggest that psychosocial development is an important factor to consider when working with older people and that a sense of ego-integrity is important to an individual's perception of quality of life.

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**Correlates of quality of life in older people with severe mental
illness: A systematic review**

Prepared in accordance with requirements for submission to Clinical Psychology

Review (see Appendix 1 for guidelines for contributors)

Abstract

The number of people living in to old age with a severe mental health problem is increasing. As individuals age with these difficulties they continue to need support appropriate to their needs to ensure best quality of life. The current review aims to bring together existing research on the correlates of quality of life in older people with a severe mental illness diagnosis. A systematic search of PsycInfo, Embase and Medline for peer reviewed articles identified 13 cross sectional or cohort studies. The most consistently identified significant correlates were the levels of depression and psychiatric symptoms. This may suggest that, while symptoms may decline in older people with a long history of severe mental illness, the current symptomatology still has a significant impact on quality of life. Studies with greater methodological rigour are required in order to provide a stronger evidence base for future research and to guide clinical interventions.

Key words: severe mental illness, quality of life, older people

Highlights

- Severe mental illness in older people is an under researched area
- Psychiatric & depressive symptoms still have a significant impact in the population.
- There is a lack of research considering more ageing specific factors.
- Further research with greater methodological rigour is required.

1. Introduction

Severe mental illness (SMI) is defined in a number of different ways. Some researchers define it in terms of specific diagnoses such as schizophrenia and bipolar disorder, others in terms of any chronic mental health difficulty. For the purpose of this review SMI is defined as schizophrenia and related disorders and bipolar disorder.

1.1. Severe Mental Illness in Older People

There are disagreements as to the prevalence of severe mental illness in older people. The Epidemiological Catchment Area study (Robins & Regier, 1991) suggested that lifetime prevalence of late-life schizophrenia in those over 65 was 0.3 per cent and one year prevalence was 0.2 per cent. This was a large survey of over 8000 individuals who were living in the community in America who were screened for DSM-III-R disorders. More recently there has been a replication of the study; however, this did not include schizophrenia or other non-affective psychoses (Kessler, Chiu, Demler & Walters., 2005). There are a number of reasons why key researchers in the field feel the prevalence rates given in the Epidemiological Catchment Area study are an underestimation. Both individuals and those involved in their care may misattribute psychiatric symptoms to changes associated with “normal” ageing, cognitive impairment or as associated with physical disorders. Therefore, they may not report symptoms to health professionals or researchers which would indicate a diagnosis. Participants may also underreport due to forgetfulness or to avoid perceived social stigma associated with symptoms (Jeste et al., 1999; Palmer, Heaton & Jeste, 1999). In an overview of the research, a group of

specialists in old age psychiatry reported that approximately 2 per cent of individuals over 54 have a SMI other than dementia (Cohen et al., 2000).

Schizophrenia, bipolar disorder and psychosis have a significant impact on the individual and their family. While some individuals have one episode and then make a full recovery, others experience recurrent episodes with reduced functioning in a number of psychosocial domains. As individuals age with these illnesses they continue to require support appropriate to their needs. However, SMI in older people is a much neglected area of research (Cohen et al., 2000; NICE, 2010). As the population ages and individuals with SMI live longer and healthier lives due to improvements in care, the number of older people with SMI is likely to rapidly increase and therefore focused research is needed to ensure services continue to meet their changing needs.

There are potentially important differences between younger and older people who have a diagnosed SMI. There is some research to suggest that psychiatric symptoms, although still present, tend to be less severe and functional decline stabilises in later life (Belitsky & McGlashan, 1993; Jeste et al, 2003). In a large cross sectional study, younger individuals with bipolar disorder reported significantly more symptom days and greater impact on psychosocial functioning than the older population (Calabrese et al., 2003).

However, when considering the outcome of different interventions in individuals with severe mental illness, a focus on positive symptoms such as hallucinations,

delusions and thought disorder, misses many of the dimensions of the impact of the illness (Meltzer, 1999). Therefore a measure of overall impact may provide an outcome measure which is more relevant to the individual.

In a comparative study of older people with severe mental illness in the community to those in nursing homes, Bartels, Mueser and Miles (1997) found that functional impairments and lack of social support were the key differences between the two groups. The prominence of functioning over symptoms suggests that it is important to consider a more general impact on an individual's life rather than symptoms alone when supporting individuals in the community.

1.2. Quality of life in older people with severe mental illness

Even when symptoms have remitted there is still an impact on quality of life found in people with severe mental illness. Younger people with bipolar disorder who were not currently experiencing bipolar symptoms still reported that the disorder impacted upon multiple areas of their life. Their health related quality of life was on a par with, or worse than, that of people with a number of chronic physical health conditions (Dean, Gerner & Gerner, 2004). Therefore, it appears that, even when typically characteristic symptoms are not present, the disorder continues to have a significant impact on the individual. This is partly reflected in mortality rates which remain high in this population (Talaslahti et al., 2012). In a study of mortality in older people with schizophrenia, mortality rates were almost threefold those of older people in the general population and deaths from unnatural causes such as accidents and suicides were more common (Talaslahti et al., 2012).

The World Health Organization defines health as not only the absence of disease and infirmity but also the presence of physical, social and mental well-being (WHO, 1952). As such, quality of life is now commonly used as an outcome measure in health related research (Testa & Simonson, 1996) with some clinical trial organisations introducing the assessment of quality of life as standard in new trials (Fayers & Machin, 2007).

Factors such as health, cognitive ability, social functioning and psychopathology, which are predictors of quality of life, may change with ageing (Cohen et al., 2000).

It has been previously suggested that quality of life in older people might be poorer due to objective factors such as physical health co-morbidity, cognitive impairment and reduced social supports (Mittal et al., 2006). However, research indicates no effect of ageing on life satisfaction or in some cases improved life satisfaction (Herzog & Rodgers, 1981; Diener & Suh, 1998; Brown & Roose, 2011). In a large cross sectional study, Diener and Suh (1998) found an increase in life satisfaction with age in a sample aged from 20 to 80 years. Brown and Roose (2011) found that increased age did not translate to decreased quality of life. When different domains were considered separately this relationship held true for psychological, social and environmental domains but not for the physical domain (Brown & Roose, 2011).

It appears from the literature that ageing itself does not have to be associated with reduced quality of life. However, differences might be found in those individuals

who experience mental health difficulties, particularly those who experience a life long disorder which impacts on a number of areas of functioning. Severe mental illness is associated with impairments in daily living skills, interpersonal relations, and cognitive impairment (Palmer et al., 2002; Siegel et al., 2006). In older people there is also the possibility of a cumulative effect of multiple episodes (Depp et al., 2006), which may have a further negative impact on functioning.

1.3. Measuring Quality of Life

There are questions regarding how best to measure quality of life; the increasing view being that self appraisals are the 'gold standard' (Cohen et al., 2003). The use of subjective measures may have even more importance in the older people population, as quality of life scores do not seem to reflect what might be expected when objective measures are taken into account such as age and number of social contacts (Brown & Roose, 2011). Some authors have suggested that individuals with severe mental illness may have distorted perceptions of quality of life. They often report their quality of life as higher than would be expected on the basis of objective factors such as living conditions (Nilsson & Levander, 1997). Similarly there is a suggestion that older people have lower expectations for quality of life and this is why they report being satisfied. It is thought that the next cohort of older people, the 'baby boomers' will have higher expectations for quality of life in old age (Bowling et al., 2002). However, self appraisals can help to identify the areas that the individual feels are most problematic and this can guide those involved in their care. If the individual does not feel that the factors identified by therapists are important and relevant to them they are less likely to engage in change directed interventions.

1.4. The purpose of the review

A key focus for research, and ultimately intervention, should be towards improving quality of life. While ageing itself is not necessarily associated with a reduction in quality of life, the combination of ageing and factors associated with long term mental health difficulties may have a significant impact on quality of life. For example, the difficulties in interpersonal relations associated with SMI coupled with fewer social contacts as found in the older people population may result in limited social support which has been found to be an important factor in quality of life, whether objectively or subjectively defined.

It is therefore important to specifically consider the factors which determine quality of life in older people with severe mental illness (Cohen et al., 2003).

The following review aims to consider the currently available research on quality of life in older people with severe mental illness and to identify the correlates of quality of life in this population. It aims to answer the question: what factors have been identified in the literature as having a significant impact on quality of life in an older adult population with a history of severe mental illness?

2. Method

2.1 Data sources and search strategy

The literature search was conducted in October 2011 using three databases: Embase (1974 to October 19 2011), PsychINFO (1806 to October week 3 2011) and

MedLine (1948 to October week 2 2011) to identify potentially relevant articles. The electronic search used seven key terms to reflect the population of interest for the review question. The following terms were used in the search:

1. Elderly
2. Older people
3. Older adult
4. Schizophrenia
5. Bipolar
6. Psychosis
7. Severe mental illness
8. 1 and 4 combined using AND
9. 1 and 5 combined using AND
10. 1 and 6 combined using AND
11. 1 and 7 combined using AND
12. 2 and 4 combined using AND
13. 2 and 5 combined using AND
14. 2 and 6 combined using AND
15. 2 and 7 combined using AND
16. 3 and 4 combined using AND
17. 3 and 5 combined using AND
18. 3 and 6 combined using AND
19. 3 and 7 combined using AND

Weekly auto alerts were set up according to the search strategy and these were reviewed to identify any new articles. In addition, two key journals (Schizophrenia Research and International Journal of Geriatric Psychiatry) were hand searched.

2.2 Selection criteria

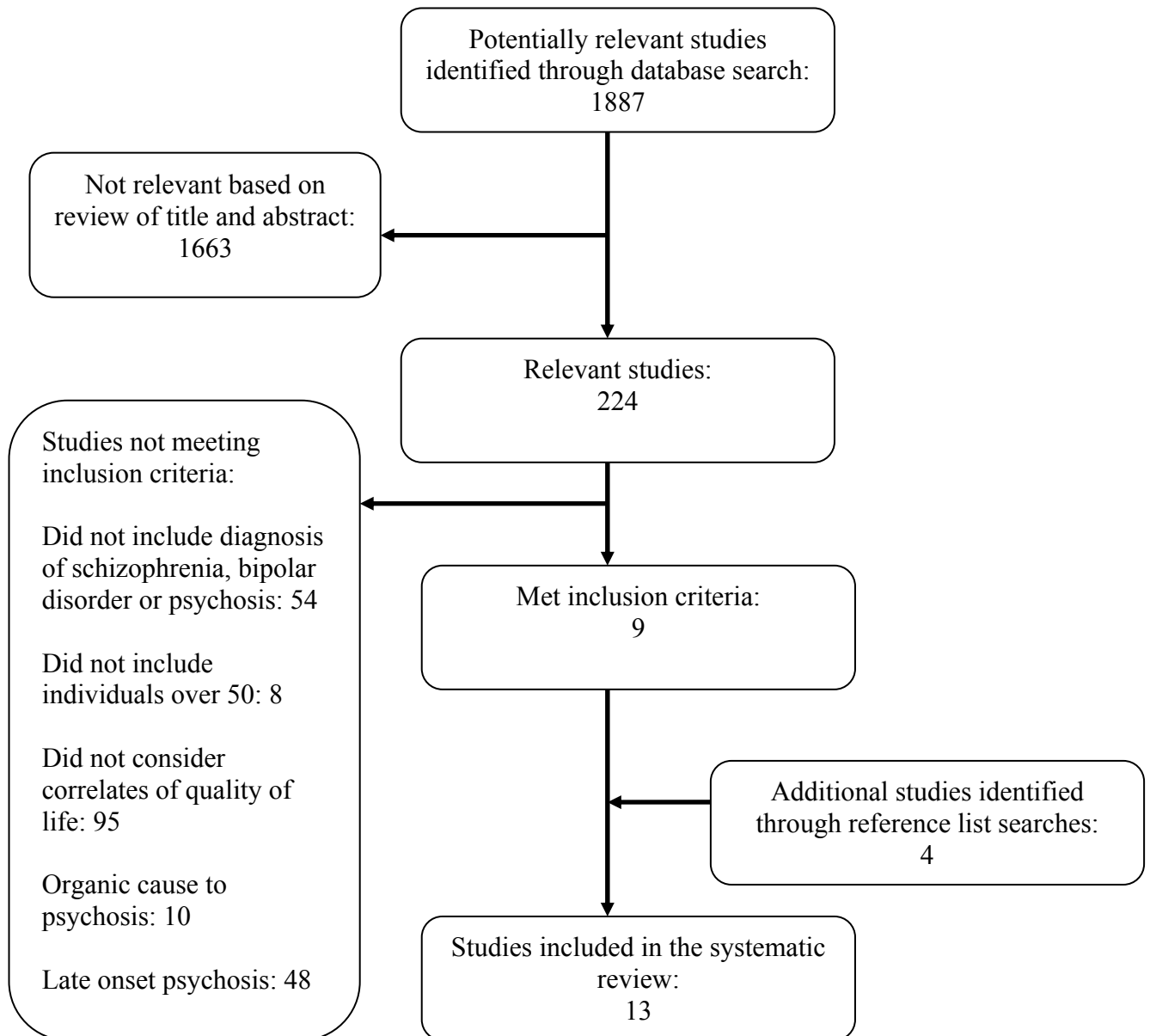
A stepwise approach was used in the selection process. First all citations, titles and abstracts, and reference sources of all primary articles were screened to identify potentially relevant articles which met the following inclusion criteria: (i) original study, (ii) published in a peer reviewed journal, (iii) published in English. Full articles were then screened to meet the further inclusion criteria: (i) diagnosis of schizophrenia, bipolar disorder or psychosis, (ii) sample made up of individuals over the age of 50, (iii) measures correlates of quality of life. In addition there were two exclusion criteria: (i) organic cause to psychosis, (ii) late onset of disorder.

3. Results

3.1. Outcome of search process

After removing duplicate articles, the search strategy yielded 1887 articles of which 1663 met exclusion criteria or were deemed not relevant to the research question on the basis of a review of titles and abstracts. The remaining 224 articles were reviewed in full, where information about the age or diagnoses of the sample or the aetiology and onset of the disorder was unclear. Nine studies met inclusion criteria and a further four articles were identified from reviewing the reference lists of these articles. Figure 1 details the process.

Figure 1. Flowchart detailing search process



3.2 Assessment of methodological quality

The studies included in the review are primarily observational rather than intervention based. In the ‘hierarchy of evidence’ such studies carry little weight in terms of the type of research considered for evidence based practice (SIGN, 2004). The method for assessing quality of the studies focused on appropriateness of design, choice of outcome measure, quality of reporting and generalisability. This reflects the recommendations of the Centre for Reviews and Dissemination (2010). The

rating system used by Scottish Intercollegiate Guidelines Network (SIGN) 'Guideline Developers Handbook' (2004) was used (see Appendix 2).

None of the studies met the 'well covered' rating for refusal rates, with only three of the studies (Cohen et al., 2003; Depla, De Graaf, van Weeghel & Heeren, 2005; Depla, De Graaf & Heeren, 2006) reporting refusal rates at all. In Cohen et al.'s (2003) study the two groups had significantly different refusal rates, 9 per cent in the schizophrenia group and 41 per cent in the community comparison group which might indicate a potential bias to the comparison group selected. Depla et al. (2005) reported on the number of care homes which were approached to take part in the study. Eighteen homes were approached of which only 8 agreed to take part. Depla et al. (2006) reported a refusal rate amongst eligible participants of 28 per cent.

Only one study (Kasckow et al., 2001) had a follow up assessment 6 months later. They were able to collect full data sets for 41 out of 54 of their inpatient sample, the follow up rate for the outpatient group is not given.

A number of the studies had no comparison group (Patterson et al., 1997; Wetherall et al, 2003; Depla et al., 2005; Mittal et al., 2006; Roseman et al., 2008). Only one study (Kasckow et al., 2001) matched the comparison group to the psychosis group on a number of different demographic variables. Cohen, Hassamal and Begum (2011) had comparable groups in terms of age and gender and Depp et al. (2006) matched on age only. A number of the studies had significantly different mean ages in the groups.

In addition, the studies which were completed by one research group, 9 of the studies in total, had very different proportions of men to women in their comparison groups. This is due to an over representation of men in the psychosis groups as they were recruited from a veterans' medical centre. The individuals who took part in these studies may also not be representative of the overall population as they are individuals who were already participating in a large research study.

Despite the fact that a number of the studies did not meet some of the quality criteria, they are still included in this review. Given the lack of research in this field, even though the overall quality is low, these studies need to be considered as part of the literature that exists. Therefore, findings extracted from the review have been interpreted cautiously given the reduced matched control/ comparison groups.

3.3 Data Extraction

Data were extracted from each of the included studies. The data reflected the variables identified in the inclusion criteria and the aim of the review. Those correlates which were reported as significant are detailed in Table 1.

The studies included in the review differed in terms of the population sampled, the diagnoses included and the measures used to examine quality of life. Therefore study characteristics were recorded and considered when looking at the reported results. Correlates of quality of life which were reported as significant are recorded below.

3.4. Study characteristics

Eleven of the 13 studies included in the review were carried out in the USA with the majority of these, nine in total, completed by a research group based in San Diego. The study sample sizes ranged from 54-486. The mean ages of the samples ranged from 52 to 75 for those with mental health diagnoses. The majority of the studies considered outpatient samples, with one study (Kasckow et al., 2001) looking at inpatient samples, one study looking at those residing in residential or hospital settings (Depla et al., 2005) and one considering residential settings (Depla et al., 2006). The diagnoses were defined differently for the studies included. Some samples were defined as having functional psychosis (Patterson et al., 1996; Patterson et al., 1997) or severe mental illness (Depla et al., 2005). The most common diagnostic categories given were schizophrenia or schizoaffective disorders (Kasckow et al., 2001; Cohen et al., 2003; Sciolla, Patterson, Wetherall, McAdams & Jeste, 2003; Wetherall et al., 2003; Mittal et al., 2006; Roseman et al., 2008). Depla et al. (2006) included bipolar disorder in their sample along with delusional disorder and Depp et al., (2006) compared a bipolar group with a schizophrenia group. In those studies where schizophrenia and schizoaffective disorder were differentiated, these tended to be grouped together for the analysis as no significant differences were found between the diagnostic groups.

Table 1. Characteristics of the studies included in the review

<i>Author (year)</i>	<i>Title</i>	<i>Aim</i>	<i>Sample</i>	<i>QOL measure</i>	<i>Significant correlates with QOL measure</i>
Patterson et al. (1996)	Quality of well-being in late-life psychosis	To examine the relationship between quality of life, psychopathology, cognitive impairment & physical comorbidity	85 OP ¹ with functional psychosis (mean age = 58) 39 NC ² subjects (mean age = 67).	Quality of Well-Being Scale (QWB)	Among the patient group Depression (r = -.44**) Psychiatric symptoms (positive symptoms r = -.48**; negative symptoms r = -.36**)
Patterson et al. (1997)	Health-related quality of life in older patients with functional psychosis	To examine the relationship between psychosocial factors, symptoms of psychosis and their impact on quality of life.	70 outpatients with functional psychosis (mean age = 58)	Quality of Well-Being Scale (QWB)	Depression (r = -.44*) Psychiatric symptoms (positive symptoms r = -.48*; negative symptoms r = -.36*)
Kasckow et al. (2001)	Health-related quality of well-being in chronically hospitalized patients with schizophrenia.	To examine quality of life in older schizophrenia inpatients and outpatients.	54 IPs ³ with diagnosis of schizophrenia or schizoaffective disorder (mean age = 61). 54 OPs with same diagnoses (mean age 60).	Quality of Well-Being Scale (QWB)	Among the inpatient group Psychiatric symptoms (positive symptoms r=-.44**; negative symptoms r=-.22 ns) Cognitive impairment (r=.35**) Among the outpatient group Depression (r=-.6**) Psychiatric symptoms (positive r=-.53**; negative r=-.44**) Cognitive impairment (r=.14 ns)
Cohen et al. (2003)	Assessing quality of life in older persons with schizophrenia	To demonstrate that self appraisals of quality of life are useful and valid in older people with schizophrenia.	99 outpatients with schizophrenia or schizoaffective (mean age = 62). 84 normal comparison subjects (mean age = 65).	Quality of Life Index	Among the patient group Depression(β=-.62**) Psychiatric symptoms (positive β = -.08 ns; negative β = .2*)

¹ OP = outpatients

² NC = normal comparison subjects

³ IP = inpatient

*p<0.05, **p<0.01, ns = non significant

Sciolla et al. (2003)	Functioning and well-being of older patients with schizophrenia	To compare quality of life scores in patients with those of a normal comparison group and to predict group membership by quality of life.	137 OP schizophrenia and schizoaffective patients (mean age = 58). 77 NC subjects (mean age = 66)	36 item short form health survey (SF-36) and QWB.	Among the patient group Depression ($p = -.44^{**}$) Cognitive impairment ($p = .19^*$) Demographics (age at onset $p = .17^*$)
Wetherall et al. (2003)	Anxiety symptoms and quality of life in middle-aged and older outpatients with schizophrenia and schizoaffective disorder	To assess the impact of anxiety symptoms on older people with schizophrenia or schizoaffective disorder	124 OPs diagnosis of schizophrenia or schizoaffective disorder (mean age 58)	QWB and SF-36	Depression ($R = .7^{**}$) Psychiatric symptoms (overall psychopathology $R = .66^{**}$)
Depla et al. (2005)	The role of stigma in quality of life of older people with severe mental illness	To gain greater insight in to the relationship between stigma, type of psychiatric disorder, type of residence and life satisfaction.	131 people residing in care homes or hospitals with severe mental illness excluding dementia (mean age = 74).	Manchester Assessment of Quality of Life (MANSA)	Other: (stigma $\beta = -.45^*$, social network size $\beta = .26^*$, $\beta = .2^*$)
Depla et al. (2006)	The relationship between characteristics of supported housing and the quality of life of older people with severe mental illness	To investigate the determinants of quality of life in older people with psychotic or non-psychotic disorders in residential settings	35 older people with schizophrenia, delusional disorder or bipolar diagnosis (mean age = 75). 38 with anxiety or mood disorder (mean age = 76). All living in residential settings	Assessment of Quality of Life (MANSA)	No significant correlations found.
Depp et al. (2006)	Health related quality of life and functioning of middle-aged and elderly people with bipolar disorder	To evaluate quality of life in older people with bipolar disorder in comparison to those with schizophrenia and normal controls	54 OPs with bipolar (mean age = 58), 55 with schizophrenia (mean age = 59) and 38 normal comparison (mean age 65).	36 item short form health survey (SF-36) and QWB.	Bipolar group Depression ($r = -.29^*$) Psychiatric symptoms (overall symptoms $r = .4^*$, positive $r = -.22$ ns, negative $r = -.19$ ns)

Mittal et al. (2006)	Correlates of health related quality of well-being in older patients with schizophrenia	To examine the correlates of quality of life in older people with psychosis	199 outpatients with schizophrenia or schizoaffective disorder (mean age = 54).	Quality of Well-Being Scale (QWB)	Depression ($r=-.23^{**}$) Psychiatric symptoms (negative symptoms $r=-.19^{**}$) Cognitive impairment ($r=.22^{**}$) Demographics (age at onset $r=.2^*$)
Roseman et al. (2008)	Insight, quality of life and functional capacity in middle-aged and older people with schizophrenia	To examine whether insight moderates the relationship between symptom severity and subjective quality of life.	144 OPs (mean age = 52) with schizophrenia or schizoaffective disorder	Quality of life scale	Depression ($r=-.19^*$) Psychiatric symptoms (positive symptoms $-.2^*$, negative symptoms $-.58^{**}$)
Folsom et al. (2009)	Physical and mental health-related quality of life among older people with schizophrenia.	To examine the relationship between age and health related quality of life.	486 older people with schizophrenia or schizoaffective disorder (mean age = 55) and 101 NC (mean age = 62).	36 item short form health survey (SF-36)	Among the patient group Depression ($\beta=-.53^{**}$) Psychiatric symptoms (total symptom score $\beta = -.35^{**}$)
Cohen et al. (2011)	General coping strategies and their impact on quality of life in older people with schizophrenia	To examine the types of general coping strategies used by older people with schizophrenia and the extent to which they affect quality of life	198 OP with schizophrenia (mean age = 62), 113 community comparison (mean age = 63)	Quality of life index	Psychiatric symptoms (total symptom score $\beta = -.14^*$)

In Depla et al.'s. (2006) study the delusional disorder, schizophrenia and bipolar groups were analysed together because the sample sizes in each group were too small to analyse separately. Three of the studies (Patterson et al., 1996; Sciolla et al., 2003; Depp et al., 2006) all used the same participants to make up some of their sample.

The most commonly used measure was the Quality of Well Being Scale (QWB) a 27 item clinician administered scale (Kaplan, Atkins & Timms, 1984). The QWB was used in seven of the studies (Patterson et al., 1996; Patterson et al., 1997; Kasckow et al., 2001; Sciolla et al., 2003; Wetherall et al., 2003; Depp et al., 2006; Mittal et al., 2006). Quality of well being was used as a proxy measure of quality of life. The Short Form Health Survey (SF-36) (Ware, Kosinski & Keller, 1994) was used by five studies (Sciolla et al., 2003; Wetherall et al., 2003; Depp et al., 2006; Folsom et al., 2009). The Quality of Life Index (Ferrans & Power, 1985) was used by two studies (Cohen et al., 2003; Cohen et al., 2011) and the Manchester Assessment of Quality of Life (MANSA) (Priebe, Huxley, Knight & Evans, 1999) was used in two studies (Depla et al., 2005; Depla et al., 2006). The majority of the measures assess subjective factors related to quality of life, however three out of the four subscales on the QWB use objective, observable measures of mobility, physical and social activity.

3.5. Correlates of quality of life

In all studies which compared older people with severe mental illness with a comparison group of older people with no mental health difficulties, quality of life was significantly lower in the severe mental illness group. The different correlates of quality of life examined in the studies included in the review are considered below.

3.5.1. Depression.

Nine of the studies examined depressive symptoms as a correlate of quality of life. The majority of the studies found a significant association between depression and quality of life, with higher scores on depression measures being correlated with poorer quality of life (Patterson et al., 1996; Patterson et al., 1997; Cohen et al., 2003; Sciolla et al., 2003; Wetherall et al., 2003; Depp et al., 2006; Mittal et al., 2006; Roseman et al., 2008). Kasckow et al. (2001) found depressive symptoms to be a significant predictor of QWB in the outpatient sample but not the inpatient sample. In the study by Roseman et al. (2008), while there was a significant relationship with depression and quality of life scores, depressive symptoms did not significantly contribute to the prediction of quality of life scores.

3.5.2. Psychiatric symptoms.

Ten of the studies looked at psychiatric symptoms such as hallucinations, delusions and blunted affect (Patterson et al., 1996; Patterson et al., 1997; Kasckow et al., 2001; Cohen et al., 2003; Sciolla et al., 2003; Wetherall et al.,

2003; Depp et al., 2006; Mittal et al., 2006; Roseman et al, 2009; Cohen et al., 2011). Cohen et al. (2003) and Mittal et al. (2006) found small but significant correlation between negative symptoms and quality of life but not positive symptoms and quality of life. Patterson et al. (1997) found a significant association between psychiatric symptoms, both positive and negative, and quality of life, however, much of this relationship was mediated by social maladjustment. Roseman et al. (2009) found significant correlations between positive and negative symptoms and quality of life. However, when these variables were entered into a regression model, only negative symptoms contributed to the prediction of quality of life. Sciolla et al. (2003) found that neither positive nor negative symptoms predicted quality of life scores in their sample. The remaining five studies found a significant association between positive symptoms and quality of life, with greater severity of positive symptoms being correlated with poorer quality of life. In one study which considered individuals with bipolar disorder (Depp et al., 2006), those in remission had higher quality of life scores than those currently experiencing an episode but considerably lower than the group who had no psychiatric illness. These differences in results do not reflect different populations or measures of quality of life.

3.5.3. Cognitive Impairment.

The majority of studies included a measure of cognitive impairment in order to describe their samples. A difference in cognitive impairment between individuals with severe mental illness and the comparison groups of non-clinical controls

was commonly found with greater impairment in the psychiatric group. Similarly, greater impairment was found in inpatient samples when compared to outpatient populations (Kasckow et al., 2001). Only five of the studies examined cognitive impairment as a possible correlate of quality of life. Patterson et al. (1996) and Cohen et al. (2003) did not find a significant relationship. Kasckow et al. (2001) found a significant association in their inpatient group but not the outpatient group. Sciolla et al. (2003) and Mittal et al. (2006) both found greater cognitive impairment predicted poorer mental health functioning and quality of well being.

3.5.4. Demographics.

Across those studies which examined demographic factors as potential correlates, the findings were inconsistent. Age at onset of psychiatric problems was a significant correlate in two studies (Sciolla et al., 2003; Mittal et al., 2006), with earlier onset being associated with poorer quality of life. Interestingly, Sciolla et al. (2003) did not find a significant association with duration of illness. The relationship between age at onset and quality of life was not found to be significant in three further studies (Patterson et al., 1996; Patterson et al., 1997; Folsom et al., 2009).

Three studies (Patterson et al., 1997; Cohen et al., 2003; Sciolla et al., 2003) looked at current age and the association with quality of life and found no significant relationship. Interestingly, Folsom et al. (2009) found that age was associated with higher mental health related quality of life in their clinical

population; the same relationship was not found in their non-clinical control group.

Folsom et al. (2009) also considered current living situation and marital status as possible correlates; neither were found to be significant. Neither gender nor ethnicity were found to be significant in those studies which included them in the analysis.

3.5.5. Other correlates.

Further significant associations were found for some correlates only considered by one or two studies. Financial strain and other stressors were found to be significantly associated with quality of life, with greater level of stressors being associated with poorer quality of life (Cohen et al., 2003; Cohen et al., 2011).

Anxiety was examined by Wetherall et al. (2003) and found to be significantly associated with poorer outcomes in quality of life, with anxiety symptoms accounting for a greater variance in quality of life scores than depressive symptoms.

Depla et al. (2005) examined the stigma experiences of older people with severe mental illness. They referred to the impact that stigma can have on self esteem, psychological well-being and social adaptation and in turn their quality of life and found that 57 per cent of their participants had experienced stigmatisation.

The majority of these stigma experiences were from family members and were negatively associated with quality of life.

Roseman et al. (2008) considered the mediating effect of insight between symptom severity and quality of life. Poorer subjective quality of life was associated with increased negative symptom severity and this relationship was stronger in those with poor insight.

A recent study by Cohen et al. (2011) found that coping strategies, both active and passive, mediated the impact of psychiatric symptom severity on quality of life, as well as independently positively impacting on quality of life.

3.5.6. Longitudinal results.

Only one study considered correlates at more than one time point. Kasckow et al. (2001) compared outpatients and inpatients with a diagnosis of schizophrenia or schizoaffective disorder. They found that QWB scores at 6 months were best predicted by total symptom scores as measured by the PANSS. Psychotic symptoms at baseline were better than psychotic symptoms at 6 months in predicting QWB at 6 months (Kasckow et al., 2001). Quality of Well Being Scale scores at 6 month follow up were better associated with cognitive impairment and symptom scores at baseline than at 6 months, in both inpatients and outpatients. QWB scores at baseline were highly correlated with QWB scores at 6 months. This correlation was strongest in the outpatient sample.

4. Discussion

The aim of this review was to consider the probable correlates of quality of life in older people with severe mental illness, by examining the available literature on this subject. Thirteen original articles using 11 cohorts all published in the last two decades were reviewed. Across the studies there is great variability in terms of the population sampled and the measures used, however despite this there were some consistent findings.

4.1. Key findings

The most consistently identified significant correlates were the levels of depression and psychiatric symptoms. Thus suggesting that, while symptoms may decline in older people with a long history of severe mental illness, the current symptomatology still has a significant impact on quality of life. The findings of Kasckow et al. (2001), that QWB scores were better predicted by symptoms at baseline than symptoms at 6 months, suggest that quality of life may be affected by chronic impairments as a result of symptoms rather than fluctuations in symptom levels. Similarly, in Depp et al.'s study (2006), individuals with bipolar disorder in remission had higher quality of life scores than those currently experiencing an episode but considerably lower than the group who had no psychiatric illness. Thus suggesting that symptom resolution is not an adequate measure of treatment outcome and that impairment in functioning does not only occur at times when an individual is experiencing an episode (Depp et al, 2006).

This relationship between quality of life and psychiatric symptoms appears to be more significant in older people in the community as opposed to inpatients. One study which compared the impact of depression in outpatients compared to inpatients found depressive symptoms to be a significant predictor of QWB in the outpatient sample but not the inpatient sample (Kasckow et al., 2001). However, the other studies which included an inpatient sample did not look at depression and therefore, it is hard to draw any firm conclusions. Other interesting correlates were identified by single studies, such as anxiety, coping strategies and the mediating effect of insight, however these need to be replicated in future studies to further examine their impact on quality of life.

Age was not found to be a significant correlate of quality of life in those studies which examined it, which replicates findings in previous research (Herzog & Rodgers, 1981; Diener & Suh, 1998; Brown & Roose, 2011). The finding here may be due in part to the fact that only studies which considered middle-aged and older people were included and that comparison with a much younger sample might show an effect of age. However, this still represents a great range of ages across which deterioration in quality of life might be expected, therefore if there was an effect of age it is likely to have been found in the studies.

Sciolla et al. (2003) looked at both the age at onset of disorder and the duration of illness. While they found a significant effect with age of onset the same was not true of duration of illness. This may suggest that what is important is the stage of life individuals are at when they begin to experience symptoms, rather

than how long they have experienced them. However, this finding was not replicated.

Where a comparison group was used all but one of the studies (Depla et al., 2006) used a “normal” comparison group and found significant differences in quality of life between the two groups. Depla et al. (2006) used a comparison group of other mental health difficulties but did not give a comparison of quality of life. Therefore, it is uncertain whether the impact on quality of life is specific to SMI or more generally the result of mental health difficulties.

4.2. Limitations of the review

The limitations of this review must be a consideration when drawing conclusions. One limitation to the search strategy used is that only published, peer reviewed studies were included. This potentially misses a number of new research studies, particularly as the majority of studies included were written recently, possibly suggesting that this is a growing area of research. Publication bias, a tendency for researchers to submit manuscripts for publication and for editors and reviewers to accept them dependent upon the direction of the findings and their strength, is a significant problem when completing a systematic review (Chalmers, 1990; Dickersin, 1990). Not all research gets published despite having clinically relevant information (Dickersin, 1990). Hopewell et al. (2009) reviewed papers which considered the association between the direction or statistical significance of results and whether or not they were published. They found that studies with positive and significant results were more likely to be

published than those with negative or null results. In addition, those with positive results were published more quickly than those with negative results on average. Studies with positive results were published within five to six years and those with negative results within seven to eight years. As a result there may be important studies which have not been included therefore this review may not provide a full overview of the research.

There was a limit in the breadth of research with one research group publishing 9 out of the 13 studies, with three of these studies sharing the same participants. This research group was also limited in terms of generalisability, as their populations had a significantly greater proportion of men and were made up of individuals who already consented to take part in a large ongoing research study. This might imply a slightly higher functioning than average group.

The majority of studies did not include any data about the number of individuals who were approached to take part and refused. It may be that those with greater symptomatology or poorer quality of life are more likely to refuse to take part in a project and if refusal rates are high, that might also represent poor generalisability.

In terms of the measures used to assess quality of life, some were more focused on objective variables of quality of life and some particularly consider the subjective experience. For example, the QWB scale considers three subscales of objective factors based on observable functioning these are mobility, physical

activity and social activity, and just one subscale for subjective respondent rated experience. These four scales are grouped together to give a single score for functional impact of illness (Kaplan et al., 1984). On the other hand, the MANSA rates an individual's subjective satisfaction with their life on a number of domains such as physical health, mental health and relationships (Priebe et al., 1999). Previous research has shown that subjective experiences of quality of life often differ from what is expected based on objective measures (Nilsson & Levander, 1997; Brown & Roose, 2011).

The key limitation of all but one of these studies is that they are cross sectional and therefore we can't make causal assumptions about the correlates found.

4.3. Conclusions

This is the first review of the existing literature on quality of life in older people with severe mental illness. There is some evidence to suggest that depression and psychiatric symptoms have a significant impact on quality of life, as is found in younger people with SMI. This is despite a general improvement in these symptoms as individuals age, as detailed in the literature.

There was little consideration of factors which may be more specific to an older people population; such as cognitive impairment, living situation or physical health. While these might also be significant in younger people, particularly those with a long standing mental health problem, they are more likely in older people and are often considered when formulating an individual's difficulties in

this population. Where these factors were considered there was little indication of an effect on quality of life. Cognitive impairment was not consistently found to be significant and in those studies which did find a significant relationship, the correlation was small. None of the studies found physical health or living situation to be associated with quality of life.

The paucity of studies, especially of higher methodological rigour, mean that the conclusions of this review are affected by the limited data on a number of correlates and particularly those which are more specific to older people. In addition, there was great variance across studies in terms of measures used and ways that SMI was defined, which further limits the conclusions that can be drawn. The quality of the literature limits what can be concluded from the findings and without a stronger evidence base, it will be difficult to progress to more clinically relevant research.

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Introduction to research papers

The systematic review highlights the paucity of research which has been carried out examining severe mental illness in older people. The number of appropriate studies was small in number and they were not of the quality expected when producing research which influences practice.

The most consistent finding across the studies was that depressive and other psychiatric symptoms such as the positive and negative symptoms of schizophrenia were found to be associated with quality of life. While a number of different variables were considered there was a lack of attention to aspects which are specific to the older people population. Some of the studies considered cognitive impairment, medication side effects and comorbid physical health problems. These are factors which are more common in older people but can be found in younger people as well, particularly those with a diagnosis of severe mental illness.

At present there is limited literature considering quality of life in older people with mental health difficulties generally. While age itself has consistently been found to not be a significant determinant of quality of life (see systematic review) there are other factors to be considered in an older people population which may have an impact on quality of life. As mentioned above, factors such as physical comorbidity, cognitive impairment and medication side effects are all

more common in an older people population but chronological age is not sufficient to tell you whether an individual will experience difficulties in these areas. The current older people population is a very heterogenous group. Psychologists working with older people need to think beyond chronological age and also consider the stage of life someone is in and the cohort which they belong to (Knight, 1996; Laidlaw *et al.*, 2003; APA, 2004).

A significant proportion of people continue to work beyond 65, many go back to education or go travelling and seek new experiences. Others stop working and choose to lead a quieter life more in line with traditional views of retirement. These people could be considered as at different stages of their lifespan development. As a result they may have different expectations and priorities which can impact on their goals in life and in therapy. The central importance of an understanding of development when working clinically with older people is demonstrated in this quote from a briefing paper on commissioning psychology services for older people:

“Clinical Psychologists’ knowledge and understanding of healthy, as well as unhealthy, psychological development enables them to provide services that optimise successful ageing for clients and their carers and adjustment to later life events.”

British Psychological Society, 2006, p. 2

‘Older people’ also represent a group of people from different cohorts. These different cohorts, have lived through different significant historical events and

have different shared experiences. As a result these cohorts have different cultural norms and expectations (Knight, 1996; Laidlaw *et al.*, 2003). For example, those individuals who grew up in the 60s will have different expectations of the world than those who grew up during the Second World War, different views about equality or the importance of community for example. It is generally felt that the baby boomer generation will expect more from their old age than the cohorts that went before them (Bowling *et al.*, 2002). An understanding of the times a person has lived through can provide information about how they might perceive the world.

While these factors are recognised to be important in working with older people, they need to be further explored in older people who are experiencing mental health difficulties.

The two research papers that follow aim to consider the relationship of these factors to quality of life in a sample of older people experiencing mental health difficulties.

Aims and Hypotheses

The aims of the current study are:

1. To examine the impact of psychosocial development, coping style and illness perceptions on quality of life in older people with mental health difficulties.
2. To consider the impact of more long standing mental health difficulties on quality of life.

Primary Hypothesis

Quality of life will be significantly correlated with more successful psychosocial development.

Secondary Hypotheses

Quality of life in older people with mental health difficulties will be most significantly correlated with resolution of the final stage of psychosocial development.

Quality of life will be significantly positively correlated with emotion focused coping styles and negatively correlated with negative perceptions of illness.

Longer duration of mental health difficulties will be associated with poorer quality of life.

Longer duration of mental health difficulties will be associated with poorer psychosocial development.

Methodology

This chapter details the methodology used in the two research papers presented in this thesis. Further information is given about the procedure, materials, ethics and power calculation for the studies than is typically included in a published research article.

Participants

Participants for the study were on the caseload for one of the 10 Community Mental Health Teams for Older People (CMHT-OP) in NHS Lanarkshire. This allowed suitable participants to be identified and also ensured that support networks were in place for those who took part in the research. The study inclusion criteria were: 1) a functional mental illness; and 2) contact with the community mental health team. All participants were required to be able to give informed consent.

Informed consent refers to an individual's ability to give consent to a specific activity or intervention at a specific time. It is widely recognised that cognitive impairment is common in older people, particularly in those with long standing mental health difficulties, which may impact upon their capacity to give informed consent. In addition, older people are considered vulnerable adults under relevant policies and are considered more likely to feel coerced. In this study the ability to give informed consent was considered in the first instance by

keyworkers prior to approaching individuals. In cases where capacity was harder to determine there was a discussion between keyworker and researcher.

Capacity was confirmed formally by the researcher using an adapted version of the Evaluation to Sign Consent (Resnick *et al.*, 2007) at the time of the consent form being signed (see appendix 3). This tool has been used in previous research to aid and make explicit the grounds on which the ability to give informed consent is made. It addresses the participant's ability to retain and explain to the researcher the key points of consent, ensuring that the relevant information has been both understood and retained in relation to participation in this study. Resnick *et al.* (2007) suggest using a five item Evaluation to Sign Consent form as a method of determining potential participants' ability to consent. They argue that this method can more appropriately evaluate the capacity to consent to participate in research studies than cognitive testing (Resnick *et al.*, 2007). The evaluation was adapted for the present study. Participants were deemed able to consent if they were able to sustain concentration, communicate with the researcher and show that they understood the key points of potential risk. These included understanding what participation involved, that they were free to withdraw at any time and that they could contact the researcher, clinical supervisor, independent member of the psychology department or their key worker if they were distressed following the assessment appointment.

Potential participants were excluded if they were acutely unwell, either in terms of mental illness or physical comorbidities, to the extent that participation would be an undue additional strain. Individuals with severe hearing or sight impairments were excluded as these factors may have had a significant impact upon psychosocial development and coping which were key factors being considered by this research project. In addition, they may be a barrier to rapport building, significantly increase duration of the sessions and add burden on participants. Adaptations were in place if required for those individuals with mild hearing or sight impairments as these are common in this population, for example the use of large print on information sheets and questionnaires or the use of clinic rooms with hearing loops.

Design and Procedure

This is a cross-sectional questionnaire design. Prior to commencing the study, the researcher contacted the teams in NHS Lanarkshire to ascertain the feasibility of completing the study in terms of the number of individuals they had on their caseloads. Once ethical approval had been granted, the researcher visited all the CMHT-OPs in NHS Lanarkshire to inform them of the project and request their assistance in recruiting participants.

Recruitment packs containing a covering letter, participant information sheet and opt-in slips⁴ were given to each team to give to their clients. Individuals who

⁴ These documents are provided in Appendix 4

were on the caseload for the CMHT-OPs had an identified member of the team as their key worker; a Community Psychiatric Nurse, Occupational Therapist or other worker. This person was aware of the individual's current situation and background history and was therefore best placed to decide on appropriateness for participation following discussion with the researcher regarding the nature of the research, and the inclusion and exclusion criteria. They then spoke with their clients regarding whether they would be happy to receive information about a research study before giving them the recruitment packs. Those individuals who wanted to find out more about the study either telephoned the researcher or completed an opt-in slip giving permission for the researcher to contact them.

The researcher contacted the individual to make an appointment at a time and location which was suitable for them. If they wanted to be seen at home the researcher asked for their address and spoke with their key worker regarding any risk issues. This procedure meant that the researcher did not have access to patient information until they had opted in to the study. At the initial appointment there was further discussion of the study, what participation involved and an opportunity to ask questions. If appropriate, informed consent was obtained and a further appointment was arranged for the assessment session. At this time demographic information was also collected. The consent form is provided in Appendix 5. If the individual did not meet inclusion criteria or triggered exclusion criteria for the study, by being unable to give informed consent for example, they were thanked for their time and the reasons for not being included were explained.

The assessment session typically took 60 minutes and was completed in a one off appointment. Participants were offered breaks during the assessment, particularly if they became tired or distressed and a second session was offered if required. Key workers were asked to consider the concentration span of potential participants and any comorbid physical health problems which might cause excessive fatigue when under the demands of participation. At the end of the session participants were thanked for their time and offered the opportunity to receive a short report on the findings of the study.

The recruitment procedure aimed to take all steps possible to ensure that participants did not feel coerced or obliged to take part in the research. While many individuals are motivated to participate in research as a way of 'giving back' this was to be a free decision to do so and not out of a sense of acquiescence or obligation.

From initial contact participants were actively involved in the study for one month. There was a delay following the phone call and before first meeting to ensure potential participants had time to consider their participation and they were encouraged to discuss participation with family and friends during this time if they wished.

Measures

All measures were administered by the researcher to allow for discussion of items and to identify any distress that may have arisen from some of the items on the questionnaires. The information sheet provided information about the nature of the questionnaires so that individuals were aware of the likely questions prior to the assessment session and could decide whether or not to take part.

The WHOQOL-Old (Power et al., 2005)

Quality of life was the primary outcome variable for this study. As the population ages it is important for researchers and policy makers to consider how best to improve the quality of these extended years. Therefore, measures of quality of life are important for evaluating how individuals view their functioning and satisfaction with life and ascertain whether interventions have a positive impact.

The World Health Organization developed the WHOQOL measures of quality of life with the involvement of fifteen different centres around the world and various adaptations have been made to assess specific populations. The WHOQOL-Old is a measure of quality of life in older people, it address factors of quality of life which were most important to the older people population. It is important to have a specific measure of quality of life for this population as the dimensions that are important to quality of life change as we age (Bowling, 2009). The items of the WHOQOL-Old were generated in part from focus groups carried out with older people, carers and health professionals regarding the

important factors for this age group (Power *et al.*, 2005). The WHOQOL-OLD considers six domains; sensory abilities, autonomy, past, present and future activities, social participation, death and dying, and intimacy. The questions relate to an individual's thoughts and feelings about these different domains over the past two weeks. An example item is given below:

To what extent do you feel in control of your future?

Not at all	A little	A moderate amount	Very much	An extreme amount
1	2	3	4	5

The WHOQOL-Old was developed as an addition to the WHOQOL-Bref or the WHOQOL-100 however it has been considered as a stand alone measure (Peel *et al.*, 2007; Margis *et al.*, 2010) and has been shown to have good psychometrics (Power *et al.*, 2005; Peel *et al.*, 2007). Power *et al.* (2006) reported acceptable internal consistency for all subscales and the total score, alphas between .72 and .89. It also has acceptable test-retest reliability, ICC = .74 to .96, which was higher than another widely used measure of quality of life (Peel *et al.*, 2007). The total score for the module has strong convergent validity with the geriatric depression scale $r = -.55$ (Power *et al.*, 2006), the Goldberg Anxiety and Depression Inventory, $r = -.51$ and moderate convergent validity with a measure of psychological distress $r = -.47$ (Peel *et al.*, 2007). The WHOQOL-Old has been shown to be strongly correlated with the WHOQOL-100 ($r = .67$).

Participant burden was another significant factor in determining the measure to use and a measure which addresses factors specific to this population is appropriate to the purpose of the study.

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983),

The Hospital Anxiety and Depression Scale (HADS) is a brief measure which was originally developed for non-psychiatric hospital patients to identify cases of anxiety and depression. It is a particularly helpful measure in older adult populations as the questions do not focus on physical symptoms of anxiety and depression, such as fatigue, which older people may experience due to failing physical health (Laidlaw *et al.*, 2003). It is routinely used in clinical practice in the NHS Lanarkshire Psychological Therapies for Older People service.

The HADS consists of 14 items, seven which relate to anxiety and seven which relate to depression. Some of the items are reverse scored. For example, one item from the anxiety subscale (HADSa) is *'I get a sort of frightened feeling as if something awful is about to happen'* and one from the depression subscale (HADSd) is *'I have lost interest in my appearance'*. Individuals rate how often they have experienced this in the past two weeks. Higher scores indicate greater levels of depression or anxiety.

The HADS has been widely used in the literature. In a review of research which used the HADS, Bjelland *et al.* (2002) found acceptable internal consistency for

the HADSa (mean .83) and HADSd (mean .82) and found it performed well at identifying caseness and assessing symptom severity of anxiety and depressive disorders in a number of different populations. In addition, they found that the measure had good internal consistency, and specificity and sensitivity of approximately .80 which was similar to that of a more comprehensive measure of anxiety and depression (Bjelland *et al*, 2002). The HADS was used to capture the characteristics of the sample and was initially intended to compare the affective symptomatology of the two clinical groups.

Modified Erikson Psychosocial Stage Inventory (Darling-Fisher & Leidy, 1988),

The Modified Erikson Psychosocial Stage Inventory (MEPSI) assesses Erikson's stages of psychosocial development with 8 subscales representing the initial 8 stages of Erikson's original model. While there has been research to support the notion of the 9th developmental stage proposed by Joan Erikson (Brown & Lewis, 2003) no formal measures currently assess all 9 stages.

Each subscale of the MEPSI has 10 items with positive statements reflecting successful psychosocial maturation and negative statements reflecting less successful maturation. An example of an item for each stage of Erikson's model is given in Table 1.

Table 1. Erikson's (1963) model and corresponding MESPI items

Stage	Approx. age	Developmental Task	MESPI item
1. Trust vs. mistrust	0 – 18 months	Attachment to mother, which lays foundation for later trust in others	Other people understand me
2. Autonomy vs. shame and doubt	18 months – 3 years	Gaining some basic control of self and environment (e.g. toilet training, exploration)	I am able to take things as they come.
3. Initiative vs. guilt	3 – 6 years	Becoming purposeful and directive	I feel guilty about many things (-)
4. Competence vs. inferiority	6 years – puberty	Developing social, physical and school skills	I'm a hard worker
5. Identity vs. role confusion	Adolescence	Making transition from childhood to adulthood; developing a sense of identity	I feel mixed up (-)
6. Intimacy vs. isolation	Early Adulthood	Establishing intimate bonds of love and friendship	I get embarrassed when someone begins to tell me personal things (-)
7. Productivity vs. stagnation	Middle Adulthood	Fulfilling life goals that involve family, career and society; developing concerns that embrace future generations	I feel I have the wisdom and experience to be of help to others
8. Integrity vs. despair	Late Adulthood	Looking back over ones life and accepting its meaning	As I look over my life, I feel the need to make up for lost time (-)

Each subscale can be considered individually and the MESPI total score reflects the strength of psychosocial attributes across the stages. Some studies have used just one subscale; the one which reflects the sample being considered. However, the current study looks at whether there is an impact on psychosocial development throughout the lifespan and therefore the whole scale is considered.

In a sample of adults, internal consistency for all subscales and total score were high (.75-.88). Studies using diverse populations suggest that the MEPSI is a reliable and valid instrument (Leidy & Darling-Fisher, 1995). In a sample of healthy older people, the internal consistency for the total scale was very high (.94 for women and .93 for men) and there was a moderate convergent validity with a measure of self-transcendence ($r = .48$ for women and $r = .54$ for men). In a sample of older people with COPD the internal consistency was high for total scale (.93 for women and .96 for men) and the MEPSI 8 subscale (.67 for women and .65 for men). Convergent validity with measures of need satisfaction was moderate for the total scale (.60 for women and .46 for men) and MEPSI 8 subscale (.53 for women and .55 for men).

The MEPSI total was used as a measure of successful psychosocial development which each subscale being considered individually for its relationship with quality of life. The MEPSI follows a similar structure and has comparable reliability to other measures of psychosocial development such as the Inventory of Psychosocial Balance (Domino & Affonso, 1990). However, it is a shorter measure and was chosen to reduce participant burden.

Brief COPE (Carver, 1997)

The brief COPE is a 28 item scale which assesses an individual's coping strategies. It has been adapted from the full COPE which has 60 items. The major

advantage of the brief COPE over the original version is that it reduces participant burden, a significant factor in coping research, while preserving validity. There are 14 subscales, which can be grouped into adaptive versus maladaptive coping, or into emotion versus problem focused coping as well as specific coping strategies. Emotion focused coping strategies aim to reduce the emotional distress that results from a stressful situation by trying to change one's feeling towards it. Problem focused coping strategies involve defining the problem and identifying actions.

The measure has been widely used, including in a study of coping in individuals with SMI (Meyer, 2001). The original COPE has been shown to have acceptable internal consistency ranging from .5 to .82 (Carver, 1997). Most of the items on the Brief COPE are taken from the full COPE and they have a similar factor structure. The original COPE has been shown to have good reliability and validity (Carver, 1989). The COPE has significant convergent validity with measures of positive affect, and was found to better predict outcomes than other widely used measures of coping (Clark *et al.*, 1995). In a sample of middle aged and older people, good internal consistency was found for the emotion focused, problem focused and dysfunctional subscales (.72, .84 and .75 respectively). They also found convergent and divergent reliability on measures of attachment and social support (Cooper *et al.*, 2008). Research has found that the COPE and Brief COPE have predicted clinically relevant outcomes across different potentially stressful situations (Kennedy *et al.*, 1995; Carver, 1997; Meyer, 2001).

An important issue in studying coping in mental health populations is whether to look at how individuals cope with stressors related to their symptoms, or whether the focus should be on how individuals cope with everyday stressors. The literature on coping in schizophrenia has focused on symptoms and distress, however, the data does not support the effectiveness of this as a focus (Farhall & Gehrke, 1997).

The Brief COPE was used in this study to examine the coping style of participants and examine whether this was correlated with their perceived quality of life. The explanation prior to administering the Brief COPE was to consider coping with day to day stressors and dispositional wording was used to get a sense of how individuals cope overall. For example, “I take action to try and make the situation better” rather than “I took action to try and make the situation better”.

Personal Beliefs about Illness Questionnaire (Birchwood *et al.*, 1993),

The Personal Beliefs about Illness Questionnaire (PBIQ) aims to capture the extent to which an individual accepts scientific and societal beliefs about mental illness. It considers control over illness, self as illness, expectations, stigma and social containment which have been shown to impact upon feelings of depression in individuals with SMI. Examples for each subscale are given in table 2. Individuals were asked to indicate whether they agree or disagree with each statement.

Table 2. Items on the PBIQ

<i>Subscale</i>	<i>Item example</i>
Control over illness	I am powerless to influence or control my illness
Self as illness	There is something strange about me which is responsible for my illness
Expectations	I will always need to be cared for by professional staff
Stigma	My illness is a judgement on me
Social containment	People like me must be controlled by psychiatric services

The measure has been widely used and has been shown to have good reliability and validity in individuals with a diagnosis of schizophrenia or bipolar disorder, with internal consistency alphas ranging from .51-.71 (Birchwood *et al.*, 2003).

The PBIQ has primarily been validated in severe mental illness populations and as was originally selected for the study to consider any differences between illness beliefs of the two clinical groups. The items do not specifically refer to a severe mental illness diagnosis and reflect the possible beliefs regarding mental health difficulties that the literature identifies older people might hold. Therefore, the PBIQ was used in this study as a measure of participant's beliefs regarding their own mental health difficulties.

The PBIQ provided a measure of how individuals perceived their illness and the impact it has had on their life.

Confidentiality

The researcher did not have access to patient information until they had opted in to the study. All participants were given an ID number which was on all of their measures and data when it was entered into the database. Consent forms and demographic information were stored separately from measures. All information was stored in locked filing cabinets on NHS premises, and when being transported they were kept in a locked briefcase. All data was anonymously entered into a password protected database on an NHS computer on a secure server and a secure University network.

The keyworkers reviewed their own caseload for potential participants. Therefore, only workers currently involved in the potential participants' care, who had access to this information as part of their routine care, had access to the patient records.

Contact details were required in instances when the potential participant requested to be seen at home and when feedback about the study was requested. These were kept until feedback about the study had been given.

Ethical Approval

Ethical approval was sought from the West of Scotland Ethics Committee in November 2011. At this time the recruitment procedure involved key workers identifying potential participants and sending recruitment packs through the post.

This procedure was initially trialled in three of the ten CMHT-OPs in NHS Lanarkshire. Feedback from clinicians was that they felt that it would be more helpful for their clients if they were given the packs by their key workers and given an opportunity to talk about it prior to opting in. In addition, clinicians felt that it would be less of a burden if they contacted the researcher rather than requiring their client to make contact. This feedback, along with a slower than expected recruitment rate, led to a notice of substantial amendment being submitted to the West of Scotland Ethics Committee in January 2012. The committee gave approval for packs to be given to participants but decided that contact with the researcher should come directly from the potential participant. A copy of the approval letter is provided in Appendix 6.

Power Calculation

The true power of the primary analysis of this study was calculated as the sample and analyses differed from what was initially intended. GPower version 3.1 was used to calculate power. With a standard α -level of .05, using Pearsons' correlation coefficient for an effect size of .69 and with 24 participants, the true power of the study was .99.

Statistical Analysis

Prior to analysis, all continuous variables were examined for accuracy of data entry, missing values, and fit between their distributions and the assumptions of parametric analysis, i.e. skewness, kurtosis, and homogeneity of variance. Years

of contact with mental health services and subscale scores on the PBIQ were non-normally distributed.

ANOVA and chi square tests were carried out to determine the significance of any differences between the groups. Pearson's correlations were carried out to examine the correlation between beliefs about illness, psychosocial development, coping style and quality of life. Preliminary correlational analyses were performed to investigate relationships between demographic characteristics, psychological variables, and quality of life using Pearson correlation coefficient. The most significant variables were entered into a multiple regression model to further examine the impact of these factors on quality of life. Spearman's correlations were carried out between quality of life and non-parametric data; years of contact and PBIQ subscales.

There were a number of possible variables considered for their impact on quality of life and as a result a number of correlations were carried out. The probability of a Type I error, finding an effect when there isn't one, was therefore increased. Post hoc tests were carried out to correct for this.

Significance level was set at standard .05 for initial analyses and SPSS version 19.0 was used.

Quality of life in older people with mental health difficulties: The impact of psychosocial development, coping style and illness perceptions.

Prepared in accordance with requirements for submission to Ageing and Society

(see Appendix 7 for guidelines for contributors)

Abstract

Introduction: There is a need to identify the specific factors which impact on quality of life in older people with mental health difficulties in order to develop appropriate interventions. Psychosocial development and the stage an individual is in appears to be important in itself but may also impact on other psychological factors such as coping strategies utilised and perceptions of mental health. The current study considered the impact of psychosocial development, coping style and beliefs about illness on quality of life.

Method: Questionnaires were administered to 24 individuals who lived in the community and were in contact with secondary care mental health services.

Results: Quality of life was found to be significantly positively correlated with both psychosocial development and an adaptive coping style. Quality of life was negatively correlated with poorer perceptions of mental health problems. In a regression model no objective factors were significantly associated with quality of life and successful resolution of the final stage of psychosocial development was the strongest predictor.

Discussion: There appears to be a role for considering tailoring interventions to the psychosocial developmental stage an individual is in. The role of acceptance of past and present life may be particularly important and research is needed to explore this further.

Key words: Older people; quality of life; mental health

Introduction

The world population is ageing, it is predicted that by 2031 those aged over 65 will account for 22 per cent of the population, while those under 16 will account for just 18 per cent (Office for National Statistics, 2007). This is due in part to the ageing of the 'baby boomer' generation, the first of whom have recently turned 65. In addition, advances in healthcare mean that people are living longer and, in most parts of the world, healthier lives (Kinsella & Wan He, 2008).

Poor physical and mental health is no longer considered an inevitable part of growing old (Laidlaw *et al.*, 2004; Laidlaw & Pachana, 2009). The concept of successful ageing posits that ageing is not an inevitable decline and that individuals have a significant role to play in determining their own success and quality of life (Baltes & Baltes, 1990).

Quality of life in older people

There has been a recent increase in interest in understanding quality of life in older people. This is partly in response to the change in demographics and an expectation that the next cohort of older people will have higher expectations for their later years (Bowling *et al.* 2002). There are also service based and economic factors that are important in thinking about improving quality of life. Helping older people to maintain their independence and cope with the challenges of older age will help to them remain in their homes and communities for longer rather than in hospital or residential care. Remaining at home is both what people tend to want and considerably less expensive for health and social

care and therefore would reduce the overall cost of services (Bowling *et al.*, 2002). For these reasons, an understanding of how to enhance quality of life in older people is vital.

Poor quality of life in older people is not inevitable. Research indicates no effect of ageing on life satisfaction and in some cases improved life satisfaction (Herzog & Rodgers, 1981; Diener & Suh, 1998; Brown & Roose, 2011). Although for some individuals, older age is associated with poor physical health, greater dependency and a loss of control, for others it is a time of greater independence and freedom from restrictions and expectations of family and work (Bowling *et al.*, 2002). Most individuals who are over 65 report being happy and satisfied with their lives (Bowling *et al.*, 1993).

Quality of life is a complicated concept and as such there are great differences across disciplines, and within them, in how to define and measure quality of life and there are no clear models of quality of life in older age (Walker, 2005). It is generally agreed that the concept of quality of life is multifaceted and takes into consideration objective and subjective factors, both positive and negative on a micro and macro level (Walker, 2005). In addition, quality of life in the older population needs to account for a combination of factors over the life course as well as immediate situational stressors and life experiences.

Bowling *et al.* (2002) considered the perspectives of 999 individuals aged over 65 when attempting to identify the constituents of quality of life. This was done with the aim of producing a model which would be of clinical and research utility. They looked at both objective and subjective variables. Objective factors are those which can be measured by someone other than the individual and includes physical health, mobility and social contacts. Subjective factors are those which are rated by the individual such as perceptions of illness and satisfaction with the support they receive. The most significant variables that they found were social comparisons and expectations, optimism-pessimism, health and functional ability, health perceptions, number of social activities, number of social contacts, social support scores, feelings of loneliness, rating of quality and safety in the area they lived in, their health values and respondents' gender. The model produced explained 26.7 per cent of the variance in quality of life ratings, thus reflecting the amorphous nature of the concept of quality of life. Subjective variables rather than objective indicators were significantly associated with quality of life. This finding that quality of life is better associated with subjective rather than objective factors, gives support to the idea that quality of life is alterable as an individual's thoughts and feelings can be targeted in interventions.

Quality of life in older people with mental health difficulties

In a Department of Health report on 'Securing Better Mental Health Services For Older Adults' (Department of Health, 2005) it was estimated that 40 per cent of those attending GP surgery, 50 per cent of those in general hospital and 60 per

cent of those in care homes have unmet mental health needs. In a review of prevalence studies of depression in older people, Beekman *et al.* (1999) suggested that 13.5 per cent of those living in the community experienced depression. In a later review, Blazer (2003) suggested a prevalence rate between 8 and 16 per cent. The prevalence of anxiety disorders in older people living in the community has been suggested to be between 1.2 per cent and 15 per cent, however, the presence of anxiety symptoms was much higher, between 15 per cent and 52.3 per cent according to a review of the literature (Bryant *et al.*, 2008). The authors argue that due to hierarchical diagnoses, i.e. depression is more likely to be the given diagnosis if both depression and anxiety are present, the prevalence rate of anxiety disorders in the community is an underestimation. There is evidence that the rate of co-morbidity for depression and anxiety is greater in the older people population than in the working age population (Katona *et al.*, 1997).

Prevalence rates take account of late onset depression or anxiety (that which develops after the age of 65) as well as individuals who have lived with longstanding chronic depression or anxiety. Other chronic mental health difficulties are also prevalent in older people. Approximately 2 per cent of individuals over the age of 54 have a severe mental illness (SMI) such as schizophrenia, schizoaffective disorder or bipolar disorder (Cohen *et al.*, 2000).

There is a growing body of research examining the impact of mental health difficulties on quality of life in older people. Bowling *et al.* (2002) found that depression and anxiety failed to account for any significant proportion of variance in quality of life in their predictive model. This is in contrast to a study by Chachamovich *et al.* (2008) where even subthreshold levels of depressive symptoms were associated with poorer quality of life. In older people with a diagnosis of severe mental illness, depressive and other psychiatric symptoms have been shown to be associated with poorer quality of life (Roseman *et al.*, 2008; Folsom *et al.*, 2009).

There needs to be further exploration of the correlates of quality of life specific to older people with mental health difficulties. With the proposed changes to service delivery in response to the Equality Act (2010), it is possible that all adults with mental health difficulties will be seen by an ageless service. This represents a more equitable service based on needs rather than age. However, there is a risk that when the age barrier is removed it could result in indirect discrimination due to older people's needs not being recognised. The "understandability phenomena" (Blanchard, 1992) which posits that depression is an expected and normal part of ageing may mean that individuals are deemed less likely to be in need of a service to improve their mental health. An understanding of ageing and the impact this can have on presentation and ways of coping with mental health difficulties is important when working with older people experiencing depression, anxiety and other mental health difficulties. Furthermore factors other than age *per se* are important to consider. The stage of

psychosocial development someone is in and the cohort to which they belong may also be important to consider when formulating an individual's current difficulties.

Psychosocial development

An understanding of psychosocial development is recognised to be vitally important when working clinically with older people (BPS, 2006). The key developmental theory of ageing is Erikson's Theory of Psychosocial Development (Erikson, 1963). The original theory posits that there are 8 developmental stages. At each stage there is a conflict between the individual's identity and a change in social and personal expectations. Successful resolution of each stage results in the emergence of a new ego quality and increases the individual resources for successful resolution of the following stage. Erikson suggested that normal development required positive resolutions to outweigh the negative (Brown & Lewis, 2003).

The 8th stage was reached in late adulthood and was seen by Erikson as a culmination of successful resolution of all previous stages and resulted in ego integrity (Hannah *et al.*, 1996). This idea has been reflected in the research. For example, Hannah *et al.* (1996) produced a model for predicting successful ego integrity in which five of the seven previous stages of psychosocial development were included as strong predictors of the 8th stage.

Erikson's model suggests that the task of late adulthood is looking back over one's life and accepting its meaning, reaching ego integrity. Affective problems in late adulthood were proposed to be the result of unsuccessful resolution of the 8th stage, if individuals do not accept their lives they give way to despair. Resolution of the 8th stage could be seen as successful ageing.

Building on this theory, that the developmental task of late adulthood was looking back over one's life and accepting its meaning, Carstensen (1993) proposed the Socioemotional Selectivity Theory. This theory suggests that an individual's life goals change as they age. In the earlier years of life, when an individual perceives that they have more life to live than has already been lived, their life goals may reflect investments that will pay off in the future, such as knowledge acquisition, career planning and development of social networks. Life goals in the later years of life focus more on maintaining emotional balance in the present or very near future, and may involve spending time with important people in their social network and engaging in activities with more immediate benefits.

There are limitations to Erikson's model. There is uncertainty as to what behaviours clinicians should look for so as to identify which stage someone is in and therefore evaluate their development (Hamachek, 1988; 1990). It has also been questioned as to whether the model is applicable to individuals from different ethnic backgrounds, including criticism that it reflects the experience of

White, heterosexual boys (Kropf & Greene, 2009). Others have questioned the sequential nature of the model and the proposed age ranges for each stage (Whitbourne *et al.*, 1992). However, the model continues to offer a helpful framework by which to understand psychosocial development and motivational factors throughout the life course.

While the importance of psychosocial development is recognised clinically there is a limited evidence base demonstrating the impact of successful development on outcomes. In a large study of 840 older people, Ranzijn and Luszcz (1999) looked at the role of acceptance of one's life, which they considered a proxy measure for ego integrity, in the maintenance of well being. They found a significant relationship between the two variables which was of similar magnitude to that found between well being and self rated health, which is recognised as a strong predictive factor (Ranzijn & Luszcz, 1999). Therefore they concluded that a sense of ego integrity had a positive impact on an individual's well being. In a clinical sample of 35 older people, Chimich and Nekolaichuk (2004) also looked at ego integrity and found that ego integrity was negatively correlated with depression and positively correlated with hope. In both of these studies there is a suggestion that the relationship between variables may be reciprocal. A sense of ego integrity may act as a resilience factor against stresses and therefore improve well being. Similarly a sense of well being may result in the individual feeling more accepting of their life.

An understanding of how successfully an individual has met developmental challenges across the life span and developed a sense of ego integrity can provide a context for formulating their difficulties and considering areas for intervention. Those people who have reached old age but not developed a sense of acceptance towards the challenges of ageing are likely to feel distress as a result. It may also offer insight in to the coping strategies a person adopts and thus how they manage their difficulties.

Coping

Coping involves cognitive, behavioural and emotional processes aimed at managing challenges faced by the individual. There are a number of different ways that coping is conceptualised, with some researchers considering adaptive coping compared to maladaptive coping. Maladaptive coping might include strategies such as denial, venting at others or using substances. Adaptive coping allows individuals to manage the difficulties that they face. Within adaptive coping strategies there is a further differentiation between problem focused and emotion focused strategies. Examples of problem focused strategies include making a plan of action to change the situation or getting advice from others. Examples of emotion focused strategies include seeking support from others or trying to find humour in what has happened.

There is a great deal of research on coping and its impact on mental health and on quality of life, particularly in clinical health and severe mental illness

populations. The coping strategies used and their perceived effectiveness has been shown to have a significant impact on mental health related quality of life in a number of different physical health conditions (Wahl, Hanestad, Wiklund & Moum, 1999; Gibson *et al.*, 2011; Westerhuis *et al.*, 2011). Within severe mental illness coping strategies have been found to have an impact upon the severity of psychotic and depressive symptoms, adherence to medication and quality of life (Meyer, 2001; Lincoln, Lullman & Rief, 2007; Ritsner *et al.*, 2003). While there is less research on the impact of coping on quality of life in individuals with less severe mental health difficulties; building coping is often a key focus for psychological interventions with all mental health difficulties.

It has been suggested that the effectiveness of different ways of coping may change as people age. In a comparison of younger adults with severe mental illness and an age matched non-clinical control group, those with severe mental illness reported less effective coping and more emotion focused coping than the non-clinical controls (Macdonald, Pica, McDonald, Hayes & Baglioni, 1998). While problem focused coping may be a more effective coping strategy at earlier stages of life, it may be that emotion focused coping is more effective in dealing with later life stressors where less can be done to modify stressors such as failing health and mobility. Berry, Barrowclough, Byrne and Purandare (2006) looked at coping strategies and their effectiveness a sample of older people with severe mental illness and again compared with a non-clinical control group. They found that those individuals with a severe mental illness diagnosis used significantly more problem focused strategies and rated their coping as less effective when

compared to controls (Berry *et al.*, 2006). As there was no non-clinical control group it can not be ascertained whether this result is specific to the severe mental illness population or more general to those who experience mental health difficulties.

It is possible that coping is related to ageing and more specifically to psychosocial development. Those people who have successfully developed ego integrity may adopt more emotion focused strategies, accepting that some things can not be changed. Whereas someone who has not reached this stage may still try to use problem focused strategies as they try to change things. This may prove an ineffective strategy in dealing with some of the problems more likely to be faced by an older population. There may be a need to identify the coping strategies used by an individual and develop interventions targeted to help people adopt more stage appropriate coping, increasing acceptance which in turn maximises functioning and reduces distress.

Cohort beliefs

When working with older people there also needs to be a consideration of the cohort to which they belong. Different cohorts have lived through different significant historical events and have different cultural norms (Knight, 1996; Laidlaw *et al.*, 2003). One area where cohort beliefs are likely to impact upon an individual's quality of life is in their illness beliefs.

The perceptions that a person holds about their mental illness in terms of its controllability, sense of stigma and expectations for the future can have a significant impact on mood and quality of life. In a sample of individuals with a diagnosis of severe mental illness, beliefs regarding the controllability of their illness discriminated between those who experienced depression and those who did not (Birchwood *et al.*, 1993). In a later study Birchwood *et al.* (2000) found depression to be associated with beliefs about the cause of illness being related to the self. Beliefs about illness have been found to be significantly correlated with self rated quality of life when symptom severity is controlled for (Lobban, Barrowclough & Jones, 2004).

Older people are likely to have different beliefs about mental illness itself compared to younger people due to the lived experiences of their particular cohort, their understanding of mental health difficulties when growing up and their knowledge of how people were treated. Older people are possibly more likely to hold stigmatising beliefs about mental illness, with people in the old-old age range commonly believing it to be a sign of personal failure or deficiency (Lebowitz & Niederehe, 1992). This stigma towards mental illness may come from the people around the individual or may be in the form of self-stigma, meaning the individual is doubly impacted (Corrigan & Watson, 2002).

Negative beliefs about mental illness may prevent older people from accessing support, engaging in support that is offered, adhering with medication or impact

upon their sense of self (Evans, 2007), all of which could have an impact on quality of life

In light of the theoretical basis of psychosocial development and the existing research, it seems likely that successful psychosocial development will have a positive impact on quality of life. Other factors which are known to be important when working with individuals experiencing mental health problems, such as coping strategies and illness perceptions, represent possible areas where an individual's age or stage will have an influence.

The current study aims to examine the impact of psychosocial development, coping style and illness perceptions on quality of life in older people with mental health difficulties. It is hypothesised that better psychosocial development will be associated with better quality of life. The relationship between quality of life and resolution of different stages of psychosocial development will be explored and it is hypothesised that successful resolution the final stage, development of ego-integrity, will be most significantly correlated with quality of life in an older people population. It is also hypothesised that the use of emotion focused strategies, which might be considered more adaptive in this population and therefore more successful in managing stress, will be associated with better quality of life. And that negative perceptions of illness, which are likely to be influenced by an individual's cohort beliefs, will be associated with poorer quality of life. The relative contribution of these psychological variables to quality of life as well as more objective factors will be considered.

Method

Participants

Participants were 24 individuals aged over 65 with mental health difficulties living in the community and receiving care from the community mental health team for older people (CMHT-OP) in NHS Lanarkshire. Clinicians in the CMHT-OP reviewed their caseload for potential participants and then made the first approach to individuals for whom they were a key worker. Potential participants were given information about the study and asked to opt in by contacting the researcher. All measures were administered by the researcher. Demographic information was gathered by the researcher via participants' guided self reports.

Measures

The WHOQOL-Old (Power et al., 2005).

The WHOQOL-Old is a measure of quality of life in older people which considers six domains: sensory abilities; autonomy; past, present and future activities; social participation; death and dying; and intimacy. It has been shown to have good reliability and validity (Peel, Bartlett & Marshall, 2007). Quality of life was the primary outcome variable for this study.

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).

The Hospital Anxiety and Depression Scale (HADS) is a brief measure which was originally developed for non-psychiatric hospital patients to identify cases of

anxiety and depression. Scores range from 0-21 with higher scores indicating more significant symptoms, a cut off of 11 is used to identify clinical cases. It has been suggested to be a particularly helpful measure in older people populations as the questions do not focus on physical symptoms of anxiety and depression which can often be accounted for by comorbid physical health problems. The HADS has been widely used in research, and has good reliability and validity (Bjelland *et al.* 2002). The HADS was used to describe the symptomatology of the sample.

Modified Erikson Psychosocial Stage Inventory (Darling-Fisher & Leidy, 1988).

The Modified Erikson Psychosocial Stage Inventory (MEPSI) assesses Erikson's stages of psychosocial development (Erikson, 1963) with 8 subscales representing the 8 stages of Erikson's original model. Each subscale can be considered individually and the MEPSI total score reflects the strength of psychosocial attributes across the stages. Studies using diverse population suggest that the MEPSI is a reliable and valid instrument (Leidy & Darling-Fisher, 1995). The MEPSI was used to capture the psychosocial development of the participants and the extent to which they had reached ego integrity.

Brief COPE (Carver, 1997).

The Brief COPE is a 30 item scale which assesses individual's coping strategies. There are 14 subscales, which can be grouped in to adaptive versus maladaptive

coping or into emotion versus problem focused coping. Research has found that the COPE and Brief COPE have predicted clinically relevant outcomes across different potentially stressful situations (Carver, 1997; Meyer, 2001). This tool was selected to examine the coping style of participants.

Personal Beliefs about Illness Questionnaire (Birchwood *et al.* 1993).

The Personal Beliefs about Illness Questionnaire (PBIQ) aims to capture the extent to which an individual accepts scientific and societal beliefs about mental illness. It considers control over illness, self as illness, expectations, stigma and social containment. Higher scores on the scale reflect more negative illness perceptions. The scale has been shown to have good reliability and validity (Birchwood *et al.*, 1993).

Statistical Analysis

The data met assumptions for parametric tests and therefore Pearson's correlations were carried out to examine the correlation between psychosocial development, coping style, illness perceptions and quality of life. Preliminary correlational analyses were also performed to investigate relationships between demographic characteristics, psychological variables, and quality of life. Again Pearson's correlations were used for most analyses, however, the subscales of the PBIQ did not meet the assumptions for parametric tests and therefore Spearman's correlations were used for analyses which included the subscales. The most significant variables were entered into a multiple regression model to further examine the impact of these factors on quality of life. As multiple

correlations had been carried out there was a greater risk of Type I error therefore a Bonferroni correction was applied. Significance level was set at standard .05, with the Bonferroni correction, with 30 correlations being carried out, the significance level was .002. SPSS version 19.0 was used for all analysis.

Results

Sample characteristics

Twenty six individuals opted in to the study. One was unable to give informed consent to take part in the study and one individual decided not to take part. The demographic and clinical characteristics of the sample are given in Table 1.

The most up to date demographic information for North and South Lanarkshire comes from the 2001 census which details information for the age groups 60 – 74 and 75+. Comparison with this information indicates that the sample is representative in terms of spread of ages, gender mix and ethnicity (National Records for Scotland, 2012a; National Records for Scotland, 2012b).

Reliability of outcome measure

Cronbach's alphas were carried out on the subscales and total score of the WHOQOL-Old. All were in the acceptable range with the total score displaying a consistency coefficient of $\alpha = .87$.

Table 1. Demographic and clinical characteristics of the sample

<i>Characteristic</i>		
Gender:	Male	11 (46%)
	Female	13 (54%)
Age:	Mean (SD)	72 (5.2)
	Median	72
	Range	66-84
Marital status:	Married	12 (50%)
	Bereaved	7 (29%)
	Separated	3 (13%)
	Never married	2 (8%)
Living situation:	Living alone	9 (38%)
	Living with partner	12 (50%)
	Living with family member	1 (4%)
	Supported accommodation	2 (8%)
Ethnicity:	White British	23 (96%)
	White European	1 (4%)
Occupational status:	Retired	23 (96%)
	Never worked	1 (4%)
Primary diagnosis:	Anxiety	8 (33%)
	Depression	11 (46%)
	Schizophrenia	1 (4%)
	Bipolar disorder	2 (8%)
	Psychosis not otherwise specified	2 (8%)
Years contact with MH services:		
	Mean (SD)	11 (16.10)
	Range	1-60
HADS anxiety:	Mean (SD)	8.08 (4.69)
	Range (IQR)	0-17 (6-11)
HADS depression:	Mean (SD)	7.63 (4.55)
	Range (IQR)	0-19 (5-10)
COPE:	Adaptive – Mean (SD)	19.71 (7.40)
	Maladaptive – Mean (SD)	10.42 (4.11)
PBIQ:	Mean (SD)	30.71 (7.90)
MEPSI total:	Mean (SD)	284.75 (42.27)
WHOQOL-Old:	Mean (SD)	85.63 (14.14)

A comparison was made between the scores found in Power *et al.*'s original sample and the scores in this sample. There was a significant difference between the two samples on scores for social participation ($t = -2.31, p < .05$), the effect size was moderate ($r = -.25$). No other significant differences were found.

Psychosocial development and quality of life

Pearson's correlations were carried out to between MEPSI scores and the WHOQOL-Old to test the hypothesis that better psychosocial development will be associated with better quality of life. Also, to test the hypothesis that quality of life would be most significantly correlated with MEPSI 8 in a sample of older people. The total score gives a measure of psychosocial development overall and each stage was also considered separately. Correlations are given in Table 2.

Table 2. Correlation between WHOQOL-Old and MEPSI scores

	<i>r</i>	<i>P</i>
MEPSI 1	.65	.00
MEPSI 2	.39	.06
MEPSI 3	.63	.00
MEPSI 4	.50	.01
MEPSI 5	.65	.00
MEPSI 6	.46	.02
MEPSI 7	.51	.01
MEPSI 8	.69	.00
MEPSI total	.69	.00

Correlations between the WHOQOL-Old and MEPSI 1, 3, 5 and 8 and the total score all remained significantly when the Bonferroni correction was applied.

Total score on the MEPSI was significantly positively correlated with

WHOQOL-Old suggesting that better quality of life was associated with more successful psychosocial development. Of the individual stages MEPSI 8 had the strongest correlation with WHOQOL-Old as hypothesised. However, a number of other stages were also strongly and significantly correlated.

Coping style and quality of life

There was a large positive correlation between use of adaptive coping strategies and WHOQOL-Old (see Table 3 for correlations) indicating that greater use of adaptive coping strategies, either problem or emotion focused, was associated with greater quality of life. It was hypothesised that quality of life would be associated with the use of more emotion focused strategies. This relationship was not found, there were no differences between reports of emotion and problem focused coping. A moderate negative relationship was found between the use of maladaptive coping strategies and quality of life.

Illness perceptions and quality of life

It was hypothesised that negative illness beliefs would be associated with poorer self rated quality of life. There was a large negative correlation between PBIQ and WHOQOL-Old scores indicating that more negative beliefs about illness were associated with poorer quality of life.

Exploratory analyses were carried out to consider which factors in perceptions of illness were significant. The subscales on the PBIQ look at feelings of control over illness, sense of self as illness, expectations about illness, stigma and social

containment. The subscale scores were not all normally distributed and therefore appropriate non-parametric tests were carried out. There were large and significant correlations between control over illness, sense of self as illness and expectations of illness and quality of life. No significant correlations were found between stigma or social containment and quality of life.

Predictors of quality of life

The relative contribution of the objective and subjective factors assessed in this sample to quality of life was considered using a multiple regression model. There were no significant associations between quality of life scores depending on marital status or living situation. Ethnicity was not included as only one individual did not report their ethnicity as white British. Correlations between all other demographic and clinical variables and the quality of life scores were carried out (see Table 3). None of the demographic characteristics were associated with quality of life.

After the Bonferroni correction was applied, adaptive coping, expectations and total PBIQ and HADS anxiety and depression scores remained significantly correlated with quality of life. Due to the small numbers in the sample and the assertion that the absolute minimum for a multiple regression is five times as many participants as predictors (Brace, Kemp & Snelgar 2006), the four variables with the strongest correlations with quality of life were identified to be entered in to the regression model. All subscales of the measures were included in the correlation matrix.

Table 3. Correlations between WHOQOL-Old and clinical and demographic variables.

		<i>Correlation coefficient</i>	<i>P</i>
Age		.27	.21
Brief COPE	Adaptive	.66	.00
	Maladaptive	-.44	.03
PBIQ	Control	-.54	.01
	Self as illness	-.53	.01
	Expectations	-.63	.00
	Stigma	-.24	.26
	Social	-.22	.31
	Total	-.63	.00
HADS	Anxiety	-.62	.00
	Depression	-.76	.00

To test for multicollinearity the correlation matrix was examined for very strong (greater than 0.8) correlations between predictors. The five strongest correlations were depression as measured by the HADS, MEPSI 8, total MEPSI, adaptive coping scores from the COPE and negative illness perceptions from the total PBIQ scores. There was a very strong correlation between MEPSI 8 and total MEPSI ($r = .91, p < .001$) and so only one variable could be entered in to the model. Both were equally correlated with quality of life and MEPSI 8 was selected as this is the stage that reflects the population being examined, overall ego integrity and the stage hypothesised to have the strongest relationship. The predictors were entered in to the model simultaneously, which is considered the best method when numbers are small (Field, 2005). The results are given in Table 4.

Table 4. Multiple regression predictor variables

<i>Predictor</i>	<i>B</i>	<i>SE</i>	<i>Beta</i>	<i>t</i>	<i>Sig.</i>
HADSd	-1.21	0.67	-.39	-1.82	.09
MEPSI8	0.76	0.34	.43	2.26	.04
Adaptive coping	0.46	0.34	.24	1.38	.18
PBIQ total	0.11	0.39	.06	0.27	.79

The overall model was significant $F(4, 19) = 11.70, p < .01$ and predicted 65 per cent of the variability in scores on the WHOQOL-Old, Adjusted R square = .65. Only MEPSI 8 independently contributed significantly to WHOQOL-Old scores.

Discussion

Main findings

The sample appeared to be representative of the general population of Lanarkshire in terms of age, gender and ethnicity. However, the generalisability to the wider population beyond Lanarkshire may be limited by the very limited ethnic diversity in the sample.

The mean HADS scores for depression and anxiety were both below the suggested cut off points for identifying clinical cases which are scores of more than 11 for both anxiety and depression (Zigmond & Snaith, 1983). In a large cohort study, Beekman *et al.* (2002) found that even subthreshold depression can be significant and chronic in older people. In this study depression and anxiety were still found to be significantly associated with quality of life despite being below clinical cut off.

Psychometrics of the primary outcome measure generally reflected those found by Power *et al.* (2006) in their large scale study. There was a significant difference between the two samples on scores for social participation, with the current sample reporting poorer participation in social activities than found by

Power *et al.* (2006). This may be a reflection of more limited opportunities for people with mental health difficulties. The WHOQOL-Old is a measure specifically designed for the older people population and therefore comparison with younger populations was not possible within this study.

As hypothesised, quality of life was strongly correlated with psychosocial development, with more successful development being correlated with better quality of life. This relationship was strongest with scores on the 8th stage of development, however, there was also a strong correlations between quality of life and a number of other stages of psychosocial development, namely stages 1, 3, 5 and 7. This may reflect the idea that successful resolution of the 8th stage is a culmination of previous stages. Those people who successfully resolved the earlier stages are more likely to successfully resolve stage 8 and may therefore have better quality of life.

Quality of life was strongly correlated with the use of adaptive coping strategies. The individuals in this sample were no more likely to use emotion focused compared to problem focused strategies which was not what was expected in an older people population where emotion focused coping being employed to deal with uncontrollable stressors was predicted. This may be due to the dispositional wording used in the COPE rather than identifying a specific stressor which might be relevant to this population such as failing health.

Negative perceptions of illness were strongly correlated with perceived poorer quality of life. The exploratory analysis provided some interesting results with regards to the impact of negative illness perceptions on quality of life. The factors of perceptions of illness that were significantly negatively correlated with quality of life were those related to perceptions about self as illness, controllability about illness and expectations for the future. There was no significant relationship between stigma and a need for social containment. Stigma and the need for social containment might be factors that would be expected to be more significant in an older cohort due to research which suggests they hold stigmatising beliefs towards themselves (Lebowitz & Niederehe, 1992). The results reflect those found by Birchwood *et al.*, (1993) in a sample of younger adults with psychosis. They found that controllability of illness was the important differentiating factor between individuals who reported depression and those who did not (Birchwood *et al.*, 1993).

The relative contribution of the variables considered in this sample was assessed using a multiple regression model. None of the objective demographic variables were strongly correlated with quality of life and were therefore not included in the model. This supports the majority of research with older populations generally, and with older people with severe mental illness (see review). The regression model predicted 65 per cent of the variance in quality of life scores which is a significant proportion and greater than found in other predictive models. The large percentage of variance explained may be due in part to the older people specific measure of quality of life used in this study. The subscale

of the MEPSI which reflected resolution of the 8th stage was the main contributor to the model. This could suggest that a sense of ego integrity and acceptance of life is of particular importance in this sample, over current symptoms, coping style and illness perceptions.

Limitations

The key limitation of this research is the small number of participants. This is due in a large part to the recruitment method utilised. Due to concerns regarding acquiescence or feelings of coercion in older people who are in contact with mental health services the recruitment method for this study was very passive but in turn expected a lot from people in order to opt in. It required potential participants to read and take in a lot of information and make a decision to get involved in something that might be quite new to them. Whereas younger adults may be used to the idea of being approached to take part in research and familiar with the role research plays, this could be new to older people (Williams, 1993). The sample size limited the number of variables that could be considered in the regression model and only those with the strongest correlations could be included. It is therefore possible that the results are vulnerable to Type II errors and that important variables have been missed.

The recruitment method may also have affected the representativeness of the sample. Those individuals who opted in could be considered to be more likely to be highly motivated and well functioning older people who engage well with services. In order to receive the packs and make contact with the project they

have to have had contact with services, taken time to read the information and make the phone call or post a letter suggesting that they may be more independent and motivated. This idea of good engagement with services is partly reflected in the very low drop out rate from the study. Therefore, although the more passive recruitment method had an impact on numbers it may have assured that those people who took part did not find it too onerous or burdensome.

All of the demographic information used in the analysis concerning diagnosis and years of contact with mental health services for example was collected via self reports. This potentially could mean that the information received was not accurate. However, the questionnaires rely on self report and gaining this information from the participants meant that the researcher did not have unnecessary access their medical records and people could choose what they disclosed.

Another key limitation is the cross sectional design of the study which does not allow any causal relationships to be drawn. It is likely that reciprocal relationships exist between the significant variables found in this research.

Clinical Implications

Subthreshold levels of affective disorders, particularly depression, were found to have a significant relationship with quality of life. It may be that measures such as the HADS are not picking up the clinically significant levels of depression. Therefore other measures, more appropriate for this population and the

symptoms they experience, such as apathy and anhedonia as opposed to unhappiness, are required to ensure that symptoms which have a functional impact are identified and targeted in intervention. This may be of particular importance in an ageless service where using a generic measure for all ages may mean that the depression an older person is experiencing is missed.

What was found to be particularly important in this sample is psychosocial development which had a significant relationship with quality of life and may indicate an importance of understanding developmental issues when working with older people. Direction of causality can not be assumed, however, it seems likely that an individual's psychosocial development across the lifespan has an impact on current perceptions of quality of life as opposed to the relationship working in the other direction. If services in the future are to change so that older people are seen in a generic adult service for functional illnesses, it may be important that professionals consider psychosocial development, as is routinely the case in child and adolescent services. Identifying earlier psychosocial stages where a person has faced difficulties and helping them to resolve these may help them to successfully resolve the final stage. Psychosocial development may be as important as considering comorbid physical health difficulties and cohort differences when working with this population.

The correlation between use of adaptive coping strategies and quality of life adds weight to work already carried out with older people around developing good coping strategies. Contrary to what was expected, there was no difference

between the use of problem focused and emotion focused strategies. What may be important is helping people to develop a range of strategies and recognise the appropriate strategies for each situation. While older people may be more likely to experience stressors which cannot be changed, they continue to experience stressors that do have a solution that they can manage.

There was a strong correlation between illness perceptions and quality of life. The further exploratory analysis suggests that helping people to feel in control of their illness may be beneficial. This might involve helping them to recognise signs that they are facing difficulties, again using good coping strategies and using self help resources to help them feel empowered. This could be tailored to life stage. Based on Erikson's model (1963) there is a reduction in motivation to acquire knowledge and so self help materials would need to be emotionally meaningful and initially guided by support from services.

Future research

Future research is needed to explore the role of psychosocial development further and could involve qualitative research to help to understand what the key elements in building ego integrity are. Further studies should be longitudinal to explore causality and help to determine those effects which are related to age and those which are due to cohort experiences.

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Quality of life in older people with mental health difficulties: The impact of chronicity.

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Abstract

As the population ages, individuals with long standing, chronic mental health difficulties are more likely to live into old age. While research suggests that psychiatric symptoms reduce as people age with mental illness, there is still an impact on quality of life. This study explores the impact of long standing mental health difficulties on psychosocial development and quality of life. Twenty four individuals (mean age 72) who were living in the community and had contact with secondary mental health services participated in the study. The mean number of years contact with secondary mental health services was 11 years. No significant relationships were found between years of contact with services and either quality of life or psychosocial development. These findings are discussed with reference to the limitations of the research and could suggest an adaptation or resilience building as people age with mental health problems.

Key words: severe mental illness, older people, quality of life, chronicity

Introduction

Mental health in older people

With advances in health care, the world population is ageing and people are living longer and living healthier lives (Kinsella & Wan He, 2008). Poor physical and mental health is not an inevitable part of growing old. However, where mental health problems are present, older people require the same standard of care, tailored to their specific needs, as children, adolescents and adults of working age in order to ensure best quality of life. Therefore, services need to address the needs of the population and this requires a clear evidence base as to what those needs might be.

Mental health problems in older people may present as an acute first episode difficulty relating to life events or the challenges of getting older. Alternatively, the difficulties faced may be the result of a more chronic and long standing mental health problem that they have experienced throughout their lives. Individuals with long standing mental health problems include those with diagnoses such as schizophrenia or bipolar disorder but also chronic depression. It may be more meaningful to consider chronicity rather than focus on diagnoses *per se* as it appears that it is the functional impact of mental health difficulties rather than specific symptoms which are important to an individual's sense of well being (Meltzer, 1999).

As people live longer, the proportion of those with long standing or chronic mental illness that require community mental health and psychology services will increase.

In the past individuals with long term mental health difficulties were less likely to live to old age. The psychoactive medications available had a significant impact upon their physical health after many years of use and individuals received less support to maintain their physical health as medicines were less well developed and needs less recognised (Bentall, 2009). In addition, poor self care and factors associated with low socioeconomic status, as is common in those with significant mental health difficulties, resulted in poorer physical health. There remains an excess mortality in severe mental illness due to such factors, however, they are likely to have been more problematic in the past (Brown, Iskip & Barraclough, 2000).

Those individuals who did live to old age may have experienced significant cognitive impairment due to the long term side effects of medication or through having treatments such as ECT. As a result they may have been more likely to be looked after in institutions and more recently in long stay wards and care homes. However, with improved care and support and a drive to provide services in the community over the coming years there will be an increase in the number of older individuals with chronic mental health difficulties that are seen by community mental health and psychology services.

Research suggests that in individuals with severe and enduring diagnoses such as schizophrenia and bipolar disorder, psychiatric symptoms, although still present, tend to be less severe in later life (Belitsky & McGlashan, 1993; Jeste et al, 2003; Calabrese et al., 2003). Jeste et al., (2003) examined 290 outpatients given a diagnosis of schizophrenia, with an age range of 46 – 65. They found that ageing was associated with decreased psychiatric symptomatology and fewer depressive symptoms. This effect remained even when duration of illness was controlled for. Despite this reduction the sample reported significantly more problems with day to day functioning and overall well being when compared to a non-clinical control group (Jeste et al, 2003). This continued impact on quality of life compared to non clinical controls has been found in recent studies considering the correlates of quality of life in older people with severe mental illness (Folsom et al., 2009; Cohen, Hassamal & Begum, 2011).

Research that has been carried out into the correlates of quality of life in older people with severe mental illness has typically used a non clinical control group. Therefore, they have not addressed whether older people with chronic mental illness differ from older people with more acute or first episode mental health difficulties. As people age with mental health difficulties there may be a cumulative impact across the life span which has an impact on psychosocial development and on their current quality of life.

Psychosocial development

An important theory of lifespan development is Erikson's Theory of Psychosocial Development (Erikson, 1963). The theory posits that there are 8 developmental stages. At each stage there is a conflict between the individual's identity and a change in social and personal expectations. Successful resolution of each stage results in the emergence of a new ego quality and increases the individual's resources for successful resolution of the following stage. Therefore difficulties at a preceding stage may impact on the ability to resolve the next stage. Erikson suggested that normal development required positive resolutions to outweigh the negative (Brown & Lewis, 2003). The 8th stage, reached in late adulthood, was seen by Erikson as a culmination of successful resolution of all previous stages (Hannah, Domino, Figueredo & Hendrickson, 1996). Erikson's model suggests that the task of late adulthood was looking back over one's life and accepting its meaning and in doing so achieving ego integrity. Failure of this integration leads to despair.

The presence of a chronic mental health problem may have a negative impact upon an individual's ability to successfully resolve the different psychosocial stages across the lifespan and in turn reach ego-integrity. They may be less able to develop strategies to adapt to the challenges of ageing. They may see their current situation as unchangeable and not in line with where they want to be, which leads to feelings of despair.

There are a number of ways in which long standing mental health problems might impact upon successful development. Individuals may have spent long periods in mental health hospitals or institutions which reduced their opportunities for growth and developing interests which may be important for developing identity accounted for by the 5th stage. They may have a reduced social network, be less likely to have close friends and a partner due to difficulties they faced in younger adulthood when such relationships are most often formed. This may impact on the ability to resolve the 6th stage of intimacy versus isolation. Similarly, mental health difficulties may interfere with an individual's ability to secure and maintain employment and in turn gain a sense of productivity which is integral to the 7th stage. All of these challenges may impact upon an individual's ability to reach later adulthood and look back over life and accept its meaning. These individuals are also more likely to carry previously unresolved crises into old age which could further impact upon their perceived quality of life.

The current study aims to consider the impact of chronic mental health difficulties on quality of life in older people. It is hypothesised that longer duration of mental health difficulties will be associated with poorer quality of life. It is also hypothesised that longer duration of mental health difficulties will be associated with poorer psychosocial development.

Method

Participants

Participants were 24 individuals aged over 65 with mental health difficulties living in the community and receiving care from the community mental health team for older people (CMHT-OP). Clinicians in the CMHT-OP reviewed their caseload for potential participants and then made the first approach to individuals for whom they were a key worker. Potential participants were given information about the study and asked to opt in by contacting the researcher. All measures were administered by the researcher.

Measures

The WHOQOL-Old (Power et al., 2005).

The WHOQOL-Old is a measure of quality of life in older people which considers six domains: sensory abilities; autonomy; past, present and future activities; social participation; death and dying; and intimacy. Scores range from 24 to 120. It has been shown to have good reliability and validity (Peel, Bartlett & Marshall, 2007). Quality of life is the primary outcome variable for this study.

Modified Erikson Psychosocial Stage Inventory (Darling-Fisher & Leidy, 1988).

The Modified Erikson Psychosocial Stage Inventory (MEPSI) assesses Erikson's stages of psychosocial development (Erikson, 1963) with 8 subscales representing the 8 stages of Erikson's original model. Each subscale can be considered individually and the MEPSI total score reflects the strength of

psychosocial attributes across the stages. Studies using diverse populations suggest that the MEPSI is a reliable and valid instrument (Leidy & Darling-Fisher, 1995). The MEPSI was used as a measure of psychosocial development and the total score was used as an overall measure of successful development.

Other measures

Information regarding years of contact with mental health services was used as a proxy measure for duration of illness. This information and demographic information was gathered by the researcher via guided reports from the participants. The presence of affective symptoms, to give an indication of current functional symptoms, was assessed using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983).

Statistical Analysis

The participants were grouped according to diagnoses and differences between the groups were examined. The groups were severe mental illness (e.g. schizophrenia, bipolar or psychosis not otherwise specified) and affective disorders (e.g., anxiety or depression). Categorical variables were compared using chi-square and continuous variables using ANOVA. The data on years of contact with mental health services did not meet assumptions for parametric tests and therefore Spearman's correlations were carried out to examine the correlation between years of contact with mental health services and quality of life and between years of contact and psychosocial development.

Results

Sample characteristics

Twenty six individuals opted in to the study. One was unable to give informed consent to take part in the study and one individual decided not to take part. The mean age of the sample was 72. The majority were female (54%), white British (96%) and retired (96%). Half of the sample were married and lived with their partners, nine lived alone, two in supported accommodation and one was supported at home by a family member. The mean number of years of contact with services was 11, median 2.5 with a range of 1-60. The majority of individuals had a primary diagnosis of depression (11) followed by anxiety (8), bipolar disorder (2), psychosis not otherwise specified (2) and schizophrenia (1). The mean score on the WHOQOL-Old for the sample was 85.63 (SD = 14.14).

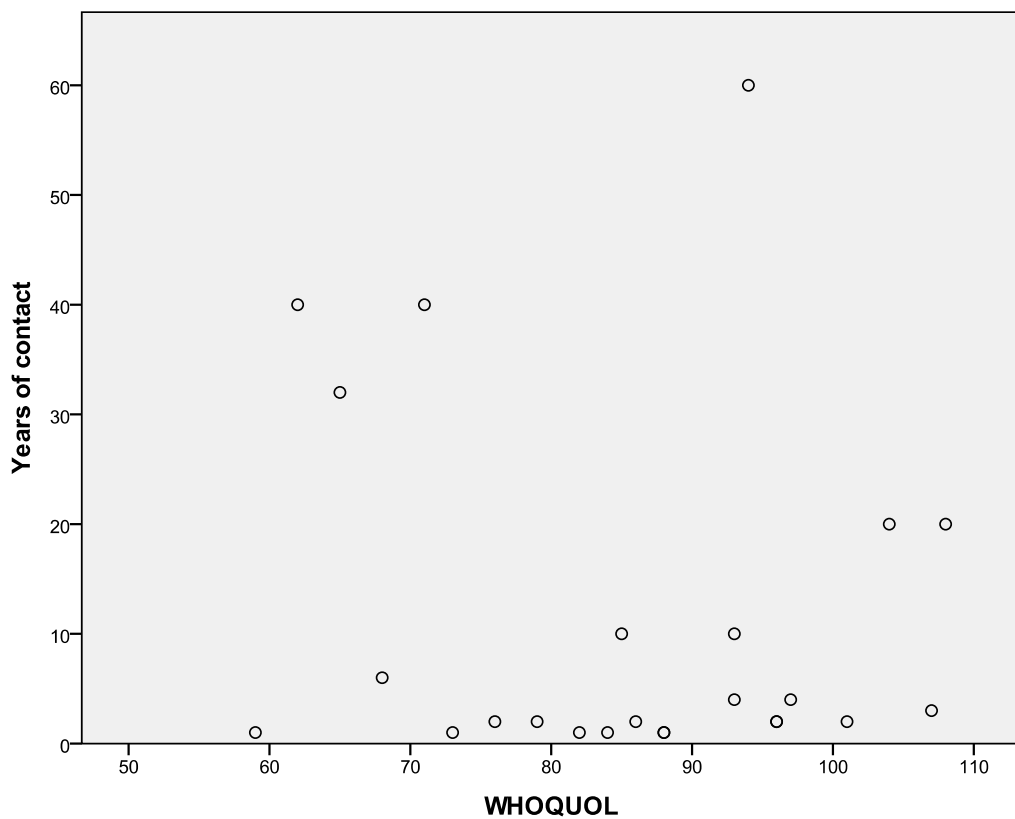
The participants were initially considered in two groups; those who had a diagnosis of a severe mental illness such as schizophrenia, bipolar disorder or psychosis and those with an affective disorder such as depression or anxiety. Differences between the two groups were analysed, the only significant difference was in years of contact with mental health services ($F(2,22) = 29.64$, $p = .00$, $r = .74$). The groups were therefore combined for further analysis.

Impact of chronicity

To examine the hypothesis that longer duration of mental health difficulties would be associated with poorer quality of life, Spearman's correlations were carried out on number of years contact with mental health services and

WHOQOL-Old scores. A non significant relationship between these two variables was found ($\rho = -.10$, $p = .65$). Removing the outlier (one individual reported 60 years of contact) did not alter the result ($\rho = -.05$, $p = .84$). A scatterplot of the relationship between years of contact with mental health services and quality of life indicated no trend, see figure 1.

Figure 1: Scatterplot of the relationship between WHOQOL-Old scores and years of contact with mental health services.



There are four clear outliers from the data, the three in the top left represent individuals who were in the SMI group when participants were grouped by diagnoses.

To examine the hypothesis that longer duration of mental health difficulties will be associated with poorer psychosocial development, Spearman's correlations were carried out between years of contact and MEPSI scores. A non significant relationship between these variables was found ($\rho = -.27$, $p = .20$; $\rho = .26$, $p = .22$ respectively).

Discussion

Discussion of main findings

Initially, a comparison of two groups, a severe mental illness and a clinical control group, was planned in the analysis. However, no differences in clinical characteristics such as extent of affective symptoms or reports of quality of life, were found between the two groups and therefore all of the data were considered together. Much of the research suggests that psychiatric symptoms diminish as a person ages and those symptoms that are left are more of the negative or affective symptoms (Belitsky & McGlashan, 1993; Jeste et al, 2003). Both groups reported subthreshold levels of anxiety and depressive symptoms on the HADS, it is possible that the HADS does not pick up the characteristic symptoms, such as flattened affect, that might differentiate between those with SMI and those with more recent onset of affective disorders.

There was no significant correlation between duration of mental health difficulties and quality of life. A scatter plot indicated no trend in the relationship. There were four outliers in the data, three of which had a severe mental illness diagnosis. This indicates those individuals who had a longer duration of contact with mental health services and were at the lower end of the distribution of quality of life scores. This might suggest that people with a diagnosis of severe mental illness perceive their quality of life as poorer than those with affective disorders. However, the numbers are too small to draw any conclusions.

There was also no significant correlation between duration of mental health difficulties and psychosocial development.

Years of contact with mental health services was used a proxy measure of chronicity of mental health difficulties. The lack of significant impact of chronicity may suggest that the population of older people with enduring mental health difficulties does not have more significant unmet needs compared to other older individuals with more acute mental health difficulties. This may be because symptoms have diminished in the main and therefore cause less distress and have less impact on functioning. Individuals may also have learnt to cope with those difficulties that they do face and have developed good support networks over the years. They may successfully overcome these difficulties through inner resources, self efficacy or social support and develop resilience. It is known that resilience develops as a result of adversity and challenging experiences in life, so

those who do not face such challenges do not develop resilience (Richardson, 2002). Those individuals who have overcome adversity may look back over their lives and feel a sense of achievement in what they have overcome and feel accepting of their life as it is now. As a result they may perceive the quality of life as better than might objectively be expected. These may be the people who are happy to speak with mental health professionals and share their experience in clinical research. Anecdotally, two of the individuals with more chronic mental health difficulties talked about wanting to share their experience to help others.

It is possible that there are people with chronic mental health difficulties who that were not accessed by this study. There may be an optimal window of challenging experiences, whereby, dependent on individual resources, excessive challenges result in people being more likely to be overcome by adversity and develop functional problems and therefore require greater levels of care. As such it would be expected that they may perceive their quality of life as poor and feel despair as they reach late adulthood with a sense that there is not enough time for things to change for the better. These might be the people that research studies need to access in order to identify their unmet needs and the difficulties they face.

Limitations

The key limitation of this research is the small number of participants. This limited the power of the study to detect any differences between the groups based

on diagnosis and increased the risk of making a Type II error when concluding a lack of relationship between chronicity and quality of life.

The recruitment method may also have affected the representativeness of the sample. Those individuals who were approached by their keyworkers, made contact with the researcher and were willing to discuss their difficulties may be likely to be people who are not experiencing significant difficulties and engage well with services. This idea of good engagement is partly reflected in the fact that all but one of the individuals who opted in to the study took part despite there being two appointments that they needed to keep.

Years of contact with secondary mental health services was used as a measure of chronicity of a mental health condition. This was chosen as a more objective and easily identified estimate of when mental health problems started. However, it is known that older people are less likely to access services than younger people and those people who first experienced mental health difficulties a number of years ago may have been even less likely to access services due to stigma or a lack of awareness of mental health and fewer well developed and accessible services available. The result of using this proxy measure was that the majority of the sample reported a limited number of years of contact which may not have reflected the duration of their illness.

Clinical Implications

The results of this study suggest that in older people long standing mental health difficulties do not have a significant impact on quality of life as they age. There may be an important role for acceptance and resilience in determining quality of life in this population and if so interventions should focus on fostering acceptance. Older people may be considered an important source of knowledge for clinicians working with younger individuals with chronic mental health difficulties (Solano & Whitbourne, 2001). Attempts may be made with younger people to help them to build resilience. Interventions aimed at developing and recognising internal resources, being optimistic, keeping things in perspective and maintaining self esteem and self efficacy (Resnick, Gwyther & Roberto, 2011) may help to build resilience across the lifespan.

Future research

While this study raises more questions than it answers it introduces ideas for future research. There may be no significant impact of severe mental illness on quality of life in older people. Their needs may be the same as other people with more acute mental health difficulties, however, further studies are required to confirm this. There is a possibility that this study has not accessed the individuals whose quality of life has been more significantly impacted by chronic mental health problems. Clinicians do work with older people with chronic mental health difficulties with unmet needs and poor quality of life but they are a difficult population to recruit into a study with this design. In order to further explore the impact of chronic mental health difficulties it is important that

clinicians working with these individuals publish their experiences, in the form of case series for example, to help guide research and clinical work.

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Conclusion

While the results of this study should be interpreted with caution there appear to be potentially interesting and clinically relevant findings. Building coping strategies and addressing negative perceptions about illness are important areas for clinical intervention aimed at improving quality of life. The research here adds to a body of evidence supporting this. What appears to be particularly important is a sense of achievement and ego-integrity in older people and ways to foster this and help younger adults to reach this stage may help to improve quality of life for older people in the future. One thing to consider is whether as a society in general we need to be more active in promoting awareness of psychosocial development and give people 'permission' to adapt psychologically as they age. This is something we consider when working with younger people. In adolescents we interpret risk taking behaviours as a natural part of their development. Development does not stop in childhood.

Older people with chronic mental health difficulties are a hard population to recruit which may be reflected in the limited research in this area. The research included in the systematic review does not produce compelling evidence that older individuals with severe mental illness require further research and a more focused intervention. Similarly the study discussed here, which has many of the same limitations of those papers included in the review, does not suggest an impact of chronicity on quality of life.

However, there is not strong evidence to the contrary either. It can not be said to be conclusive that chronicity does not have an impact on. It is therefore important that further research is carried out. It is possible that given the very small numbers and the bias within the sample due to recruitment style, this study has identified a subgroup of individuals with chronic mental illness who have developed resilience in the face of adversity and developed acceptance of their life and as a result report good quality of life. There may be other older individuals living with severe mental illnesses who have not developed resilience and struggle to face the challenges of ageing. It is these individuals who anecdotally exist and experience more distress and for whom clinicians have little literature to draw on to guide their work. Unfortunately, due to the very nature of their difficulties, they are less likely to engage in research.

If it is found that older people with severe mental illness are not necessarily disadvantaged compared to their same age cohorts and do not have different needs and resources than their younger counterparts with severe mental illness it is important to know this. These findings still need to be published to prevent further studies being carried out when the question has already been answered. Other clinically relevant research can then follow.

**The challenges of conducting research in older people with severe
and enduring mental health difficulties.**

Prepared in accordance with requirements for submission to the PSIGE

Newsletter (see Appendix 9 for guidelines for contributors)

This paper outlines the importance of conducting research into severe mental illness in older people and highlights some of the challenges. Suggestions for overcoming these challenges are put forward.

The proportion of older people with severe mental illnesses (SMI) will increase over the coming years (Jeste *et al.*, 1999). In the past individuals with a SMI may have died earlier due to physical health problems related to lifestyle choices, reduced self-care or adverse effects of medication for their psychiatric illness. However, over the years there have been overall improvements in living standards, better access to treatments for physical health difficulties and more effective treatments for psychiatric symptoms, meaning that individuals are living longer (Jeste *et al.*, 1999).

Research suggests that psychiatric symptoms, although still present, tend to be less severe in later life (Belitsky & McGlashan, 1993; Jeste *et al.*, 2003; Calabrese *et al.*, 2003). However, individuals continue to experience problems with day to day functioning and report poorer quality of life (Jeste *et al.*, 2003; Folsom *et al.*, 2009). Also, SMI is extremely costly to the health service and to public services, as well as to the individual and their family (Knapp, 1997).

A study of mental health service use and cost in the USA suggested that, while services are less likely to be accessed by older people in general, estimates of the cost of care for older individuals with a diagnosis of schizophrenia were comparable to the youngest individuals with schizophrenia, both being considerably higher than for those aged between 30 and 65 (Cuffel *et al.*, 1996).

They hypothesised that this was due to increased medical comorbidity, cognitive impairment and the side effects of long term medication. A further study of a similar population by Jin *et al.* (2003) found that older people with schizophrenia were underrepresented amongst those using public health services. Individuals aged 65 and over were less likely to be hospitalised or use crisis services or day treatment; the only service which increased with age was case management (Jin *et al.*, 2003). The authors recognise that this may be due to the fact that in the USA, people may switch from public to private healthcare once they become eligible for financial support at the age of 65. However, the results could also be due to the fact that services are less accessible to older individuals. Research on a similar scale does not appear to have been carried out considering the cost to the NHS, however, the factors identified by Cuffel *et al.* (1996) regarding medical comorbidity and cognitive impairment would suggest a higher cost and impact on service use. Greater physical health problems and cognitive impairments have been shown to be associated with higher use of community support services (Shaw *et al.*, 2000).

With the drive towards community based support and helping people to remain independent in their own homes, it is important to know what can be done to help ensure good quality of life for older people with SMI. An important part of this support involves being able to offer appropriate therapeutic intervention to these individuals. In order to develop effective therapeutic interventions, research needs to be done considering the needs to be met and the resources of the individual.

There is extensive research on SMI in children, adolescents and adults of working age. This research has helped inform services and resulted in better outcomes for individuals experiencing SMI. Published research looking at SMI in those over 65 is very limited by comparison. Very few studies have looked at SMI in older people specifically. In a search of two key research databases (PsycINFO and MedLine), Cohen *et al.* (2000) found that only 1 per cent of all research into psychosis had an older adult perspective, and many studies had excluded those over the age of 65 from their sample (NICE, 2010). Due to changes with age in physical health, social functioning, psychiatric symptoms and neuropsychology, findings from studies of younger populations can not be assumed to apply to older people (Cohen *et al.*, 2000). Focused research on different client groups is important to ensure interventions are equitable across the lifespan. A 2010 Government White paper which outlined the importance of research in the NHS said that “focused research is vital to improve health outcomes and reduce inequalities” (Department of Health, 2010).

The discrepancy between the published research activity in older adult populations and the rest of the population seems to reflect a lack of attention to the psychological needs of later life which must be remedied.

I have recently completed my Clinical Psychology training and elected to complete my final year working in an Older People’s Psychological therapies team. At the time of planning my doctoral thesis project, I was working in an

Older People's service as one of my core placements. I had a previous research interest in severe mental illness and was surprised when I realised just how little research there was considering severe mental illness in older people. All that I was learning about working with older people on my placement led me to feel that this was an important area in which to complete some research as there were likely to be key psychological variables in this population which could offer scope for psychological interventions.

The planned study involved comparing older people with a diagnosed severe mental illness with older people who had more recent contact with mental health services for affective disorders to consider the differences between the two groups and identify possible areas for intervention.

Unfortunately, due to difficulties in recruiting participants a comparison study was not feasible. Instead the sample was examined as a whole to examine the ageing specific factors which might be important to consider. The study produced some clinically relevant findings and important questions for further research which are published elsewhere. I also feel that there are things that I could have been done differently. I hope that sharing my experiences of conducting research in this population there will be of benefit to researchers in the future.

The first issue is related to the recruitment method I used, which limited the total number of participants. The recruitment method involved individuals being approached by their Community Psychiatric Nurse (CPN) or other key worker,

given information about the study and opting in to the study by contacting me by phone or by post. The recruitment method was conceived to ensure that people did not feel obliged to take part.

Research participants may be considered vulnerable if they are more likely to agree to take part without considering the impact on them. Older people may be more vulnerable, as it is generally recognised that they have a high regard for professionals and may want to please them. Older people and their families may not realise that participation is voluntary and that not taking part will not affect the care they receive (Williams, 1993). It was hoped that by asking individuals to opt in to the study, they would not feel coerced by their CPN or the researcher to take part.

Feedback from CPNs was that people were initially interested in the study and expressed a wish to take part but they did not then opt in. CPNs felt that their clients were unlikely to read through all the information that was sent to people prior to opting in and that contacting me, someone they had not had previous contact with, may have caused them anxiety. The CPNs felt that if the person could speak with them and then the CPN made contact with me that would be less anxiety provoking. This amendment was proposed however it did not gain ethical approval.

There are other issues with a recruitment method which requires the individual to opt in. Those most likely to opt in may be more likely to have a good

understanding of research and why it is important and be motivated to give their time. As a result, it is possible that those who did opt in to this study were more likely to be well motivated and highly functioning individuals in the main.

It is important to ensure that potential participants do not feel coerced in to taking part in research. However, if the recruitment method limits the number of individuals entering the study for reasons other than an informed decision not to take part, this can also be problematic. Research that is methodologically sound and has a clinical benefit requires a sufficient number of participants (Harris & Dyson, 2001). Asking people to participate in research that they could find stressful or a burden (even when every effort is made to reduce this) that is then not used to further knowledge is unethical in itself. Particularly when, anecdotally, many of the participants reported this as the main incentive for them taking part.

The second issue is more specific to the severe mental illness population. I chose to recruit from older people's community mental health teams, this was in order to identify potential participants and ensure there was a support network in place. However, for a number of reasons, this may have resulted in missing a more representative sample of this population. Severe and enduring mental illness in older people may be more likely to be considered from a medical perspective; maintaining an individual on medication to prevent relapse and hospitalisation. Individuals who have been seen by adult services may remain with their current psychiatrist rather than being transferred to older people's services when they

reach 65. This is understandable and reflects a need rather than age based model. However, when needs related to ageing do arise these might not be recognised by adult mental health workers and appropriate referrals to mental health teams may not be made.

A further consideration is that those individuals with a long history of mental health difficulties may be more likely to have cognitive problems due to long term use of medication, or the side effects of medications they received when they were younger (Karim, 2005, Berry & Barrowclough, 2009). They may therefore be more likely to be in long term mental health wards or care homes rather than in the community (Andrews *et al.*, 2009; Manderscheid *et al.*, 2009). Therefore, those individuals who are in contact with community mental health services could be considered more likely to have successfully overcome the challenges associated with their mental health difficulties. While we can learn important things from these individuals, they may not represent the wider severe mental illness population.

What can be learned from the experiences of carrying out this research? In hindsight the recruitment method could be considered paternalistic and a more assertive recruitment style may be appropriate, enabling people to make their own decisions when given all the information and a chance to discuss it., A more active role for CPNs in recruiting may be beneficial, within the scope of their busy workloads, entrusting that they will not want to coerce their clients and will support them to make the decision that is best for them. Future research would benefit from beginning with more consultation with staff and service users

regarding the best method of recruitment. Although ethical approval was not granted when a more proactive method was suggested, it may be that ethics committees will be more likely to give approval to a proposed recruitment method which has arisen directly from discussion with potential participants.

The recruitment rate may have been improved using the same procedure if I had spent more time within each CMHT, reminding them about the project and helping to identify potential participants. When on placement I was based within two of the teams and these were the teams that identified the greater proportion of participants. While all teams were visited to tell them about the project and again to remind them of the project and help them identify participants, the time constraints of this project and the number of teams meant that more frequent contact was difficult. Future projects looking to recruit in this population may need to consider how this could be managed.

In order to consider a more representative sample, and gain a better understanding of the needs and resources of this population, different services may need to be accessed for recruitment purposes. This could include adult mental health services and long term community care wards. Previous research has also been successful in recruiting from community support groups and charity run organisations. However, this may pose further ethical issues around how the participant information is held and whether people involved in potential participants care need to be informed of their participation.

A further possibility is research on a smaller scale, sharing the experiences of the people we work with clinically, through case series or qualitative research, for example.

I feel it is important that clinicians share their experience of research which has faced difficulties, in order that these factors can be taken in to account when future research projects are being designed. In turn this will increase the likelihood that future research will be methodologically sound, have sufficient numbers and result in clinically important findings. Research with this population may be a difficult prospect, however, I feel that it is important that researchers take on the challenge to ensure appropriate support for these individuals as they face the challenges of ageing.

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