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Ageing with a Serious Mental Illness: A literature and policy review

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Introduction

A definition of serious mental illness (SMI) with a wide consensus is that of the National Institute of Mental Health (NIMH) (Schinnar *et al.*, 1990) and is based on diagnosis, duration and disability (NIMH, 1987). People with serious mental illness have conditions such as schizophrenia or bipolar disorder, over a protracted period of time, resulting in erosion of functioning in everyday life (Tosh *et al.*, 2011). People with SMI have a higher morbidity and mortality from chronic diseases than the general population, resulting in a significantly reduced life expectancy (Robson *et al.*, 2007). With population projections indicating that the number of older adults in the UK (those aged 65 years and over) will increase from 9.6 million in 2005 to 12.7 million in 2021, the numbers of those growing older with SMI is likely to rise. Godfrey (2005) highlight the “layers of invisibility” that older adults with SMI face, suggesting that they are the “most complex, vulnerable, resource poor and high risk long-term service users in society today.” In this discussion the policies we refer to relate to health policy in England, unless otherwise stated and the term “older adults” refer to those aged 65 and over however, we acknowledge in other parts of the UK, for example, Scotland, the picture is somewhat different as the term “adult” refers to all adults aged 18 years and over.

While individuals differ and there is no point at which populations become discretely separate, age does affect the prevalence and nature of illness. As people grow older, certain needs become more common and this changes the context in which mental illness occurs (RCP, 2009a). For example, as well as having physical health needs as a result of their mental health diagnosis and its subsequent treatment over time, older individuals are more likely than younger adults to have physical co-morbidities, thus requiring complex individualised treatment and management. Regarding care provision, the nature of mental health problems in hospitals differs substantially between young and older adults, with higher levels of SMI in older individuals predicting poorer outcomes.

Older adults with mental illness, regardless of other factors, are more likely to die, stay in hospital longer, lose independent function and be discharged to a care home (RCP, 2009b). Historically, people with serious mental illness have not received the same care and attention

in hospital settings compared with the general population due to one or a combination of the following four factors: 1) geographic (lack of co-located medical and mental health services), (2) financial (separate funding streams for medical and mental health services), (3) organisational (difficulty in sharing information and expertise across these systems), and (4) cultural (providers' focus on particular symptoms or disorders, rather than on the patients with those problems) (Druss, 2007).

With older adults being less likely to be included in research, evidence on treatment is often extrapolated from younger populations or absent. It is suggested that ageism, stigma and other forms of discrimination such as gender differences, sexual orientation, disability or religion/belief combine to make: “those growing older with severe mental illness invisible in policy, practice and research” (Age Concern, 2007). Although the Equality Bill and New Horizons (DH, 2009) mental health policy have made important steps towards tackling discrimination, urgent action is needed to raise awareness of the needs of individuals growing older with SMI. Yet, little research has been undertaken with older adults with SMI: most focuses on younger or mixed-age SMI populations. This situation is compounded with an erroneous and defeatist assumption that mental illness in older adults inevitably occurs as a result of ageing and that effective treatments are unavailable. Where evidence has existed in respect of SMI, sample populations frequently have not been sufficiently subdivided in terms of age grouping to enable easy identification of those aged 65 years or over.

The purpose of this paper is to add to the policy discourse and debate which have emerged primarily in North America with the UK lagging behind in relation to older adults with a SMI. First, we review some of the published literature which has contributed to the evidence in this field. Secondly, we review recent policy initiatives emanating from central government in England, NICE and professional organisations. We conclude with a discussion of these findings and signpost relevant issues for policymakers, researchers, clinicians and service users.

The search strategy used for the purposes of this particular review was selective. Drawing on their professional experiences the authors were mindful that there appeared to be only a very limited literature in respect of ageing with a SMI with any availability of research-based studies involving the use of randomised controlled trials (RCTs) being even more restrictive. This dearth of available literature made systematic reviewing of the literature in its true definition very challenging and, potentially, a valueless exercise in terms of actual findings.

With this in mind, and drawing upon the work of Grant and Booth (2009), analysing different review types, their associated methodologies together with their perceived strengths and weaknesses, it was felt the most appropriate approach to adopt, at this point in time, was a selective literature review in order to discover and study any recent or current literature. Policy documents were selected in a similar manner drawing on the authors' expertise in the field and searching relevant websites such as mental health charities, NICE, Department of Health, Scottish Government, and the Royal Colleges of Nursing and Psychiatry.

Background literature

Much of the relevant literature originates from the US, with older adults with SMI perceived as an under-served population in need of urgent attention (Bartels, 2003). In the UK, an Inquiry into Mental Health and Well-Being in Later Life was established in 2003, its purpose being to investigate the neglect of older adults' mental health within policy, practice and research. Its initial report Promoting Mental Health and Well-Being in Later Life (Age Concern, 2006) offered recommendations on how to make positive mental health and well-being a reality for older adults.

The Inquiry's second report (Age Concern, 2007) described over a third of older adults experiencing symptoms of mental health problems such as depression, anxiety, delirium (acute confusion), dementia, schizophrenia, bipolar disorder, and alcohol and drug (including prescription drug) misuse. Suicides, self-harm and self-neglect are common amongst older adults and may be related to mental health problems. Available evidence suggests that the majority of older adults with mental health problems do not receive services and that there exists a tremendous amount of unmet need within this population (Age Concern, 2007).

To date this report appears to be the most comprehensive available on ageing and mental health in terms of current statistics. It also offers an explanation of how the term "adult" varies in definition across the UK: within England the term "adult" refers to working age adults; namely, those aged 18 to 65 years of age. The definition excludes those aged 65 years and over who are classed as "older people" and not as adults. Subsequently, this has led to "deep-rooted" age discrimination within mental health services. The report states:

the exclusion of mental health in policies for older people and the exclusion of older people in some policies for mental health have created the gap into which older people's mental health often falls

(Age Concern, 2007: 29)

With population projections indicating that the absolute number of older adults in the UK (those aged 65 years and over) will increase, it is suggested that within the next 15 years, over 6% of the total UK population (1 in every 15 people) will be an older person experiencing a mental health problem (Cummings and Kropf, 2011). Attributing statistics to those older adults who currently live with SMI is even more challenging since readily available statistics on prevalence rates are lacking in the UK. It would appear that mental health problems tend to occur together which results in the risk of "double counting". Precise comparisons between UK and US data (and any available data from other countries) also may be difficult for a number of reasons (such as the manner in which the data is collected in terms of groupings) but trends between these two geographical areas appear to demonstrate degrees of commonality.

Using US-based statistical sources, it is suggested that whilst estimates of mental disorders amongst those aged 65 years and over appear to be few and variable (Kelley, 2003), there is evidence that anxiety and depressive disorders are the most prevalent mental illnesses amongst older adults, with smaller numbers being affected by more serious mental illnesses such as schizophrenia, bipolar disorder and treatment refractory depression (Bartels *et al.*, 2005). It is anticipated that the number of people with schizophrenia aged over 55 years will double during the next twenty years. There is, however, very little research data on older adults with schizophrenia (Collier, 2011) or bipolar disorder.

For those older adults with SMI, co-morbid medical conditions appear to be common and, as such, ready access to primary healthcare services is an important aspect of health care (Folsom *et al.*, 2006). People experiencing SMI are at higher risk of developing serious physical health problems such as obesity, diabetes and heart disease (Tosh *et al.*, 2011). Bipolar disorder, for example, is regarded as a very disabling condition; associated with substantial functional limitation and premature mortality, together with significant personal and societal costs. There is increasing awareness of the burden of general medical co-

morbidity with cardiovascular disease being seen as a main cause of morbidity and mortality for people with bipolar disorder (Kilbourne *et al.*, 2007).

Older adults with SMI are also at greater risk than younger adults, of receiving inadequate and inappropriate care (Bartels, 2003). Lack of appropriate support has arisen, principally, as a result of several major shortcomings. First, it appears that there is a lack of age-appropriate clinical interventions, rehabilitative or residential programmes for older people with SMI. Secondly, there is a significant lack of suitably trained specialist staff, such as psychiatrists, clinical psychologists, and specialist mental health nurses amongst others, to address the ongoing care and support needs of those living with severe and enduring mental illness (Rethink, 2012). Additionally, there has been a failure to incorporate what little research findings and evidence-based practice there has been into clinical practice (Bartels *et al.*, 2002). Finally, to our knowledge, there are few or no studies which specifically ask older adults with SMI what services, interventions, and treatments they would like to receive from clinicians and other individuals providing recovery focused support and care.

It is likely that the needs of older adults with SMI are different to those of younger and middle-aged adults with SMI. As well as having physical health needs resulting from their mental health diagnosis and its subsequent treatment (for example, help to manage adverse side-effects of medication), older individuals are more likely than younger adults to have physical co morbidities, thus requiring complex individualised treatment and management. It also may be posited that older adults with SMI have similar and distinct psychological and emotional needs to younger people (for example, in the maintaining of relationships) and psychosocial needs (such as assistance in dealing with financial issues); however, to date, there appears to be little research on which to base interventions which are acceptable and appropriate for older adults. One recent study in the USA by Hendrie *et al.* (2012) indicates people with SMI have higher rates of emergency care, longer hospitalizations, and increased frequency of falls, substance abuse, and alcoholism compared to older adults without SMI who attend primary care clinics. Evidence from the *Inquiry into Mental Health and Well-Being in Later Life* suggests that older adults with SMI experience ageism, stigma (for example, that which may occur in BME communities where mental illness may be seen as a form of spiritual failing) and other forms of discrimination such as gender differences, sexual orientation, disability (such as learning disability, sensory impairment) or religion/belief (Age Concern, 2007).

Policy, Guidelines & Protocols

In the UK there is a dearth of policy guidance for both service provision and treatment modalities for older adults with a SMI. Existing guidance tends to derive from public or government policy (Table 1), NICE guidelines (Table 2) or professional bodies such as the Royal College of Psychiatrists (Table 3). The National Service Framework (NSF) for Older People (DH, 2001) included a chapter on mental health but the focus of the standard was on people experiencing dementia and depression. The standard recognises older people will experience SMI but guidance suggests they should receive packages of care and treatment in line with working age adults despite the possibility these two groups may have different age related needs. Following on from the NSF was *New Horizons a shared vision for mental health* (DH, 2009) which offered much guidance for older adults with a mental health problem, particularly dementia and depression, however, there was no explicit guidance for older adults with a SMI. More recently in February 2011 the UK coalition government produced its latest strategy, *No health without mental health: a cross-government mental health outcomes strategy for people of all ages* (DH, 2011), to improve the mental health and well-being of the population. Domain 1 of the strategy: Preventing people from dying prematurely recognises the need to reduce the premature death rate of people with serious mental illness. Like many public policy documents these statements are aspirational and there is no specific guidance concerning how to improve outcomes for older adults with a SMI.

Table 1: Public policy

Government Policy	Year	Provision for older people with SMI
The National Service Framework (NSF) for Older People	2001	None
New Horizons A shared vision for mental health	2009	None
No health without mental health: a cross-government mental health outcomes strategy for people of all ages	2011	Aspiration to prevent premature death for people with SMI

NICE (2011, 2009, 2006) have produced guidance on both service provision and evidence based interventions for people with SMI. Guidance for people experiencing schizophrenia (CG 62 Schizophrenia Core interventions in the treatment and management of schizophrenia in adults in primary and secondary care) is aimed at people with an established diagnosis of schizophrenia with an onset before age 60 and those that require treatment beyond 60; the

guideline does not address the specific treatment needs of older adults. Conversely, guidance for people experiencing bipolar disorder (CG 38 Bipolar disorder: the management of bipolar disorder in adults, children and adolescents, in primary and secondary care) states that special consideration should be given for older people in relation to using medication at lower doses, being alert to the increased risk of drug interactions when prescribing psychotropic medication to older adults and ensuring that medical co-morbidities have been recognised and addressed. Additionally, it recommends older adults experiencing bipolar should be screened for cognitive impairment. The guidance on bipolar disorder for older adults is encouraging in that it addresses the specific needs of older adults with a SMI.

Table 2: NICE guidance

CG 38 Bipolar disorder: the management of bipolar disorder in adults, children and adolescents, in primary and secondary care	2006	Excellent guidance on medication regimes, monitoring illness and cognitive decline
CG 62 Schizophrenia: core interventions in the treatment and management of schizophrenia in adults in primary and secondary care	2009	An established diagnosis of schizophrenia (with onset before age 60) who require treatment beyond age 60.
Common mental health disorders: identification and pathways to care	2011	Guidance on improving services for older people, nothing specific to SMI

The Royal College of Psychiatrists (2011, 2009c and 2006) have produced guidance and position papers on service provision and discrimination issues concerning older people experiencing mental health problems. Their focus is on older adults who experience the range of mental health illnesses including depression and dementia which are the two most common disorders in later life. Despite this, it is estimated that in service planning populations of c250, 000 this will include 37 500 people aged 65 and over, among these 750 older adults will have a psychoses and with an ageing population in the UK it is anticipated these numbers will increase in the future (RCP, 2006). Much of the guidance and recommendations from these documents is of a generic nature and relates to the types of services, such as community mental health teams, day hospitals and provision of psychological services that older adults should receive. There is little or no guidance of specific service provision or treatments for older adults with a SMI.

Age Concerns report: *Improving services and support for older people with a mental health problem* acknowledges the specific problems of older adults or “graduates” of asylums or

long-stay hospitals. According to this report, women are particularly vulnerable as the majority of older people with schizophrenia are women and, as a group, they are more likely to develop late or very late onset schizophrenia (Age Concern, 2007). It is difficult to ascertain what policies and guidance local Mental Health Trusts are following in the care and treatment of older people with a SMI. Local Trusts provide a range of services and guidance tends to be patchy and even when there are policies and procedures available they are often vague, difficult to read and confusing (Tosh *et al.*, 2010).

Table 3: Royal College of Psychiatrists

Royal College of Psychiatrists	Year	Provision for older people with SMI
Raising the standard: Specialist services for older people with mental illness	2006	None
CR153:Links not boundaries: service transitions for people growing older with enduring or relapsing mental illness	2009b	Makes a series of recommendations aimed at improving the care of people who are growing old with enduring or relapsing mental illness and who face the possibility of moving between psychiatric services
Position statement PS2/2009 Age discrimination in mental health services: making equality a reality	2011	Guidance on age discrimination issues, nothing specific to older adults with SMI

Discussion

Central government, policymakers, service providers, researchers and clinicians have, for too long, ignored the specific needs and service requirements of older adults with a SMI despite the well documented evidence they have a range of particular needs (Age Concern 2007, Godfrey *et al.*, 2005; Bartels, 2003). Despite the coalition governments rhetoric that mental health should “have parity with physical health in the NHS” real time spending for older adults in the NHS witnessed a fall in 2011/12 (DH, 2012). These are not insignificant amounts and this decrease comes after a decade of rising investment in mental health spending since 2001 (*The Guardian*, 2012). Despite these austerity measures the service needs and requirements of older adults are beginning to be addressed by governments, commissioners, service providers, clinicians and researchers. However, it is vitally important

that stakeholders mainstream the needs of older adults with a SMI in policy and service provision including the initiation of high quality research in this area.

Policymakers, in particular central government need to provide leadership, direction and the financial resources to initiate and fund high quality research programmes to increase the evidence base for treatments and interventions to improve outcomes for older adults with a SMI. A growing body of evidence highlights the shocking statistics that people with a SMI have a significantly reduced life expectancy compared with the general population. As a society we are failing to address the age related needs of this most vulnerable group of citizens. Recently, in November 2011 Rethink established “The Schizophrenia Commission” an independent commission to review how outcomes for people with schizophrenia and psychosis can be improved. The Commission’s report “*The Abandoned Illness*” (Rethink, 2012), make several key recommendations for Government, National Bodies (including the Royal Colleges), the NHS Commissioning Board, Mental Health Providers and Research Funding Bodies to address the specific needs of this group. Although it is not explicitly clear, we assume these recommendations are aimed at both working age and older age adults experiencing schizophrenia. Mental health clinicians and service users should be aware there is little in the way of good quality evidence to improve outcomes for older adults with a SMI and Higher Education Institutions have a role to play in offering health and social care programmes that address the needs of all older adults and, specifically, older adults with a SMI. Such programmes have a role to play in raising awareness of this group and can help foster the attitudes and values future healthcare clinicians require to meet older adults’ specific needs.

Conclusions

In this paper we have identified the distinct lack of policy provision and research evidence addressing the needs of older adults with a Serious Mental Illness in the UK. There are limited pockets of good practice particularly the NICE Clinical Guidance 38 Bipolar disorder (2009), which offers explicit guidance on the meeting the needs of older adults with a bipolar disorder. However, this is an isolated aberration and both policy and practice provision in this area is sadly lacking. There is a simple message emanating from this brief policy and literature review: Leadership and direction is required from central government to provide the focus and attention on the service and treatment requirements for older adults with a Serious Mental Illness. Clinicians, researchers and other stakeholders must engage with service users,

their family and/or friends to produce quality and meaningful research. Finally, the policy, practice and service user communities needs to collaborate in a spirit of “boundary spanning” which creates the 'strategic alliances, joint working arrangements, networks, partnerships and many other forms of collaboration across organizational boundaries' to produce the meaningful outcomes for this group of disadvantaged citizens (Williams, 2002).

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