



The Palliative Care Needs of People with Serious Mental Illness In Ireland

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CHAPTER 1 INTRODUCTION AND OVERVIEW

1.1 INTRODUCTION

It is estimated that 25% of the population will experience mental health problems during their life (McManus *et al* 2009, DoHC 2013), with an estimated 14% experiencing enduring mental illness (Kessler *et al.* 2005). Specifically within Europe, one in five people will experience a serious mental illness such as depression in the course of their lifetime (Chambers, 2007). Despite an increase in the life expectancy of the general population over the last two decades, the disturbing reality is that those with severe mental illnesses are now dying younger than they were 30 years ago (Saha *et al.* 2007). It is now accepted that those with SMI have higher rates of general and specific causes of mortality. Chang *et al* (2011) have identified that the impact of serious mental illness on life expectancy is marked and all mental disorders located within the serious mental illness classification (SMI) are associated with substantially lower life expectancy.

1.2: SERIOUS MENTAL ILLNESS

Serious mental illness is estimated to affect 14% of the population (Kessler *et al.* 2005; Andrews *et al.* 2001) and the burden of this illness is frequently compounded by co-morbidities, particularly cardiovascular, respiratory and metabolic disorders. The prevalence of cardiovascular morbidity and mortality is estimated to be 2 to 3 times greater than the general population for those with a diagnosis of schizophrenia, particularly those in younger age groups; 35% to 250% higher in those with bi-polar disorders and up to 50% higher in major depression (De Hert *et al.* 2011). Additionally, people with schizophrenia taking antipsychotic medication are reported to be three times more likely to die from sudden cardiac death than the general population (Koponen *et al.* 2008; Ray *et al.* 2009).

For the purposes of this study the term Serious mental Illness (SMI) is used to reflect the longer term nature of some mental health difficulties. It is generally accepted that mental health difficulties lasting longer than one year in an adult can be classified as serious, enduring or persistent. Within this study this definition includes those mental disorders normally referred to as serious mental illness as denoted by ICD-10 criteria for Schizophrenia, schizophrenia spectrum and delusional disorders (F20-29); Mood [affective] disorders (F30-39) and Mental and behavioural disorders due to psychoactive substance use – drug induced psychosis (F10-19) (ICD-10). Where appropriate disorders in other ICD categories including Anxiety Disorders (F40 – F48) and Eating Disorders (F50) are also included where their duration has lasted longer than one year in an adult population

1.3: INEQUALITIES IN HEALTH CARE PROVISION

Inequalities in health care provision for the severely mentally ill have been attributed to system issues. The clear division between physical and psychiatric medicine has meant that those with co-morbid physical and mental illness are poorly served. Mental illness frequently acts as barrier to accessing and obtaining effective medical care, and is associated with undue medical morbidity; particularly when diagnostic overshadowing results in the misattribution of physical symptoms to the person's mental state (Lambert *et al.* 2003; Thornicroft, 2011). The result is delays in diagnosis and treatment, consequently increasing the possibility of a terminal diagnosis, and making palliative care the first line of treatment for a number of people with SMI. The fragmentation of mental health services from other medical services, the pervasive nature of stigma associated with mental illness as well as the consequences of the illness itself along with the effects of antipsychotic medications combine to further compound these health care disparities (Lawrence & Kisley, 2010). People diagnosed with a serious mental illness (SMI) who subsequently develop a chronic physical health condition and/or terminal illness, and whom require palliative or end of life care are a particularly vulnerable group and may according to Davie (2006) be one of the most underrepresented and deprived populations in society.

It is therefore imperative that the health disparities associated with experiencing a SMI are reduced and in this regard adopting a human rights perspective can be helpful in evaluating the gaps in access to physical health care. However, achieving this requires the collaboration of multiple agencies and stakeholders to close the gaps in inequality and to improve access to physical health care in order to improve the general physical health and life expectancy of those with SMI. The demand for a multidisciplinary approach for the physical health management of individuals with severe mental illness is emphasised by Chaudhry *et al.* (2010) suggesting the involvement of psychiatrists, psychiatric nurses, primary care clinicians, dieticians, internal medicine specialists, pharmacists, community mental health workers, patients and their carers.

The study reported here examined if a need for palliative care exists among people with serious mental illness (SMI) in Ireland and identified how and by whom those needs are identified, the referral pathways into palliative care and once needs are identified how palliative care is managed for those with SMI.

CHAPTER 2 LITERATURE REVIEW

2.1: INTRODUCTION

The WHO (2009) have estimated that by the year 2020 depression will be the second leading cause of disability in the developed world. The National Institute of Mental Health (US) found that there were 9.6 million adults in the United States with a severe mental illness in 2012, which was representative of 4.1% of all Americans over the age of 18 (Substance Abuse and Mental Health Services Administration (2013). Specifically, Marcus *et al.* (2012) estimated that approximately one in twenty people internationally experience an episode of depression per year. The WHO (2013) also highlighted that 4.3% of the global burden of disease is accounted for by depression alone. Additionally, Schizophrenia is one of the most common disorders with effects of psychosis, affecting between 1.1% and 2.4% of the population. It affects approximately 24 million people worldwide and a majority of the care of people with schizophrenia is provided at a community level with active primary care and family involvement (WHO Schizophrenia Fact Sheet, 2016). Wiles *et al.* (2006) identified that 4.4% of British people surveyed reported experiencing at least one symptom of psychosis such as hallucinations or delusions. Risk factors for this presentation included smoking, excessive drug and alcohol consumption, reduced social support and experiencing adverse life events. Chambers *et al.* (2007) illustrated the prevalence of severe mental illness in Europe at a primary care level, finding that thirty percent of general practitioner consultations in the EU are focused on treatment of mental illness (Chambers, *et al* 2007).

2.2: PREVALENCE OF SEVERE MENTAL ILLNESS IN IRELAND

The prevalence of mental illness in Ireland has increasingly been documented in recent years by charities such as Aware, Pieta House and the Samaritans. Chambers (2007) reported that 11% of Irish people in a nationally representative sample reported experiencing a serious mental health difficulty with suicide and self-harm also highly prevalent in Ireland. Approximately 12,000 cases of deliberate self-harm are admitted to hospital emergency departments annually and there are around 500 reported deaths by suicide each year (Chambers, 2007). Again, due to the negative stigma surrounding self-harm and suicide in Irish society, these may be conservative figures; no record of self-harm episodes which do not result in presentation to emergency departments are available and the cause of death may not be on record for many suicide deaths (Corcoran and Arensman, 2010).

Studies reporting on mental health in general populations in Europe have indicated a life-time prevalence of between 23%-27% in the general population for psychological distress or mental health problems. (European Opinion Research Group, 2003). Figures from Ireland report a point prevalence of between 7% and 12% for psychological distress (Barry *et al.* 2009; Blake *et al.* 2000; Tedstone Doherty *et al.* 2007). Similar to other countries, Ireland has a high prevalence of mental health problems and psychological distress in the general population. The Health Research Board National Psychological Wellbeing and Distress Survey (NPWDS) showed that 60% of the Irish population who reported mental health problems in the year previous sought help through primary care with only a small minority consulting more specialised mental health services (Tedstone Doherty *et al.*, 2007). Mental illnesses such as depression and anxiety frequently co-occur with chronic physical health conditions and it is recognised that the links between depression and physical health conditions are bi-directional. Depression can increase the risk of the development of other health conditions through mechanisms such as lifestyle factors, poor health behaviours, delayed help-seeking and treatment non-compliance, and depression can develop subsequent to the diagnosis of a chronic health condition through physiological, pharmacological or psychological mechanisms (Gunn *et al.*, 2012).

In a study of mental health difficulties in Irish general practice (Coptly and Whitford, 2005), it was identified that general practitioners estimated that 25% of their patients exhibit mental health problems. This is in line with the European estimate by the WHO (2003) that 30% of consultations with general practitioners are for mental health difficulties. Of the respondents in Tedstone-Doherty and colleagues (2008) who reported experiencing mental health difficulties in the previous year, 93% reported visiting their GP at least once for a physical health complaint, compared with just 70% of the general population not using mental health services, thus highlighting the demands that those with mental health difficulties place on GPs.

Tedstone-Doherty and colleagues (2008) documented the projected figures from the total adult population and suggest that over a one-year period approximately 320,381 people will attend their GP for mental health problems, 160,190 people will attend outpatient clinics, 51,261 will attend day centers and 19,222 will use inpatient mental health facilities (Tedstone-Doherty *et al.* 2008).

However, given the nature of the telephone household survey, individuals who may be most at risk of psychological distress or mental health difficulties may not have been accessed; these would include the homeless, individuals living in sheltered accommodation, refugees and non-nationals who may not have access to a landline and whose first language may not be English. As such, the estimates presented in Tedstone-Doherty *et al.* (2008) are likely to be conservative. Similarly in

order to fully determine the severity of the psychological distress experienced by respondents who exhibited high scores on the GHQ12, it would be necessary to carry out a follow up study using a clinical instrument such as the WHO CIDI. Unfortunately it was concluded by a report by the Mental Health Commission of Ireland, that to date there is no comprehensive data on the prevalence of people attending mental health services in Ireland (O'Shea & Kenelley, 2008).

2.3: INCREASED MORTALITY AND DECREASED LIFE EXPECTANCY IN SMI

Increasing attention is being paid to premature mortality among people with serious mental illness (SMI) and it is now accepted that those with SMI have higher rates of both general and specific causes of mortality. The presence of higher mortality rates attributable to natural causes among those with co-morbid physical and psychiatric conditions was identified by Black and colleagues as far back as 1987. Initial conclusion attributed the higher mortality rate to complicating medical disorders as opposed to the psychiatric condition. The possibility that the psychiatric condition had adversely influenced the patients' health by preventing them from reporting early symptoms and/ or seeking medical help from a healthcare professional was subsequently identified by Baker in 2005. Thus the recognition that external factors including the mental illness itself, and internal factors such as the physical illness had negatively impacted patients life expectancies was identified.

2.3.1 CO-MORBID PHYSICAL AND MENTAL ILLNESS

A systematic review by Saha, et al. (2007) of studies from 25 countries reported that standardized mortality ratios for schizophrenia increased from around 1.8 in the 1970s to 3.2 in the 1990s. This relative increase in early mortality has also been observed in US studies that have demonstrated that years of potential life lost for individuals with SMI may have increased from around nine years between 1989 to 1994 (Dembling et al. 1999), to as much as 30 years from 1997 to 2002 (Colton & Manderscheid, 2006; Miller et al. 2006). Colton and Manderscheid (2006) noticed, that as much as 30 years of potential life was lost prematurely for those with SMI from 1997-2002 in the US. This trend is undoubtedly continuing more recently, as Piatt (2010) showed that the mean number of years of potential life lost in patients with SMI was 14.5(SD) when compared with 10.3 (SD) for the general population in 2010. Over a six-year period (2000-2006) Laursen (2011) found that patients with schizophrenia had a reduced life expectancy of 18.7 years for men and 16.3 years for women. More recently, it was found that over a three-decade period with schizophrenia died an average of 11 years earlier than the general population (Neilsen et al. 2013). In an extensive study, based on the Premier Perspective Database (USA), of hospitalised patients with SMI and comorbidity, it was found that patients with schizophrenia had a numerically higher incidence of hypertension,

hyperlipidaemia and diabetes; higher number of comorbidities; longer hospital stays; higher 30 day readmission rates and higher mortality rates than had people with bipolar disorder (Correll et al., 2017).

Thus despite the overall increase in life expectancy of the general population across all European countries over the last two decades (Leon, 2011), individuals with SMI are at risk of dying up to 30 years more prematurely than the general population, and that risk appears to be increasing (Colton & Manderscheid, 2006; Miller et al. 2006). Chang *et al* (2011) have identified that the impact of serious mental illness on life expectancy is marked and that all mental disorders located within the serious mental illness classification (SMI) are associated with substantially lower life expectancy. Highest reductions in life expectancy were found for women with schizoaffective disorder (17.5 years lost) and men with schizophrenia (14.6 years lost). As in physical illness, where psychiatric co-morbidity worsens outcomes, medical co-morbidity in those with serious mental illness is associated with more serious psychiatric symptoms and worsened health outcomes.

People with SMI are often late in seeking treatment for a physical illness. Not only are their outcomes thereafter adversely affected by this delay, but the cost of treatment may also be increased (Morgan, 2016). Patients with SMI are known to be vulnerable to, and have a higher incidence of risk factors for chronic diseases and some cancers, and are more likely to die up to 20 years earlier than the general population (20 years premature mortality for men and 15 years for women) (Irwin et al., 2014; Rethink Mental Illness, 2013; Taylor et al., 2012; Thomson & Henry, 2012; Chadwick et al., 2012; Thornicroft, 2011; Wahlbeck et al., 2011, Madrigal, 2010; Woods et al., 2008; Ellison, 2008). It is accepted that cardiovascular, cancer and respiratory diseases are common among persons with SMI (Irwin et al., 2014; Chadwick et al., 2012; Thornicroft, 2011; Woods et al., 2008; Carney et al, 2006); and that people with schizophrenia and bi-polar disorder are twice as likely as other patients to develop diabetes, ischaemic heart disease, strokes, hypertension and epilepsy (Correll et al, 2017; Chadwick et al., 2012).

The association of obesity and metabolic syndrome with antipsychotic medication is now well established and affects 15 to 72% of those taking them. Weight gain effects have also been established, particularly with Clozapine and Olanzapine (De Hert 2011; Mitchell et al. 2011). A range of other physical health conditions have been identified as being more prevalent in people with enduring mental health issues including respiratory particularly chronic obstructive pulmonary disease; musculoskeletal disorders including osteoporosis; and sexual health disorders. While studies examining cancer rates among people with SMI have yielded inconsistent results, trends are emerging to indicate an increased risk for certain cancer types in people with SMI, most notably

breast cancer in women with schizophrenia (Bushe et al 2009; Seeman, 2011) and lung and pharyngeal cancer related to increased smoking and alcohol consumption (Howard et al, 2011). In 2014, the Irish Cancer society reported that whilst cancer affects all people in society, the risk is considerably higher for poorer people and those living in deprived areas (ICS 2014), thus as people with SMI are significantly more likely to be a part of these socially and financially vulnerable groups, their risk of developing cancer is likely to be increased.

Kendler's (1996) longitudinal study, which followed 179 patients with schizophrenia, found that 22% had died over a 15-year period. Of these, twenty deaths were from cardiovascular or respiratory diseases. Since then, many investigations into the premature death of those with severe mental illness have been undertaken. Of note, studies documenting the raised mortality in those with schizophrenia are particularly plentiful (Hennekens et al. 2005; Brown et al. 2010; Laursen, 2011). In one of the first in depth studies examining the causes of premature death in those with SMI, Brown and colleagues (2000) carried out a 13-year follow-up study of 370 middle-aged patients with schizophrenia, identifying those who had died and taking into account the circumstances of their deaths. Seventy nine of these patients died and it was found that smoking related deaths were more prominent in this group than in the general population, while medical or chronic conditions such as Neoplasms (n=14), Endocrine diseases (n=5), Circulatory diseases (n=27), Nervous diseases (n=3), Respiratory diseases (n=6) and Digestive diseases (n=2) accounted for over half of the deaths in this cohort. Failed recognition of medical disease by the patient themselves or their career/health care practitioner was evident among this sample.

Evidence of lower life expectancy for people with SMI was also identified in an analysis of three years anonymised data collected by South London and Maudsley NHS Foundation Trust (SLAM) (Chang et al., 2011). The SLAM data (165,000 medical records from a general population of 1.2 million residents) identified a significant difference in life expectancy between men and women. Among the findings it was found that men with schizophrenia had a 14.6 years lower life expectancy than women (9.8 years). Interestingly, a reversal in life expectancy findings was identified for schizophrenia affective disorders where men were identified to have a lower life expectancy of 8.0 years while women had a significantly lower life expectancy at 17.5 years (Chang et al., 2011). The life expectancy outcome for women with a depressive disorder was 7.2 years as compared for men (10.6 years).

2.3.2: ACCESS BARRIERS

Mental illness acts as barrier to accessing and obtaining effective medical care, and is associated with undue medical morbidity; particularly when diagnostic overshadowing results in the misattribution of physical symptoms (Lambert et al. 2003; Thornicroft, 2011). Likewise misinterpretation of symptoms by health professionals and unclear perception and expression of symptoms by patients can hamper early identification of symptoms of ill health (Swiss Academy of Medical Sciences, 2013).

Diabetic patients with mental health conditions are less likely to receive standard level diabetic care, a lack of screening and intervention for dyslipidaemia, hypertension and low rates of surgical interventions such as stenting (Wahlbeck et al. 2011; Thornicroft 2011). People with mental illness are likely to receive less, and poorer quality, physical health care than other population groups, and structural and systemic health disparities impact on access to and utilisation of health care and this is frequently related to continuing confusion as to which division of health services should take responsibility for health care for those with SMI.. While attempts have been made particularly in the USA and UK to address the issue of screening through publication of guidelines, evidence indicates that sub-optimum medical care continues for people with mental illness (Mitchel et al. 2009; 2011).

Moreover, the iatrogenic effects of some psychiatric medications predispose people to conditions such as obesity and diabetes that, if not adequately managed, will in time cause physical morbidity. Medications used to treat mental illness are also known to cause a higher tolerance of non-healing lesions or tumours (Terpstra & Terpstra, 2012); higher rates of suicide, accidental and violent death and poorer access to physical health care than for the population as a whole (Thornicroft, 2011). Regrettably, suicide among patients with cancer who have a pre-existing SMI is higher than among patients with cancer alone (Thomson & Henry, 2012).

2.3.4: LIFESTYLE FACTORS

There is a general understanding that people with severe and enduring mental illness lead less healthy lifestyles than the rest of the population thereby predisposing them to physical illness (Chang et al., 2011; Osborn et al., 2007; Brown et al., 2000). Poor mental health has an impact on health behaviours, and people with mental illness frequently have poor compliance with treatment regimes. Mental illness is also associated lifestyle factors for chronic disease including smoking, reduced activity, poor diet, increased alcohol and illicit substances use. People with mental illness also experience additional risk factors for poor health as they are more likely to be unemployed and dependent upon social benefits; live alone or with unrelated others in supported accommodation;

be unmarried, have no children and have limited social and family networks (Sheridan et al. 2012).; they are also less likely to exercise, often influenced by apathy and reduced motivation, as well as secondary effects of treatment including sedation. Poor diet further contributes to physical health problems, with higher likelihood of consuming diets high in saturated fats and low in fibre – the dietary determinants are multi factorial, influenced by the illness, treatment, socio-environmental factors including unemployment, poverty, living arrangements and restricted social networks (von Hausswolff-Juhlin et al. 2009).

2.4: PALLIATIVE CARE FOR PEOPLE WITH SERIOUS MENTAL ILLNESS

Palliative care is a concept that has been in circulation, defined, used, adapted and re-defined since the 1960's. Earlier definitions have seen palliative care being concerned primarily with the care of patients suffering from inoperable or terminal cancer, in the final weeks, days or hours of life. The term 'palliative care' often overlaps in literature and clinical practice with terms such as 'terminal care', 'supportive care', 'hospice care', 'end of life care', 'comfort care' and 'thanatology' (Carlson, Devich & Frank, 1988).

In 1995, Ireland was the second country in Europe to recognise palliative medicine as a distinct specialty, specifying that all people are entitled to access the service and expertise appropriate to their individual needs (National Advisory Committee on Palliative Care, 2001). Following this, the devolvement of the National Cancer Strategy in 1996 acted as a catalyst to the rapidly evolving area of palliative care by promoting the appropriate models of care to best address the palliative needs of patients and their families.

However, the impetus of these reports was to primarily improve palliative care services for patients with inoperable or terminal cancer.

In 2001 the National Advisory Committee on Palliative Care acknowledged that the principles of palliative apply to all patients with advanced progressive disease regardless of the aetiology. Since then, McIlfaltrick and Murphy (2013) have reported an increase in the number of studies in palliative care published from Jan 2002 to May 2012, 72% of which were published in the last four years. Their review identified eight themes from the palliative care literature in existence in Ireland from 2006-2012. The research examined focused primarily on palliative care for specific groups/populations, palliative care services and settings, physical and psychological symptoms of patients availing of palliative care, bereavement, communication and education, death and dying, spirituality, and complementary or alternative medicines and interventions.

In (2001) the NACPC believed that patients with cardiovascular and respiratory diseases would be the main cohorts of non-cancer patients that required specialist palliative care services. They hypothesized that patients with multiple sclerosis, motor neuron disease and other similar degenerative conditions, despite being a small percentage, would have a longer prognosis than most cancers. And it was estimated at this time that inclusion of patients with non-malignant conditions would double the requirement for specialist services. In 2004, the prevailing view was that access to palliative care should be based on need rather than diagnosis (NICE, 2008). To this end many patients with non-malignant diseases qualify also.

In terms of provision of palliative care to people with a serious mental illness a systematic review of the literature by Woods *et al.* (2008) identified that very few empirical studies exist. The systematic review yielded four main themes pertaining to provision of palliative care for those with SMI, these are: 'decision making capacity and advance care planning', 'access to care', 'provision of care' and 'vulnerability'.

2.4.1: DECISION MAKING

Decision making capacity in health care refers to "the ability to understand and appreciate the nature and consequences of health care treatment decisions, including the risks, benefits and alternatives" (Appelbaum, 2007). Four abilities are required for informed decision making, namely, the ability to comprehend important information, appreciate the information, use logic and reason to making a choice and express a stable choice (Appelbaum, 2007). In their Review, Woods *et al.* (2008) identified research to indicate that discussions concerning end-of-life often do not occur with people who have severe mental illness, under the pretence that they have reduced or eliminated capacity to understand or make decisions, and will be emotionally and cognitively destabilised by engaging in such a conversation (, Appelbaum 2005; Candilis *et al.* 2004). Studies illustrated that traditionally if patients are unable to make informed decisions due to incapacity, health care professionals would turn to family members or next of kin, however it was found that many people with severe mental illness did not have family and friends and could not identify a substitute decision maker (Foti *et al.* 2005; Baker, 2005; Kushel & Miaskowski, 2006). In instances such as these, Woods *et al.* (2008) found that people with SMI had decisions made for them by health care professionals in their own 'best interests' but that may not have been to their preference.

2.4.2: ADVANCED CARE PLANNING

Foti (2005) was the first researcher to describe end of life treatment preferences for people with severe mental illness. Specifically, Foti *et al.* (2005) highlighted the dearth of knowledge and awareness of the preferences of those with severe mental illness in terms of their end of life care and as such this may result in these patients receiving care that they would not have chosen, had they been consulted or presented the option without a mental illness. Foti and colleagues (2005) have developed advance care planning tools to explore the decision-making capacity and preferences for end of life care and advanced care planning for people with severe mental illness. It was concluded that despite the challenges and difficulties experienced by those with severe mental illness in understanding and reasoning in comparison to the general population, appropriate interventions have been shown to improve their comprehension to a level that facilitated their informed decision making capacity. It was found that people with severe mental illness were capable of engaging in treatment related decision-making and end of life discussions. Their most common concerns were the emotional and financial burden on family and loved ones, experiencing pain and suffering, spiritual concerns and funeral and deposition of their bodies (Foti et al.2005).

2.4.3 ACCESS TO CARE

Research concerning the access to appropriate and timely care has shown that this is difficult to achieve for those with SMI (Woods et al. 2008). Specifically, studies have found that people with severe mental illness often experience pain differently and in many cases do not respond to physical symptoms and therefore delay in seeking medical care or indeed may not seek medical care at all (; Spiess et al. 2002). In certain instances, the symptoms of those with SMI may not be recognised by their health care providers and may go untreated (Davie 2006). These factors result in an inability to provide curative treatment and palliative care may become the only treatment option available from the time of diagnosis. In addition, Woods and colleagues (2008) illustrated that the limited access to close friends or family may in many cases imply a lack of emotional and social support, as there is no one available to truly advocate for their care on their behalf.

2.4.4: Vulnerability

Another issue arising in Woods and colleagues (2008) review requiring further discussion and examination of existing research, is the concept of increased vulnerability in patients with severe mental illness and those requiring palliative care. There is a notable knowledge and power difference between vulnerable patients with both physical illness and SMI and the health care professionals providing their treatment (Foti, 1999). In addition, often in facing death, the feelings of vulnerability are “particularly acute for people with SMI” (Baker, 2005, Pg. 298).

2.4.5: BARRIERS TO PROVISION OF APPROPRIATE PALLIATIVE CARE

In their systematic review Woods and colleagues (2008) identified, illness related issues, health care provider issues and system issues. Despite the utilisation of multidisciplinary teams and an emphasis on holistic care, to date there is no dedicated system of care to provide palliative care for people with severe mental illness (Davie, 2006; Baker, 2005). As identified in their review, Woods and colleagues (2008) noted that hospital wards and hospices often cannot facilitate people with disruptive or behavioural problems, while psychiatric units may not be able to provide palliative care and symptom management expertise. Woods and colleagues (2008) also described challenges to care as secondary to mental illness, citing a lack of knowledge on the part of the health care providers and system barriers. Good, (2006) found that people with SMI may refuse to be interviewed and may often have varying levels of comprehension and acceptance of their diagnosis (Kelly & Shanley, 2000).

2.5: THE ROLE OF INTERDISCIPLINARY AND MULTIDISCIPLINARY CARE

Interdisciplinary and multidisciplinary care provide the key to optimum holistic care for patients with SMI and an accompanying chronic and/or terminal illness (Morgan, 2016; Terpestra et al., 2014; Nelson, 2012; Miovic & Block, 2007). It is argued that the quality of care provided to physically-ill people with pre-existing mental health problems is compromised ‘by practical problems and interpersonal difficulties between service users and health-care providers and between providers of mental health services and those providing physical health care’ (Chadwick et al., 2012). According to the findings in a review of international studies on barriers to physical health in the UK, USA and Australia, this appears to be a universal problem (Chadwick et al., 2012).

In Canada, where a mixed methods study was conducted (300 hours observation in homes, shelters, transitional housing units, community-based services and on the street and interviews with vulnerable people, their families and service providers), researchers concluded that an understanding of the factors that create vulnerability and the contexts in which care happens are necessary for the provision of equitable palliative care to vulnerable persons (Stajduhar et al., 2016).

In pursuit of improving access to palliative care, there needs to be clear interdisciplinary communication between health care providers, including ancillary professionals such as medical social workers, occupational therapists etc. Meanwhile, policy makers need to link with service users, listen to their experiences and afterwards develop and implement innovative practices that will facilitate an easier and less stressful navigation of the health and social care system for individuals with SMI. Holistic care involves open communication with the patient and his/her family throughout the investigative and diagnostic phases of the illness and thereafter (Evenblij et al., 2016). The development and implementation of individualised person-centred care plans for patients in an advanced stage of mental illness may prove more difficult than for higher functioning individuals. Staff should bear in mind the limited prospect of affecting dramatic improvements in the former's quality of life but should aim always to achieve the best outcome for all patients. In the interest of patient morale and confidence, staff are advised to set attainable goals for each individual (Berk et al., 2012) and to review these goals regularly.

Interdisciplinary and multidisciplinary care must always include the family who are often best placed to assess current behaviour in light of baseline behaviour (Terpestra et al., 2014; Woods et al., 2008). Furthermore, a family who has supported their son/daughter/mother/father/sibling through years of mental ill-health will not want to see that person endure additional suffering caused by physical pain or organ dysfunction. Furthermore, it is not uncommon for there to be unresolved issues within a family that may give rise to feelings of anger, frustration and guilt among family members (Davidson & Anderson, 2014). These emotions may ultimately impact on the family's well-being. Social worker involvement is important to address the social and financial burden on families caring for their ill relative particularly if, or when, end-of-life issues arise (e.g. artificial hydration, new medications when death is imminent or 'do not resuscitate' directives). It should also be borne in mind that the stigma of mental illness marks those who are ill but also their families across generations (Turner, Kelly and Baker, 2012); a burden that might complicate the family's capacity to cope with their relative's illness.

The benefits of palliative care may not be understood by all patients with SMI, in which case a modified and individualised education consultation session that is simplified and reinforced should be provided to all patients selected for palliative care (Thomson & Henry, 2012). Care must always be person-centred taking in to account the individual's values, culture, preferences (Davidson et al., 2015) and social circumstances. Offering a collaborative person-centred treatment enhances a patient's initial engagement in treatment and the likelihood that he/she will stay in treatment long enough to derive benefit from it (Davidson et al., 2015). Nurses play a pivotal role in educating and monitoring patients with SMI and palliative care needs

2.6: CONCLUSION

Scientific evidence to support the importance of palliative care for patients with a serious mental illness and comorbidities is scarce. Nevertheless, it is accepted that the key to providing optimum palliative care begins with the recognition that a gap exists and that such care is required. Early identification of physical illness by the patient, their family and or carers, by general practitioners and by mental health care providers, will improve the patient's management of his/her physical and mental health. Timely and optimal person-centred palliative care regimes will enhance independent living; prolong the patient's life span; be cost effective and will prevent the adverse effects of illnesses common among patients with SMI.

Monitoring disease is a vital part of care and patients with SMI may require encouragement to attend for regular review of their physical and mental health conditions and should be reminded to visit their doctor promptly if unwell. Homeless people may need to be accompanied to such appointments by their community care support worker. Diversity in care provision will be required for all patients and in particular for homeless people (Krakowsky et al., 2012). For example, diverse practices such as street-based palliative care may be required for some patients.

Palliative care for people with mental illness and comorbidity is cost effective and improves care as demonstrated in a retrospective study of 60 in-patients with end-stage dementia in a large academic tertiary care hospital in New York metropolitan area, where the authors found that the provision of palliative care decreased medication costs while at the same time effecting greater use of analgesia for these patients (Araw et al., 2015). In light of these benefits it is imperative that strategies to improve current care provision are identified and this care should be provided collaboratively by mental health professionals and palliative care experts (Bloomer & O'Brien, 2013).

Opportunities to improve care can be identified at the patient, provider and systems level (Irwin et al., 2014). A possible starting point could be to bring together, for an exchange of opinion and experience, professionals from the disciplines that can make a difference to a patient's quality of life and disease outcome. Patients and families' involvement in these discussions is imperative. Furthermore, a review of attendance compliance for follow-up care and actions based on the findings of the reviews would ensure that the needs of people with an SMI and comorbidity are adequately provided for

CHAPTER 3 STUDY DESIGN AND METHODS

3.1: Introduction

The purpose of this study was to identify if a need for palliative care exists among people with SMI in Ireland and to identify how and by whom those need are identified. The study also sought to identify the referral pathways into and through palliative care services in Ireland and once identified how palliative care was managed for those with SMI.

The study objectives were to:

1. Examine how and by whom the need for palliative care is identified for people with a diagnosed mental illness – General Practitioner (GP), Psychiatrist, other health professionals.
2. Identify the referral pathways and access to physical health and palliative care services
3. Identify how palliative care needs of people with SMI are managed once identified.

3.1.1: Research Questions

The following questions have been derived from the primary aims of the study in order to provide direction for the research and guidance in survey design and analysis and following that for interview schedule development.

1. What is the demographic profile of GPs and Psychiatrists who are treating individuals with severe mental illness and palliative care needs on the island of Ireland?
2. Are patients with existing mental illness presenting to their GP and/or Psychiatrist with physical health conditions?
3. Are the physical and palliative care (PC) needs of people with existing mental illness being identified and by whom?
4. How many patients with SMI and PC needs are currently being treated on the island of Ireland?
5. What are the clinical pathways taken by GPs and Psychiatrists in the management of patients with SMI and PC needs.
6. What are the opinions held by GPs and Psychiatrists towards those with severe mental illness and palliative care needs in the community, in relation to their physical health and palliative care.

7. Explore the practice related issues emerging for psychiatrists with regard to meeting the physical health and palliative care needs of their patients with SMI
8. Explore the type of knowledge transfer and exchange activities to be undertaken as part of this project .

3.1.2: Study Design

A sequential two strand mixed methods design was employed commencing with the quantitative strand followed by the qualitative interview strand. In the quantitative strand an exploratory survey design was employed to address the first six research questions. A postal survey of all General Practitioners currently on the register of the Irish College of General Practitioners in both Republic of Ireland (ROI) and Northern Ireland (NI) was undertaken. In the absence of an alternative mechanism, the 2016 version of Irish medical directory was utilised to identify all psychiatrists listed in the ROI. The purpose of this survey was to establish baseline information concerning patients with an existing diagnosed mental illness who also have palliative care needs. Specifically the survey sought to establish the prevalence of such cases; the identification of the existence of serious physical health conditions; how palliative care needs were identified and by whom. The questionnaire was also designed to capture information on other key areas including referral pathways and accessibility to health services for clients with severe mental illnesses.

Following analysis of the survey results for both GP's and psychiatrists, the original intention was to undertake interviews with a sub-sample of GP's and psychiatrists who had completed the survey to further explore issues emerging for them with regard to meeting the physical health and palliative care needs of their patients with SMI. While a number of GP's and psychiatrists indicated a willingness to participate in interviews, no GP's participated and a total of six psychiatrists participated. The interviews also provided an opportunity to explore the preferred approach of psychiatrists with regard to the knowledge exchange and transfer activities which form part of this study.

An original aim of the study had been the inclusion of service users with SMI and palliative care needs and their carers. However, as the study progressed it became apparent that identification and inclusion of service users and carers was problematic and thus a decision was made to omit this aim.

3.1.4: Research Ethics

Ethical approval for the study was sought and obtained from the Irish College of General Practitioners (ICGP) Research Ethics Committee following a detailed ethics application. The committee were supportive of and endorsed the study and ethical approval was provided. An exemption from full ethical review was sought and obtained from University College Dublin Human Research Ethics committee on the basis that ethical approval was already granted by the Irish College of General Practitioners. The University College Dublin Safety Office provided indemnity insurance for researchers in the study.

It was not anticipated that there would be any major adverse ethical issues arising from the questionnaire. However as the original proposal intended in addition to GP's and psychiatrists to include patient with SMI and palliative care needs and their carers, original research ethics was also being sought to identify potential future participants who may be identified as a vulnerable group and also have serious health limitations, potential issues had to be anticipated for in the ethics application.

During the original proposed qualitative phase of data collection, it was anticipated that participants with SMI may be severely ill and may become physically tired during the interview process. The researchers planned to make every effort to be cognisant of the participants' abilities and needs, ensuring that regular breaks and refreshments will be offered and provided to participants as required. If participants become too tired during an interview to continue it will be rescheduled to a later date or cancelled if requested.

It was further anticipated that in the case of the death of a participant, family carers will be treated with dignity and respect and they will be free to continue or withdraw from the study as they wish. If they wish to continue with the study, they will be supported and allowed time to consider their continued participation. All case data recorded by the researcher to that point will be included in the analysis. It was also noted in the ethics application that researchers will not advise participants about treatment, should issues arise concerning treatment the researchers will refer all participants back to their clinical teams. Finally, should any participants identify malpractice and reveal information where they or other may be in danger or suffering abuse at home or in hospital, researchers will follow a duty of care protocol and a public health representative will be contacted. Participants will be made aware of the duty of care prior to commencing all interviews. All of the qualitative data collected will be anonymised or de-identified by the researchers. Participants will be

provided with the opportunity to review the interview transcripts to ensure veracity of content and to allow for any amendments, deletions or additions.

3.2: INSTRUMENT DESIGN: GENERAL PRACTITIONER AND PSYCHIATRIST QUESTIONNAIRE

3.2.1: General Practitioner

The role of General practitioners is pivotal to the identification and referral of patients with palliative care needs to a range of services. In the absence of an existing standardised questionnaire concerning the palliative care needs of patients with severe mental illness from the GPs perspective, a questionnaire tailored specifically for general practitioners was required to begin exploratory studies in this field. In an attempt to identify if general practitioners were aware of, identifying and referring people with co-morbid mental illness and palliative care for interventions to palliative care services, a questionnaire was designed and distributed to all general practitioners in the Republic of Ireland (ROI), and Northern Ireland (NI).

The questionnaire was based on a similar questionnaire utilised with General practitioners in the Republic of Ireland (ICS Report, Drennan et al. 2015). However it was substantially revised to explore issues relating to palliative care needs of people with enduring mental illness. The study project team, consisting of experts in the field of nursing, palliative care, psychology, social justice and quantitative research methods were involved in the revision of the questionnaire. Revisions to the questionnaire were based on published peer reviewed research evidence about physical health needs of people with serious mental illness. The absence of any information about the palliative care needs of this particular group of service users in Ireland and the dearth of published international literature required the development of questions for inclusion based on the experience and expertise of researchers and clinicians involved with this group.

The questionnaire was reviewed and approved by a number of general practitioners and the director of research for the ICGP as part of the development process. Prior to distribution of the questionnaire in Northern Ireland minor modification to the ROI questionnaire were made. These revisions were the inclusion of a question relating to Dementia and minor re-wording of three existing questions and these were reviewed and approved by Royal College of General Practitioners prior to distribution. These changes did not alter the focus of the questionnaire.

3.2.2: Psychiatrists

Like GP's psychiatrists are the key health professional in mental health services who are likely to identify and refer patients with co-existing SMI and palliative care needs to a range of services. As with the GP's no existing standardised questionnaire for psychiatrists existed.

The original questionnaire designed for GP's was modified and refined to reflect psychiatric practices. While there were significant similarities in the nature of data required to be collected, a number of modifications were made. The revised questionnaire was reviewed by three psychiatrists and recommended comments and revisions incorporated prior to distribution.

3.2.3: Recruitment General Practitioners and Psychiatrists

Following consultation with the research directors from the Irish College of General Practitioners and the Northern Ireland Branch of the Royal College of General Practitioners (RCGP), access to all GPs on their distribution lists was negotiated. It was stipulated that the research pack labelling and distribution of questionnaires must be managed through an external company nominated by each individual organisation in order to protect the anonymity of their members. All 2,500 General Practitioners on the distribution list of the ICGP and 1,450 general practitioners on the distribution list of the RCGP were sent a personalised research pack. The research pack contained the four-section GP Questionnaire (Appendix 3.1), information sheets (Appendix 3.2), a personal invitation letter detailing the study aim and procedure for general practitioners (see Appendix 3.3), and two return stamped addressed envelopes, a reminder pack was distributed to GPs.

The College of Psychiatrist in Ireland was contacted to ascertain if a similar procedure to that utilised with GP's was feasible. No similar procedure was available and advice was to access the current Irish medical Directory to identify psychiatrists in ROI. In the absence of any alternative mechanism, the 2016 version of Irish medical directory was utilised to identify psychiatrists listed therein for the ROI. A total of 328 questionnaires along with information sheer and letter were distributed to all psychiatrists who did not identify themselves as specialist child and adolescent or perinatal psychiatrists and were thus presumed to be adult psychiatrists. Appendices 3.4, 3.5, 3.6)

3.2.4: Data Analysis

Data were analysed using IBM SPSS Statistics (Version 20) and was revised for accuracy and errors. Data were analysed using descriptive and inferential statistics.

3.3 INTERVIEWS

3.3.1: Interview Schedule

As part of this study general practitioners and psychiatrists who completed the survey were invited to participate in individual interviews. They were also asked if any of their existing patients with SMI and in receipt of palliative care would be willing and/or able to participate in an interview. A total of seven GP's and 21 psychiatrists indicated willingness to participate in interviews. However, only two patients were nominated as potential participants. Following contact with GP's and psychiatrists a total of six psychiatrist participated with no GP's available to participate. Following analysis of survey data a brief structured interview guide containing 10 questions was developed. The guide also contained a section exploring future potential knowledge transfer and exchange activities which could be undertaken.

3.3.2: Analysis

All interviews were digitally recorded and all data collected was processed, transcribed and prepared for analysis. Working independently, two researchers undertook initial or first cycle coding of data and independently attempted a synthesis prior to meeting together (Walsh & Downe 2006). This independent work involved assigning initial codes to words, phrases and/or chunks of data which captured its' essence and subjecting initial codes to further refinement with the purpose of summarising them into a smaller number of initial themes. All initial codes and themes identified independently by researchers were then subjected to second cycle coding with the intent of examining similarities and differences, and to further refine and summarise them into agreed themes.

Table 3.2: Phases of Thematic Analysis*

Phase	Description of the process
1. Processing and reparation of data :	Data transcribed and checked for accuracy by re-listening to recording. Reading and re-reading the data, noting initial ideas.
2. Identification of initial codes:	Identification of interesting patterns within the data across the entire data set, collating data chunks/sections relevant to each code.
3. Searching for themes:	Looking for similarities across codes and collating into potential themes; checking across data for any other relevant data .
4. Reviewing themes:	Checking and verifying themes as being located within the initial coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Continuing analysis to further refine the particulars of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

***Adapted from Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. Qualitative Research in Psychology, 3 (2). pp. 77-101. ISSN 1478-0887 Available from: <http://eprints.uwe.ac.uk/11735>**

CHAPTER 4 SURVEY RESULTS

4.1: INTRODUCTION

This chapter presents the results for the survey questionnaire. Results will be presented separately for general practitioners and psychiatrists beginning with demographic profile followed by pathways into and through the palliative care services for people with severe mental illness.

4.2 GENERAL PRACTITIONER RESULTS

4.2.1: Demographic Profile General Practitioners

The 2500 questionnaires distributed to GPs in the Republic of Ireland yielded a response rate of 434 (17.4%), while a response rate of 133 (9%), was recorded from the 1450 questionnaires distributed to GPs in Northern Ireland. The Response rates from the overall total sample were recorded as 76.5% (Republic of Ireland) and 23.5% (Northern Ireland) respectively. The Results presented below concern data from both the Republic of Ireland and Northern Ireland unless otherwise specified. Individual findings of from each jurisdiction will be documented when relevant to highlight differences or similarities between the two subsections of this dataset.

Among general practitioners male represented 48.1% of the sample with females accounting for 51.3% of respondents. The majority 73.4% of all respondents were single-handed GPs working alone with 25.4% of respondents being members of a group practice. In terms of the number of years working as a GP, 42.5% were in their current role for 15 years or less, with 56.8% for 15 years or more. The majority of GPs 64.9%, provided care in rural locations specifying their location as being in a town or village with the remainder 34.4% practicing in a City location. The demographic profile of GPs is presented in Table 4.1.

Over 30% of GPs surveyed had completed a palliative care course, while only 16.8% of practice nurses had done so. The latter figure however did not account for the number of practices that actually had a practice nurse, as this question was not explicitly asked in the questionnaire. Almost half of all GPs surveyed (44.8%) reported treating at least 100 or more patients with a diagnosed SMI at their practice over the last 3 years. For more detailed reporting on these results please see Table 4.1 below.

Table 4.1: Demographic Profile of GPs in Ireland Who Completed the Questionnaire

Characteristics	n =	%
Primary Practice Location		
Republic of Ireland	434	76.5%
Northern Ireland	133	23.5%
City		
City	195	34.4%
Town	251	44.3%
Village	117	20.6%
Prison	1	.2%
Type of Practice		
Single Handed	416	73.4%
Group	144	25.4%
No. of years in current role		
5 or less years	98	17.3%
6-15 years	143	25.2%
15-30 years	209	36.9%
30 or more years	113	19.9%
Gender		
Male	273	48.1%
Female	291	51.3%
GP Completed Palliative Care Course		
Yes	171	30.2%
No	368	64.9%
PN Completed Palliative Care Course		
yes	95	16.8%
no	333	58.7%
No. of patients with SMI attending practice over last 3 years.		
10 or less patients	16	2.8%
11-20 patients	43	7.6%
21-100 patients	241	42.5%
100 or more patients	254	44.8%

4.2.2: Most Common Mental and Physical illnesses

The five most common mental illnesses encountered by GPs in the past year were i) Depression, ii) Generalised Anxiety Disorder; iii) Panic Disorders; iv) Schizophrenia and v) personality disorders (see Table 4.2 for the numbers ranked for each condition).

General Practitioners identified a number of serious physical health issues in their patients with existing severe mental illness. Seventy nine percent of GPs treated patients with SMI and Cardiovascular Disease, 71.3% treated patients with Respiratory Conditions and SMI and 70% treated patients with Diabetes and SMI. Other conditions identified were breast cancer, lung cancer,

colorectal cancer and prostate cancer. Exact figures for the prevalence of such cases were not sought in the survey (Further results are detailed in Figure 4.1)

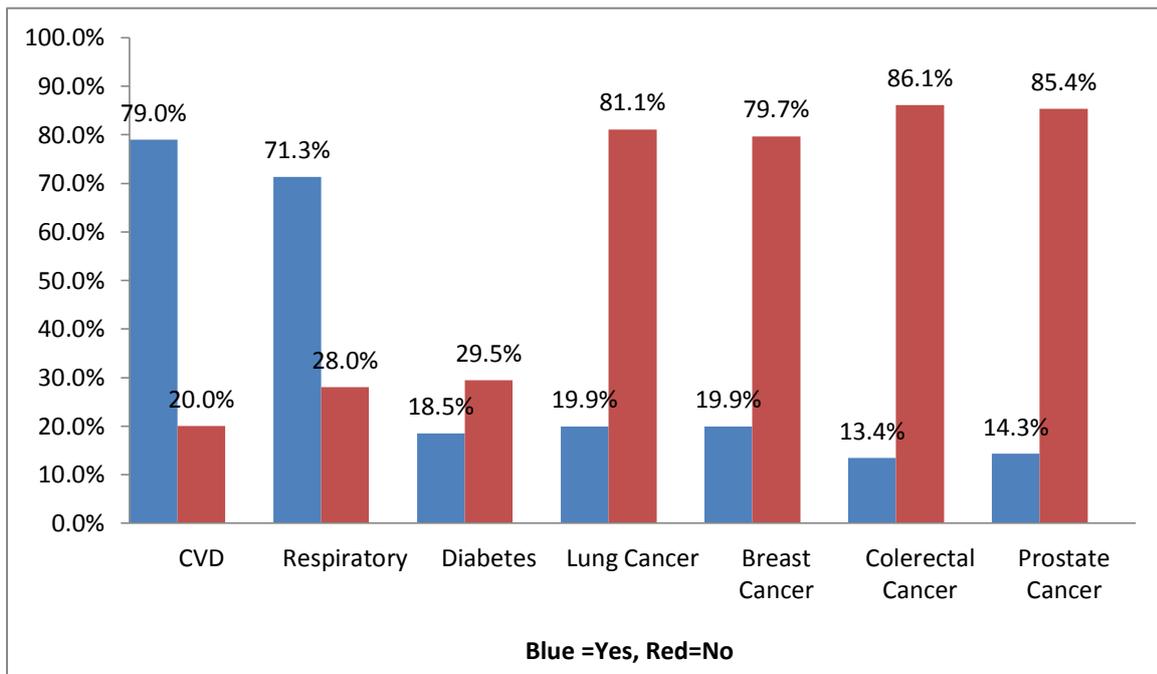


Figure 4.1: Serious Physical Health Issues in Patients with SMI (GP)

Table 4.2: Most Commonly Encountered Mental illnesses* in the past year

	1st Ranked	2nd Ranked	3rd Ranked	4th Ranked	5th Ranked
	n	n	n	n	n
Mood Disorders	173	65	86	66	29
Bipolar Disorder	10	12	40	86	91
Depression	263	174	82	14	10
Generalised Anxiety Disorder	117	248	128	32	7
Schizophrenia	12	5	23	55	124
Phobic Disorders	1	2	5	17	27
Panic Disorders	3	24	116	152	53
OCD	2	2	10	24	43
Eating Disorders	2	2	5	14	46
Personality Disorders	6	13	51	75	96

* Defined using ICD 10

4.2.3: Palliative Care Needs

Thirty five percent of GPs reported identifying one or more of their patients with diagnosed mental illness as requiring palliative care over the past year with 30.3% reporting that other clinicians or health care professionals identified their patients with SMI as requiring palliative care. Specifically, 14.1% were identified by an oncologist, 2.2% by cardiologists, 5.8% identified by a specialist respiratory physician, and 4.2% identified by a psychiatrist. Other health care professionals specified were colorectal physicians, district / public health nurses, ENT specialists, GI specialists, gynaecologists, geriatricians and home care hospice teams.

The total number of patients currently receiving palliative care as reported by 425 GPs was 1,447, with a GPs having between 1 and 80 patients (median = 2) currently receiving palliative care. It was identified that in the one year period reported on, 407 patients with a diagnosed SMI and physical health issues attending 330 practices on the island of Ireland died. Of the patients who died, 165 had a pre-identified physical condition that they were being treated for. Three hundred and sixty one of the aforementioned patient deaths had been expected due to the patient's physical illness and 47 of those 407 patients died by suicide.

The actions taken by GPs following identification of palliative care needs of their patients with SMI, approaches to managing palliative care needs patients, and the level of contact maintained by GPs and the specialist palliative care teams were identified. Over quarter of GPs 28% continued to manage their patients palliative care needs at their practice with approximately 25% of GPs referring their patients for palliative care assessment. (See Figure 4.2). Other actions taken by GPs included admittance to intermediate care beds, admittance to hospice or specialist services, referral to community palliative care and referral to nursing homes.

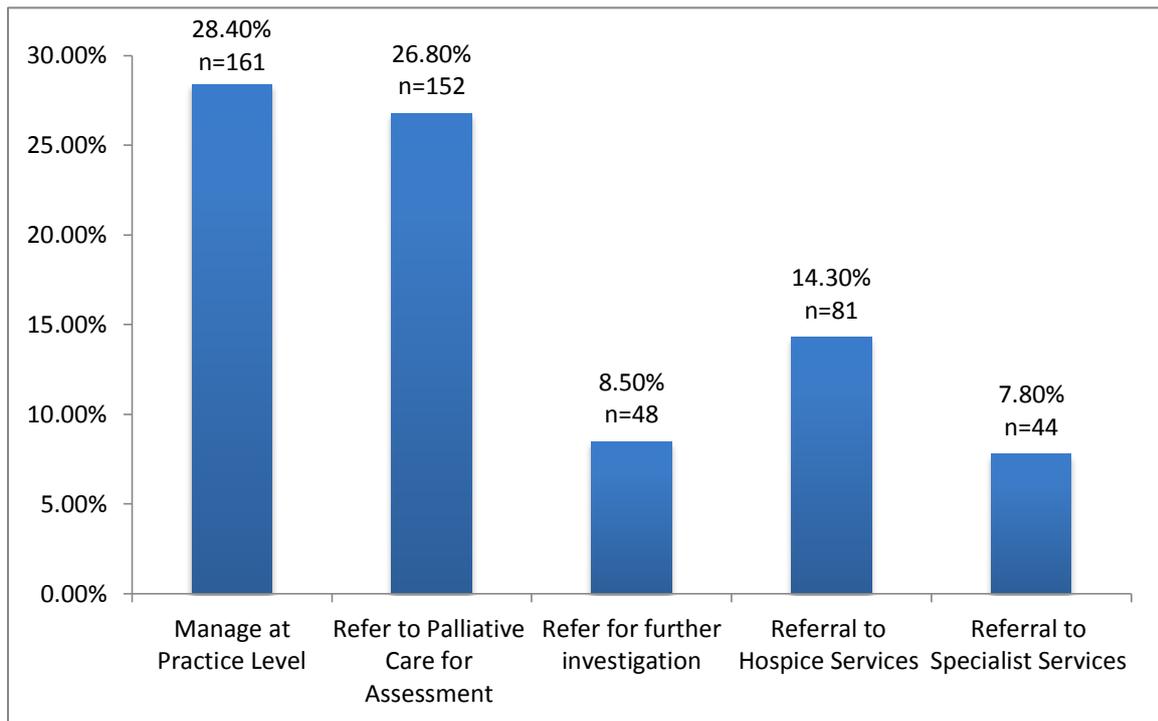


Figure 4.2: GP Management of Patients with SMI and Palliative Care Needs

4.2.4: Engagement with Palliative Care Services

In terms of engagement and communication with palliative care services, the majority of GPs (63.3%) reported rarely or never receiving communication from Specialist Palliative Care services to advise them that their patient had attended their initial appointment. Similarly 64.6% (n = 366) of GPs reported rarely or never receiving regular updates from palliative care services advising them of the current status of their patients. This is in line with the findings that 61.2% of GPs reported receiving no feedback whatsoever from specialist services whom they referred their patients to. An equal proportion of GPs reported being advised (31.5%) and not being advised (31%) if their patients did not attend referral appointments (see Table 4.3).

Table 4.3: GP Engagement with Palliative Care Services

		n	%
I received feedback to advise me that patient had attended initial appointment	For all	28	4.9
	For most	26	4.9
	For some	56	9.9
	Rarely	121	21.3
	never	238	42
I received regular updating from PC services advising me of current status of patient	For all	10	1.8
	For most	37	6.5
	For some	73	12.9
	Rarely	145	25.6
	Never	221	39
I received feedback to alert me that patient did not attend for appointment	For all	112	19.8
	For most	66	11.6
	For some	54	9.5
	Rarely	83	14.6
	Never	93	16.4
I received no feedback	For all	245	43.2
	For most	102	18
	For some	27	4.8
	Rarely	16	2.8
	Never	3	0.5

4.2.5: Opinions on Needs and Services

Using a Likert scale format GP's were asked six questions relating to their opinions on a number of concepts concerning patients in general with severe mental illness and palliative care needs. The 5-point Likert scale offered options of strongly disagrees, disagree, don't know, agree and strongly agree. The frequencies of scores for strongly disagree and disagree were combined to form a value of overall disagreement, and strongly agree and agree frequencies were combined to form a value of overall agreement with each statement.

In terms of accessing palliative care services, although it was acknowledged by 47.5% of GPs that patients with a diagnosed SMI were less likely to have their palliative care needs identified, the majority of GPs (69.1%) disagreed with the statement "patients with a diagnosed mental illness are less likely to be referred to specialist palliative care services" suggesting they believe that patients with SMI are as likely or more likely to be referred to specialist palliative care services as those

without a mental illness. In addition almost half of GPs (51.7%) disagreed with the statement “patients with a diagnosed mental illnesses have more difficulty accessing palliative care services”, again suggesting they were of the belief that patients with a diagnosed mental illness had no more difficulty than those in the general population in terms of accessing Palliative Care services.

Once referred over 60% of GPs agreed that patients with a diagnosed mental illness who were referred to palliative care services were less likely to engage fully with these services, while only 28.1% disagreed with this statement. This is in line with the findings that 50.6% of GPs agreed that patients with a diagnosed mental illness are less likely to utilise palliative care services when they are referred to them. Almost half (49.5%) of GPs disagreed that patients with a diagnosed mental illness who have palliative care needs are more likely to be cared for exclusively by a family member. However 30.7% of GPs were of the opinion based on their experience that patients with SMI and palliative care needs were indeed more likely to be cared for exclusively by a family member (Table 7.6).

4.2.6: Opinions on Physical Health and Life Style

Sixty per cent of GPs agreed that patients with a diagnosed mental illness were less likely to raise concerns about their physical health and 59.1% agreed that patients with a diagnosed mental illness are more likely to seek medical help relating to their psychiatric condition. Over 80% of GPs agreed that patients with a diagnosed mental illness have more difficulty expressing their physical health needs and a similar number of GPs agreed that patients with a diagnosed mental illness were more likely to have their physical health conditions overlooked than other patients (Table 4.4).

In terms of lifestyle behaviour patterns 94.9% of GPs agreed that patients with a diagnosed mental illness were more likely to smoke, 75% (n=428) agreed that patients with a diagnosed mental illness were more likely to drink alcohol excessively compared to those with no mental illness and 60.1% (n=341) of GPs agreed that patients with a diagnosed mental illness were more likely than those without mental illness to use non-prescription illicit drugs.

Table 4.4: GPs Opinions - Palliative Care Related Needs of Patients with SMI

	Disagree		Agree	
	n =	%	n=	%
Patients with a diagnosed mental illness are less likely to have palliative care needs identified.	257	45.3%	269	47.5%
Patients with a diagnosed mental illness are less likely to be referred to specialist palliative care services.	392	69.1%	143	25.3%
Patients with a diagnosed mental illness referred to palliative care services are less likely to engage fully with these services.	159	28.1%	344	60.6%
Patients with a diagnosed mental illness who have palliative care needs are more likely to be cared for exclusively by a family member.	281	49.5%	174	30.7%
Patients with a diagnosed mental illness have more difficulty accessing palliative care services.	293	51.7%	210	37%
Patients with a diagnosed mental illness are less likely to utilise palliative care services when referred.	193	34%	287	50.6%

The vast majority of GP's 88.9% (n=504) agreed that patients with a diagnosed mental illness were less likely to have healthy eating patterns than those without mental illness and 94.2% agreed that patients with a diagnosed mental illness were less likely to exercise than those without a mental illness. (See Table 4.5 for more details).

Table 4.5 GPs Opinions- Physical Health Related Needs of Patients with SMI

	Disagree		Agree	
	n =	%	n=	%
Patients with a diagnosed mental illness are less likely to raise concerns about their physical health.	209	36.9%	342	60.3%
Patients with a diagnosed mental illness are more likely to seek medical help relating to their psychiatric condition.	179	31.5%	336	59.1%
Patients with a diagnosed mental illness are more likely to smoke.	16	2.9%	538	94.9%
Patients with a diagnosed mental illness have more difficulty expressing their physical health needs.	73	12.9%	469	82.7%
Patients with a diagnosed mental illness are more likely to drink alcohol excessively.	94	16.5%	428	75.7%
Patients with a diagnosed mental illness are less likely to have health eating patterns.	50	8.8%	504	88.9%
Patients with a diagnosed mental illness are more likely to use non-prescription illicit drugs.	155	27.4%	341	60.1%
Patients with a diagnosed mental illness are more likely to have physical health conditions overlooked than other patients.	88	15.5%	465	82%
Patients with a diagnosed mental illness are less likely to exercise.	12	2.1%	534	94.2%

4.3: PSYCHIATRIST RESULTS

4.3.1 Demographic Profile Psychiatrists

A total of 93 questionnaires were returned giving an overall response rate of 30.5%. Of the 93 returned, 13 were excluded due to non-completion for a variety of reasons including retired/no longer practicing, no electronic patient information system from which to obtain data and no longer at address. A total of 80 questionnaires were completed representing a valid response rate of 26.2%.

Of the psychiatrists who responded, 52.6% were female and 46.1 were male, all most all, 97.4%, had practiced as a psychiatrist for longer than ten years and the majority, 85.5%, worked in the public sector with the remainder working in the private sector (10.5%) and a mix of public and private (3.9%) The demographic profile of GPs is presented in Table 4.6

Table 4.6 Demographic Profile of Psychiatrists who Completed Questionnaire

Characteristics	n =	%
City	52	65
Town	25	31.3
Village	1	1.3
Combination	2	2.6
Type of Practice		
Private	9	11.3
Public	68	85
Mix	3	3.8
No. of years in current role		
5 or less years	1	1.3
6-15 years	13	16.3
16-30 years	53	66.3
>30 or more years	13	16.3
Gender		
Male	37	46.3
Female	42	52.5
Missing	1	1.3
Completed Palliative Care Course		
Yes	22	27.5
No	58	72.5
No. of patients with SMI diagnosed with serious physical condition in past year		
10 or less patients	10	12.5
11-20 patients	19	23.8
21-40 patients	19	23.8
41-50 patients	7	8.8
51-100 patients	10	12.5
100 or more patients	15	18.8

The majority of psychiatrists 72.5% had not participated in any palliative care training with 27.5% indicating they had undertaken some form of palliative care training ranging from receiving a special interest session during initial medical education, attending one and two day workshops, working as liaison psychiatrist in hospice services and one psychiatrist who graduated with an MSc in palliative care.

4.3.2: Most Common Mental and Physical illnesses

The five most common mental illnesses encountered by Psychiatrists in the past year were i) Depression, ii) Schizophrenia iii) Generalised Anxiety Disorder; iv) Psychosis and v) personality disorders. Table 4.7 presents ranking for each condition.

Table 4.7: Most Common Mental Disorders - Ranked

	1 st Ranked n	2 nd Ranked n	3 rd Ranked n	4 th Ranked n	5 th Ranked n
Depression	49	18	2	1	3
Schizophrenia	22	12	12	11	10
Generalised anxiety disorders	19	24	10	9	3
Psychosis	17	14	16	16	6
Personality related disorders	17	17	17	9	4
Schizophrenia spectrum disorders	16	8	14	10	8
Addiction related disorders	14	22	15	5	7
BI-polar disorder	12	20	23	12	0
Dementia related disorders	10	10	7	14	23
Panic related disorder	6	15	15	18	7
Phobic related disorder	4	5	10	20	17
Obsessive compulsive disorders	3	9	14	24	10
Eating disorders	1	4	8	13	34

With regard to diagnosed serious physical health conditions, all respondents identified they had patients attending their clinic/practice who were diagnosed with a serious physical health condition. More than half of respondents (n=48) indicated they had up to 40 patients currently attending their clinic/practice with a diagnosed serious physical health condition. Of the remaining respondents 17 reported up to 100 patients with a diagnosed serious physical illness attending their clinic/practice and 15 reported in excess of 100. Cardiovascular and diabetic related disorders were the most commonly diagnosed serious physical illnesses (80%, n=64), respiratory related disorders were next (55%, n=44) with breast cancer and colorectal cancers at 27.5% (n= 22) and 25% (n=18) respectively and prostate cancer at 17.5% (n=14).

A range of other conditions reported included neurological and endocrine disorders; HIV and Hepatitis C; Laryngeal, pancreatic, oesophageal, renal and skin cancers; Lymphoma; Germ cell tumour Brain tumour; renal disease. Figure 4.3 and 4.4 presents most commonly diagnosed physical health conditions and the numbers of patients attending psychiatric practices/clinics with a serious physical health condition in the past year.

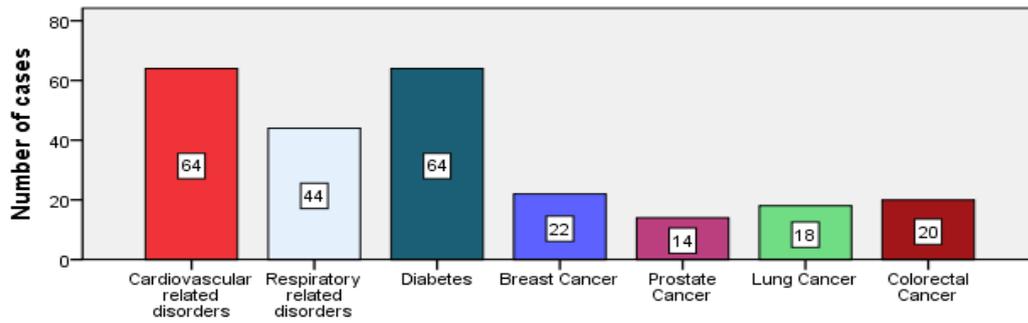


Figure 4.3: Types of serious physical health issues identified by psychiatrists in patients attending their clinic/practice in the past year.

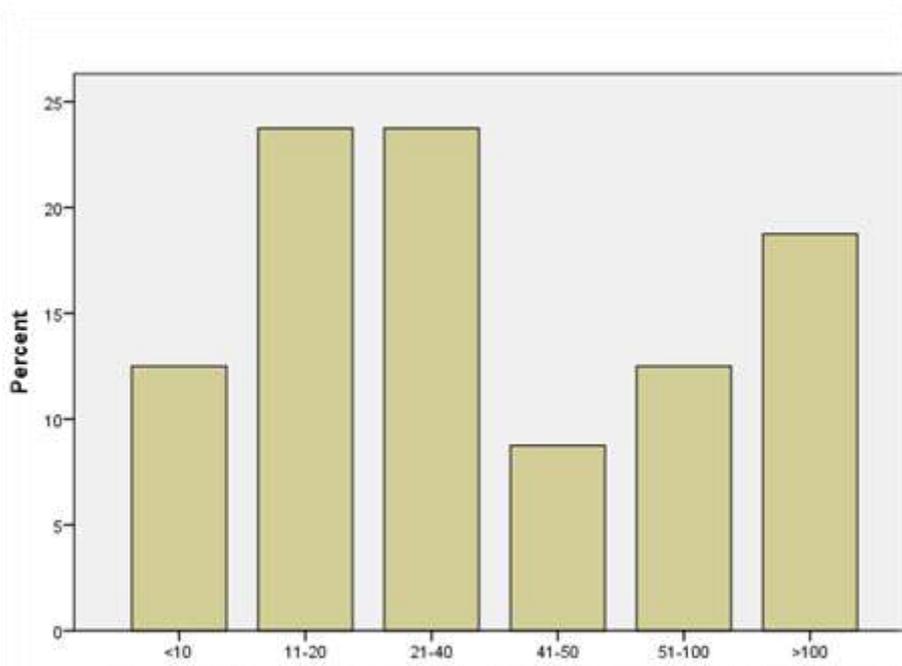


Figure 4.4: Approx number of patients attending Psychiatrist clinic/practice diagnosed with a serious physical health condition in the past year.

4.3.3: Palliative Care Needs

All respondents replied to this question regarding the approximate number of patients currently attending their practice/clinic who had palliative care needs in the past year. While 55% (n=44) of the Psychiatrists indicated that they had identified patients attending their practice /clinics with palliative care needs, over half of the psychiatrists in the study (61.3%, n=49) reported that the palliative care needs of their patients were identified by another health care professional. The professionals who most frequently identified palliative care needs in this patient group according to the psychiatrists were GPs' (32.5%) and Oncologists (27.5%), respiratory physicians (13.8%). Psychiatrists also identified a range of other professional groups who identified palliative care needs among their patients with nurses, both hospital and community based as the predominant group identifying the need for palliative care.

Palliative care needs were most frequently managed by the psychiatrist in partnership with specialist palliative care services and community/primary care services including GPs' and public health nurses. With regard to having palliative care needs identified and engaging with services the majority of respondents (56.3%) agreed that patients with SMI were less likely to have needs identified and to have more difficulty accessing palliative care services (57.6%).

Psychiatrists were asked to estimate the number of actual and expected deaths among patients attending their practice/clinic in the preceding year and if patients who died had a pre-existing physical illness. The largest number of deaths of patients reported in one year, while attending their Psychiatrist, fell within the <5 group (see Figure 4:5). The Psychiatrists who responded to question 13 which assessed the number of patients who died in the past year with a pre identified physical health condition and for which they were receiving treatment, 90% (n=72) of respondents identified 61 deaths in this group of patients.

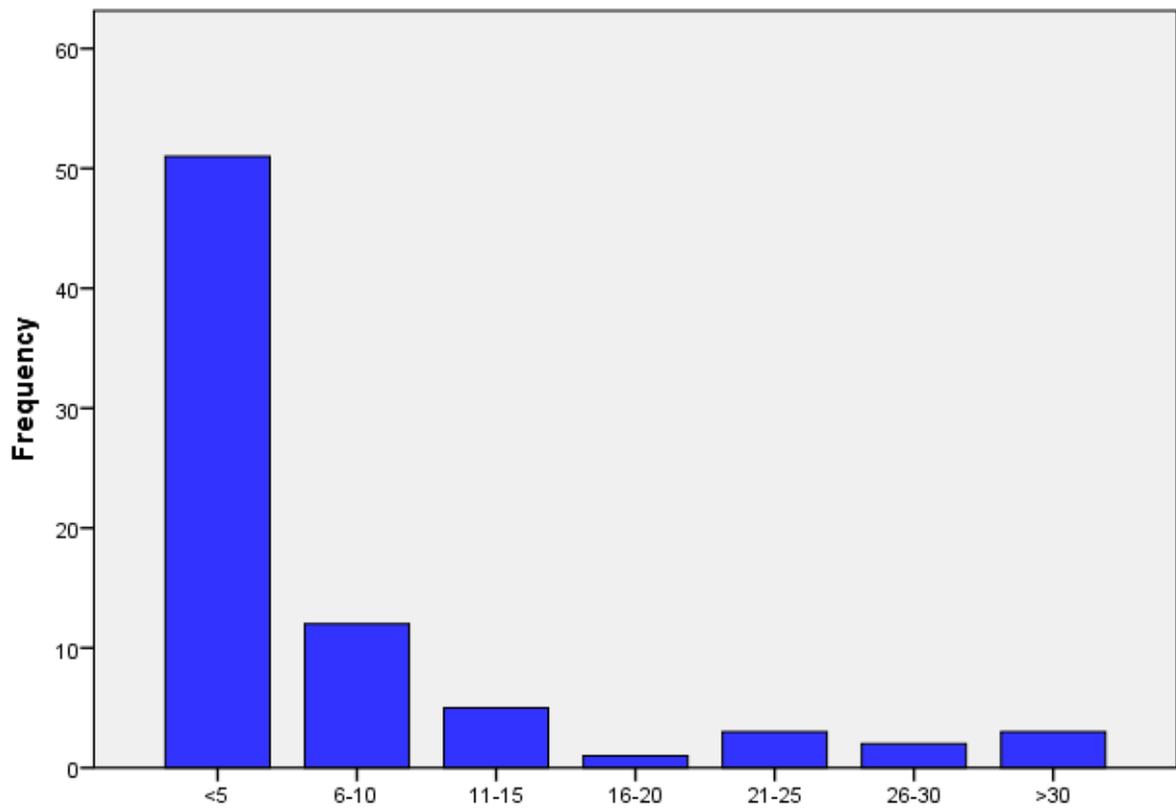


Figure 4.5: approximate number of patients attending Psychiatrist practice /clinic who have died in the past year.

In total, 358 deaths (Median =3, min = 0, max = 30) were reported by Psychiatrists as expected due to physical illness (Figure 4.6) and 68 deaths (Median =1, min = 0, max = 10) were reported as caused by suicide over the past year (see Figure 4.7).

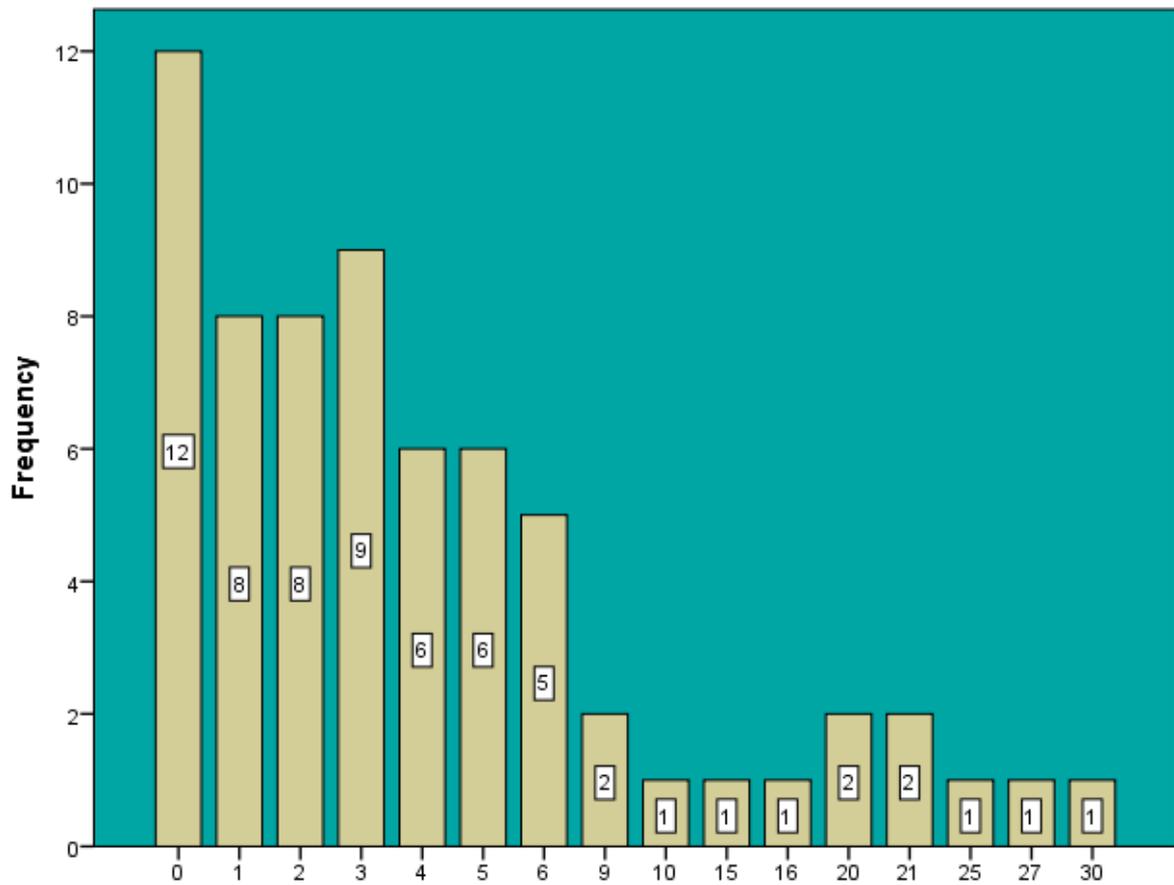


Figure 4.6: The number of deaths expected due to physical illness.

4.3.4: Engagement with Palliative Care Services

In terms of engagement and communication with palliative care services, the majority of Psychiatrists had not referred patients to palliative care. Of the 31 psychiatrists who did refer to palliative care 22.5% reported receiving communication from Specialist Palliative Care services to advise them that their patient had attended their initial appointment and received regular updating on the patients' condition. A total of 28.8% of psychiatrists reported rarely or never receiving feedback. Table 4.9 presents feedback received by psychiatrists from palliative care services.

Table 4.9: Feedback from Palliative Care Services

		n	%
I received feedback to advise me that patient had attended initial appointment	For all	18	22.5
	For most	7	8.8
	For some	3	6.3
	Rarely	2	2.5
	never	4	5
I received regular updating from PC services advising me of current status of patient	For all	18	22.5
	For most	6	7.5
	For some	5	6.3
	Rarely	4	5
	Never	4	5
I received feedback to alert me that patient did not attend for appointment	For all	6	7.5
	For most	4	5
	For some	2	2.5
	Rarely	3	3.8
	Never	13	16.3
I received no feedback	For all	7	8.8
	For most	3	3.8
	For some	3	3.8
	Rarely	5	6.3
	Never	18	22.5

4.3.5: Opinions on Needs and Services

Using a Likert scale format psychiatrists' were asked six questions relating to their opinions on a number of concepts concerning patients in general with severe mental illness and palliative care needs. The 5-point Likert scale offered options of strongly disagrees, disagree, don't know, agree and strongly agree. The frequencies of scores for strongly disagree and disagree were combined to form a value of overall disagreement, and strongly agree and agree frequencies were combined to

form a value of overall agreement with each statement. Frequency scores for don't know and missing data were also combined to form an overall score.

In terms of accessing palliative care services, the majority of psychiatrists (56.3%) agreed that patients with a diagnosed SMI were less likely to have their palliative care needs identified, with 32.5% disagreeing. Likewise over half of respondents (56.6%) agreed with the statement "patients with a diagnosed mental illness have more difficulty accessing palliative care services. Once referred 43.8% of psychiatrists disagreed that patients with a diagnosed mental illness who were referred to palliative care services were less likely to engage fully with these services, with 38.8% agreeing. Half of psychiatrists (50%) disagreed with the statement that "patients with a diagnosed SMI were less likely to utilise palliative care services when referred". See table 4.10.

Table 4.10: Psychiatrist's Opinions - Palliative Care Related Needs of Patients with SMI

	Disagree		Agree		Don't know/Missing
	n =	%	n=	%	
Patients with a diagnosed mental illness are LESS likely to have palliative care needs identified	26	32.5	45	56.3	9 (11.3%)
Patients with a diagnosed mental illness have MORE difficulty accessing palliative care services	22	27.6	46	56.6	11 (15.1)
Patients with a diagnosed mental illness are LESS likely to be referred to specialist palliative care services	28	35	41	51.3	11 (13.8%)
Patients with a diagnosed mental illness who have palliative care needs are MORE likely to be cared for exclusively by a family member	30	37.6	27	33.8	23 (28.8)
Patients with a diagnosed mental illness referred to palliative care services are LESS likely to engage fully with these services	35	43.8	31	38.8	14 (17.6%)
Patients with a diagnosed mental illness are LESS likely to utilise palliative care services when referred	40	50	24	30	16 (20.1%)

4.3.6: Opinions on Physical Health and Life Style

With regard to physical health care including identification and treatment of serious physical health conditions, the vast majority of respondents agreed that people with serious mental illness are less likely to raise concerns about physical health (73.8%), have difficulty expressing their physical health needs (81.3%); less likely to eat healthily (92.6%), more likely to smoke (96.3%), use alcohol to excess (78.8%) and to use non-prescribed and or illicit substances excessively (73.8%). Respondents also overwhelmingly agreed (90%) that people with serious mental illness are more likely to have physical health conditions overlooked than other patients. Table 4.11 presents psychiatrists opinions of physical health related needs of patients with SMI.

Table 4.11 Psychiatrist’s Opinions- Physical Health Related Needs of Patients with SMI

	Disagree		Agree		Don’t know Missing
	n =	%	n=	%	
Patients with a diagnosed mental illness are LESS likely to raise concerns about their physical health	17	21.3	59	73.8	4 (5.1)
Patients with a diagnosed mental illness are MORE likely to seek medical help relating to their psychiatric condition	42	52.5	27	33.8	11 (13.8)
Patients with a diagnosed mental illness are LESS likely to have healthy eating patterns	3	3.8	74	92.6	3 (3.8)
Patients with a diagnosed mental illness are MORE likely to smoke	1	1.3	77	96.3	2 (2.6)
Patients with a diagnosed mental illness have MORE difficulty expressing their physical needs	9	11.3	65	81.3	6 (7.3)
Patients with a diagnosed mental illness are LESS likely to exercise	2	2.5	76	95.1	2 (2.6)
Patients with a diagnosed mental illness are MORE likely to drink alcohol excessively	10	12.5	63	78.8	7 (8.9)
Patients with a diagnosed mental illness are MORE likely to use non-prescribed or illicit drugs	16	20	59	73.8	5 (6.3)
Patients with a diagnosed mental illness are MORE likely to have physical health conditions overlooked than other patients	3	3.8	72	90.	4 (5.1)

CHAPTER 5 QUALITATIVE INTERVIEWS

5.1 INTRODUCTION

General practitioners and psychiatrists who completed the survey were invited to participate in individual interviews, and if they had patients who they felt would be willing and able to participate in an interview. A total of 7 GP's 21 psychiatrists indicated a willingness to participate. All were contacted initially by letter to advise them of the purpose of the interview, provided with a brief summary of the initial survey findings and advising that contact would be made to arrange a suitable date and location. Contact was made by phone and to e-mail approximately two weeks later to arrange appointments. Upon contact no GP was currently available to participate and a total of six psychiatrists participated in interviews, five female and one male. Table 1 provides a breakdown of interview participation and the practice areas of interviewees.

Table 5.1: Interview Participants and Area of Practice

Practice Area of Interviewees	N
General Adult Psychiatry	2
Old Age psychiatry	2
Intellectual Disability	1
Rehabilitation	1
Total	6

Following analysis of survey data a brief structured interview guide containing 10 questions was developed. The guide also contained a section exploring future potential knowledge transfer and exchange activities which could be undertaken. All interviews were digitally recorded and all data collected was processed, transcribed and prepared for analysis. Working independently, two researchers undertook initial or first cycle coding of data and independently attempted a synthesis prior to meeting together (Walsh & Downe 2006). This independent work involved assigning initial codes to words, phrases and/or chunks of data which captured its' essence and subjecting initial codes to further refinement with the purpose of summarising them into a smaller number of initial themes. All initial codes and themes identified independently by researchers were then subjected to second cycle coding with the intent of examining similarities and differences, and to further refine

and summarise them into agreed themes. The process of thematic analysis employed was outlined previously in chapter 3 Table 3.2.

5.2: THEMATIC AREAS

Following this process, codes identified from the data were combined into five thematic areas including i) Psychiatry –Not a Unitary Practice; ii) Understanding and Managing Palliative Care, iii) Accessing and Negotiating the System; iv) Segregation, Discrimination and Stigma and v) Place of Residence .

5.2.1: THEME 1 - PSYCHIATRY - NOT A UNITARY PRACTICE

The initial theme to be identified related to the diverse nature of psychiatric practice. Interviewees' were asked to comment on how reflective the result of the survey was to their particular practice area. While there was broad agreement about the higher rates of all cause morbidity and mortality among those with serious mental illness, it was evident that the manifestation of these conditions differed depending upon the areas of practice of the psychiatrist. Those working in the area of old age psychiatry were less likely to encounter psychotic disorders and schizophrenia than those working in general adult and rehabilitation psychiatry, but more likely to encounter dementia, serious depressive and bi-polar disorders. Likewise the most prevalent physical illnesses in old age psychiatry differed to the overall results of the survey. In the survey cardiovascular disease was identified as the primary physical illness. In contrast, in old age psychiatry respiratory disorders such as Chronic Obstructive Pulmonary Disease (COPD) was more evident as the primary illness. They were also more likely to encounter higher number of patients with Cancer and with multiple co-morbidities resulting in the need to manage complex care across a broad spectrum of health care settings.

“about 50% of patients coming to old age psychiatry services have dementia... but we have lots of patients who have mental ill health through their life”

“the most common illnesses for me are depression and dementia, that’s what I see”

“almost everybody I see would come with some physical illness”

“I was surprised with the cancer numbers were probably slightly lower than I would have thought”

“Stroke was one I’d see a fair bit of”

“I have a huge number of people with COPD, issues around oxygen I don’t know whether it was just a bulge...you know the way you get these...I’ve only a couple of people who are actively being treated for cancer, well 4 or 5; and we always have cardiovascular disease, that’s kind of always in the background but respiratory disease at the moment is the main one”

For psychiatrists practicing in general adult, Intellectual Disability and rehabilitation psychiatry, dealing with co-morbid physical health issues was recognised as complex and challenging. People attending general adult and rehabilitation services tended to have more acute and challenging mental health needs. Within Intellectual Disability services, physical conditions were compounded by the nature of specific syndromes such as Prader- Willi and Downs Syndrome, and the dual diagnosis of an intellectual disability and mental illness.

“I have patients with cancer, patients with Hodgkin’s disease, patients with other sorts of metabolic disorders that are probably resulting from their mental illness and its treatment but that are you know quite compromised”

“most of my work now is with middle-aged people out in the community and breast cancer and prostate cancer and severe COPD and diabetes, amputations, that kind of thing”

“the big group of patients that we have here who we give palliative care to are the Down’s Syndrome people who develop dementia and we would have quite a number of people who developed it....”.

All those interviewed discussed the complex nature of managing co-morbid physical health issues. Being involved in managing this group of patients required the psychiatrists and mental health teams to engage in multi-agency and cross disciplinary working. The absence of existing and/or underdeveloped structures within the Irish health care system to support multi-agency and cross disciplinary working frequently resulted in an over reliance on locally developed working relationships with individual clinicians or teams. What was evident was that these relationships were generally based on ‘goodwill’ or were seen as ‘doing a favour’.

“clinically it’s a complex problem; it’s a problem that when it presents in practice that there’s a lot of interdisciplinary work involved, engaging with a lot of agencies who you generally don’t engage with on a regular basis”

“there’s quite a lot of different forms for interfacing with it”

“But I think we always feel that it’s a favour...., there isn’t really a service plan that they’re doing it to so they’re kind of doing it as a favour”

It was also recognised that over the past number of years psychiatrists had become more attuned to addressing physical health needs with screening practices for hypertension, hyperlipidaemia and diabetes becoming much more evident. Likewise, patients were more often being referred to their general practitioner to have physical health checks and national screening programmes including breast check and cervical screen were in some areas included as part of the mental health care planning process.

5.2.2: THEME 2 - UNDERSTANDING AND MANAGING PALLIATIVE CARE

While the WHO (2002) definition of palliative care had been used as the foundation for this study, gaining the perspective of how psychiatrists understood and interpreted palliative care was considered important. This insight assisted in gaining a deeper understanding of how palliative care needs were identified, planned, managed and organised for patients with co-morbid serious physical health conditions.

Among those interviewed there was a broad understanding of what palliative care means spanning a continuum from viewing palliative care as care at the end of life principally concerned with managing physical symptoms and care needs, to a broader understanding of palliative care as being longer term in nature, being comprised of stages and as contributing to the quality of the person’s life. This longer term view was more evident in the practice areas of psychiatry of older age and in intellectual disability than it was in rehabilitation or general adult psychiatry.

“end of life care and ensuring a good death so that would have been my ...without spending too much time thinking about a broader definition, that would be what my understanding of it would be; but speaking to some junior doctors who have trained more recently who would say palliative care now get involved in conditions like COPD, cardiac care, renal conditions when essentially it’s not even end of life care but it’s people who won’t recover ...which certainly wasn’t my understanding of what palliative care does”

“it’s about planning end of life, it’s not necessarily about those last few days, it’s about a period of time where you realise that people are kind of going into that transition of end of life care. So it’s not just about making sure that they’re pain free, that their breathing is ok, it’s about if they organise themselves in terms of wills, power of attorney, that they have the

chance to meet family, make friends with family; so it's much more than just the physical symptoms of the end of life"

"I think it means sort of end of life rather than always cancer related. I think to me it's all about sort of managing that transition and you know trying to find the right help for people to do that"

"two things, it means for some people to manage end of life care so that's a first group of patients but for other patients with severe chronic conditions I think palliative care can be very helpful in managing the ongoing care for those patients. It doesn't necessarily mean that their life is for 6-12 months or whatever it is but they may have ultimately life limiting illness and palliative care could be helpful in planning and managing those illnesses".

"I think an awful lot of psychiatrists really see palliative care as that last couple of days and they don't see it as a larger piece of work and I think for the majority of people it's around the physical aspects of end of life"

These differences in perspectives are understandable when practice areas are considered. Both old age psychiatry and Intellectual disability services have more patients with recognised life limiting conditions. These conditions including dementias and genetic disorders in intellectual disability such as Downs syndrome, Fragile X syndrome and Prader-Willi Syndrome, in additions to having protracted durations, are frequently compounded by associated congenital or higher associated risks for serious physical health problems. The emphasis on palliative care in old age psychiatry was recognised as central by psychiatrists practicing in the area and one had obtained a Master's degree in palliative care.

Consideration of the management of palliative care was also evident in this theme and the general consensus was that it should include palliative care and mental health teams and the person's general practitioner. While there was recognition of the need for a designated lead clinician to oversee and coordinate care, this was seen as a role best facilitated by the general practitioner if the person was residing in the community or if hospitalised as being determined by the dominant condition. Thus if the dominant condition related to a physical condition such as cancer the led role was by the oncologist.

5.2.3: THEME 3 – ACCESSING AND NAVIGATING THE SYSTEM

Gaining access to and navigating the health system with regard to meeting the physical health and palliative care needs of people with serious mental illness was identified as one of major significance. Two elements relating to access and navigation were identified, with the first pertaining to clinicians and the second to patients.

Psychiatrists reported a number of difficulties in trying to gain access to physical health and palliative care services and these difficulties existed even where services were co-located. Often as health professionals who were either identifying a physical health/palliative care need or attempting to coordinate and manage that patient's treatment and care, they regularly experienced significant difficulty in both communication and making contact with other physicians. Some psychiatrists explained that they were often blocked by administrative staff, whom for whatever reason were either unwilling or unable to provide them with required information or direct access to a particular clinician. Psychiatrists also highlighted that where multiple comorbidity existed, communication and access was made more complex by the need to communicate with numerous different departments and specialities involved in the care of an individual. A lead clinician charged with the overall coordination of treatment and or care does not exist. The absence of a unique patient identifier and an electronic patient record system to which all clinicians involved in the care of a patient would have access further compounded communication about, management and coordination of treatment and care.

"...communication is a problem... it would be very useful if there were more kind of liaison nurses that we could tap into that we could phone up if we had concerns instead of trying to deal with you know kind of secretaries and administrators because you just come up against a brick wall and they just block you. You're trying to explain why you're worried and they're saying there's no appointment for 2 months"

"..sometimes the patients have an awful lot of specialists they might have a respiratory physician, a respiratory surgeon for lung cancer, they might have a radiotherapist, an oncologist and there's so many of them and they all have junior doctors and you're ringing up saying you know so and so's not well, what was the last scan...oh it was grand, there was nothing on it, I think they're a bit depressed and you think I don't think so"

"Caredoc -that's another problem because they're very transient and you can't ever phone them up the next day, they're gone so really if something is not done right it will never be remediated"

“...it’s all the problems with the lack of planning, the lack of the notes being electronic, the lack of everything stopping on a bank holiday Friday. The junior doctors, a lot of them are from agencies that have no investment into the system, they don’t know the players. They don’t even know the addresses where people live”

Accessing and navigating the health system is challenging for most citizens, but for those who are already vulnerable due to serious mental illness and co-morbid physical health issues, accessing and navigation becomes even more challenging. For people with co-morbid serious mental and physical illness and palliative care needs, factors including having sufficient finances to travel to appointments, having access to public transport, and being treated as equal to other citizens were identified as areas of particular concern. Equality of treatment will be dealt with in more the theme relating to stigma.

“...people need facilities to get places and a big issue is transport. It may not apply to Dublin but everywhere else - like you’re trying to get your patient to do things and to go places and there’s no way they can get there so why does a very simple thing like the drive to Care for chemo - there’s nothing like that afterwards”

“this person was in an accident and their leg was mangled, mangled!. They were attending my clinic and was due to attend an orthopaedic unit . The person could not go, they said I don’t know how I’m going to get there, there’s no transport. I don’t have any money to pay my neighbour, he normally would bring me but he won’t go unless I give him the money for the fuel and I don’t have any. I got a letter saying the leg is being amputated and I just thought if I’d given €50 out of my wallet would that have helped? I don’t know. But like it seems very short sighted this, the getting people to services and you know even the basic transport system but also the ambulance services is not really there you know, we ‘re not a very caring kind of country”

Geographic service related boundaries were also identified as an issue particularly in rural areas. In some instances the nearest services may be only a few kilometres away but be inaccessible as the person does not reside within the county boundaries. In some instances this will necessitate the person having to travel substantial distances to obtain treatment.

“..sometimes the boundaries are stupid like if the person lives a mile from Carlow but they live in Wicklow they have to go to Louglinstown as opposed to Waterford. It should be a little bit more flexible “

5.2.4: THEME 4 – SEGREGATION, DISCRIMINATION AND STIGMA

An area given significant attention and discussion by interviewees was segregation, discrimination and stigma. While principally these issues were considered from the perspective of the person with serious mental illness, they were also identified as impacting psychiatrists by association as the clinicians who provided treatment and care to this group. There was a general consensus that people with serious mental illness had reduced access to and received a lower standard of physical health care than other citizens. This reduced access and poorer quality care had several dimensions. While exceptions certainly exist, Psychiatrists portrayed a physical health care system which is generally resistant to accepting those who are diagnosed with a mental illness. Frequently patient's physical symptoms were ignored, disbelieved or attributed to the persons "mental illness". There was also an unwillingness to admit patients with mental illness to acute care hospitals and barriers to admission were imposed such as requiring the patient to be accompanied and supervised for the duration of their hospital stay by staff from the psychiatric/mental health services.

"There's no doubt, if someone is known to have mental health problems they get the worst service but like you're saying they should be getting a better service because they have a higher chance of being sick. ; ... they don't get the care or the attention you know that other people would get. And you know we're tarred with the same brush as well"

".. we try and advocate for our patients, we get stigmatised. But I do think it's very important to try and say to people just because you're bipolar or you've schizophrenia it doesn't mean you're any less of a person and you still have breast cancer or colon cancer. Sometimes people with schizophrenia don't necessarily complain about pain as much as other people but they still get the conditions but they don't always get prioritised"

"..there's huge stigma when you try and get the person seen by you know an oncologist or whatever. Whatever ails them they are very keen to claim it's always due to their depression or whatever, so it's a bit of an uphill battle always trying to get people seen again"

While accepting that reduced access and poorer quality of care is contributing to delayed diagnosis among those with serious mental illness, it was also recognised that for many people with a serious mental illness, articulating their physical health needs often proves difficult. Work undertaken within the rehabilitation and general adult mental health services by one of the interviewees identified that for a proportion of people with serious mental illness the first indication of a serious

physical health issue may manifest as a deterioration in their mental health. In the interviewee's experience their team had retrospectively audited hospital admission where no clear rationale for deterioration could be identified. What emerged was that a significant proportion of such patients subsequently presented with a serious physical health issue and many of them had died within two years of the initial deterioration.

"... admission to hospitals for individuals who were stable in the community for many years and no clear reason why their mental health had deteriorated when all other variables were static.. medication unchanged, environment unchanged, no major stressors ...yet suddenly their mental state deteriorated, they relapsed and readmission to the acute psychiatric unit"

"it's the deterioration in mental state and subsequent diagnosis of the serious underlying physical health problem... many of them within two years were in fact dead"

"now if there is an unexplained deterioration in an individual's mental state in a community setting our priority is to rule out serious underlying physical illness in the first instance if all other variables are static and unchanged"

A further dimension of discrimination and exclusion was identified as a failure to respect the capacity and agency of the individual. There was a consensus among psychiatrists that the only way to proceed in any care situation was through full engagement and participation with the patients, their family or their designated primary person. However, it was recognised that decisions about treatments and in particular treatments which carry high risks such as chemotherapy for cancer, and/ or utilise scarce or restricted resources such as radiation therapy, were often not provided to people with mental illness. Such decisions were taken exclusively by the medical team without consultation with the person, their family, or the psychiatrist/mental health team. Psychiatrists felt this approach was often justified by the medical team on their perception of the quality of life of the persons with mental illness, or a perceived lack of capacity to be involved in decisions about their treatment or care or on the presumption that they would fail to comply/engage in the treatment.

"...and it's often done to a negative effect and it's not any one particular discipline but there can be an assumption that well this patient doesn't have much quality of life so it's not worth exploring exhaustive treatment options and we should proceed to a palliative path now rather than exploring other options... and often times that's a source of eh frustration and stress and bewilderment to the patient"

“we’re dealing with another case now at the moment of another young female who assumptions were made about her quality of life, what her preference would be without actually having that discussion with her”

“...I think it’s a bit more than that as well though .. they have multi-disciplinary discussions and again I’m not party to those so I don’t know how they operate but there are various disciplines and professionals giving their assessment of the clinical difficulties and saying well there isn’t a surgical solution to this, radiation isn’t an option, chemotherapy maybe no ; looking at what are the radiological findings, what are the clinical findings and making assumptions that the treatment isn’t worth the risk benefit analysis but that discussions not taking place with the patient”

“I think there’s a lot of negative assumptions perhaps being made about the contribution of the patient’s psychiatric condition within that setting that may be false assumptions and may ultimately not contribute to a good death or good end of life care because the patient hasn’t been made aware of what the different options are and I think that’s a deficit that I would see more and more really”

5.2.5: THEME 5 - PLACE OF RESIDENCE

Evidence about where people in Ireland would prefer to be cared for has clearly identified that for the majority their preference is to be cared for at home. Likewise for people with SMI and palliative care needs and who have resided in supported accommodation and/or supervised community based residences, their preference is to remain in their familiar surroundings, particularly as they become increasingly frail and require palliative and end of life care. However, what has emerged from interviews clearly identified that for the majority of those with a SMI and co-existing palliative care needs, remaining in their normal place of residence is not an option. A critical element of the need to relocate people when their need for palliative care increased was the absence of staff within community supported accommodation to provide this care. Thus for the majority of those living in supported community based accommodation, whether supported by mental health or intellectual disability services, their desire to remain in their ‘home’ among familiar people and objects, was not an option. The need for people to re-locate when their need for palliative and end of life care increased was seen as one of the unintended effects of de-institutionalisation. Within large institutions staffed primarily by medical and nursing staff, palliative and end of life care was not seen as unusual but rather as an expected element of long term residence. This changed with de-

institutionalisation but has now been consolidated with further changes in terms of the nature of staff employed within existing services.

It is also evident that staff who had long established relationships with individuals who due to their increasing palliative care needs had to re-locate, were upset by this as were their fellow residents.

“just coming back to the community residences..... we had provided end of life care in those settings historically and that was a great desire of the residents that when they would die that they wouldn't leave, that they would die there. Yes and we were able to accommodate that..... the resettlement programme..... the investment in the community residences and staff numbers were reduced and so the capacity to provide palliative care in those settings no longer exists now”

“ individuals with severe mental illness are invariably unless they're homeless in receipt of some kind of support from the statutory agencies or public services and so if they're in the community it becomes an issue of will they continue to reside at home and can their end of life care needs be met there. In my experience people with very severe enduring mental health problems who invariably live alone or live with social supports, there comes a time when that is untenable. I've yet to have the experience of anybody having a planned death at home with severe enduring mental illness”

“when it comes time for your end of life care you leave and leaving means death and that has changed in my opinion I suppose the contract with the tenants as well in terms of the psychological contract with them and they can see now I will not die here if it's an end of life palliative care situation, I will go somewhere else”

The need for people with SMI and palliative care needs to be re-located from their place of usual residence to either an acute hospital or nursing home was principally related to the absence of sufficient numbers and suitably skilled staff. Change in service policy and planning has favoured employing non-professional staff to supervise community residence. As a result existing staff are not in a position to provide such care due to both a lack of skills as well as the requirements of their role and the needs of other residents.

“We've looked at that and what you encounter then is going back to the issue you face with the individual in the community when they reach a critical point that you will have one staff member on duty responsible for what is essentially a psychiatric facility and the psychiatric

needs of maybe 14 individuals but somebody in a complex end of life situation with perhaps very complex medical needs and an increasing anxiety about their ability or capacity to cope with those problems and my experience is those resources simply will not come in and they can't be provided"

"Some have moved yeah, they've had to move to nursing homes because there's non nursing staff in the homes and they're having seizures at night maybe or they're not able to swallow or they're on liquid diets and there's a risk of choking, they'd be the reasons"

"if we couldn't manage them they would go into the hospice type situation but by and large our patients aren't suitable for hospice type situation which is another issue but it like you say it's a simple commitment to provide the staffing but it's the uncertainty that always comes with end of life care how long is this commitment going to last, what's the financial commitment going to be? What will the cost associated with this be and from the perspective of the mental health, mental health commissioners are budget holders, they would say they're not in a position to fund this kind of care".

CHAPTER 6 DISCUSSION

6.1 INTRODUCTION

Serious mental illness is estimated to affect 14% of the population (Kessler et al. 2005) with the burden of this illness being compounded by co-morbidities, particularly cardiovascular, respiratory and metabolic disorders as well as an increase in all-cause mortality rates. The National Advisory Council for Palliative Care (2001) has identified that patients with cardiovascular and respiratory diseases are likely to be the main cohorts of non-cancer patients requiring specialist palliative care services.

6.2 INCREASED MORBIDITY AND MORTALITY

The study presented here has clearly identified that among people with serious mental illness in Ireland, a significant proportion are identified as having serious physical health conditions including cardiovascular, respiratory and diabetes related disorders and of those a considerable proportion require palliative care. Almost half of all GPs surveyed (44.8%) reported treating at least 100 or more patients with a diagnosed SMI at their practice over the last 3 years. Likewise all psychiatrists reported having patients attending their clinic/practice who were diagnosed with a serious physical health condition within the past year. More than half of psychiatrists (n=48) indicated they had up to 40 patients, 17 reporting up to 100 patients and 15 reporting in excess of 100. Both groups of respondents (GP's, psychiatrists), identified cardiovascular, respiratory and diabetes related disorders as the top three serious physical conditions identified among patients with SMI. Thus the results of this Irish study in relation to CVD are consistent with the established literature. De Hert *et al.*, (2011) estimated the prevalence of cardiovascular morbidity and mortality to be 2 to 3 times greater than the general population for those with a diagnosis of schizophrenia, particularly younger age groups; 35% to 250% higher in those with bi-polar disorders and up to 50% higher in major depression (De Hert *et al.* 2011). Likewise Morden et al. (2012) identified CVD a significant contributor to increased mortality in those with SMI and Neisen et al. (2013) who reported that CVD was the leading cause of death (25%) in a population of people with schizophrenia. Furthermore people with schizophrenia taking antipsychotic medication are reported to be three times more likely to die from sudden cardiac death than the general population (Koponen *et al.* 2008; Ray *et al.* 2009), and are often late in seeking treatment for a physical illness resulting in their outcomes being adversely affected by this delay. Such delays may also impact negatively the cost of treatment (Morgan, 2016).

As cardiovascular and respiratory diseases account for two of the ten commonest causes of admission to emergency departments in Ireland reporting to the Hospital Inpatient Enquiry (HIPE) during 2015 (Healthcare Pricing Office, 2016), and that one in four people experience a mental health issue, it is reasonable to assume that patients with an SMI and comorbidity are regularly cared for by acute care hospital consultants. What cannot be known at this time however is, if health service providers are providing the type of long-term palliative care necessary to improve the quality of life of this group of patients who are known to have difficulties caring for their physical well-being.

6.3 PHYSICAL HEALTH AND LIFESTYLE

Populations with social and financial disadvantage are at greatest risk for poor health. Among people with SMI poverty resulting from unemployment and dependence upon social benefits; living alone or with unrelated others in supported accommodation; being unmarried, having no children and limited social and family networks further contribute to poorer physical and mental health and act to compound barriers to access and utilisation of health care including palliative care.

General practitioners and psychiatrists were asked to share their knowledge and views about how people with SMI fared when compared to the general population with regard to i) identifying their physical health needs, ii) accessing and utilising services once referred and iii) a range of life style issues such as smoking, diet and exercise.

Almost half of GPs' surveyed (47%), and 56.3% of psychiatrists surveyed agreed that patients with a diagnosed SMI were less likely to have their palliative care needs identified compared to patients without a mental illness. While over half of psychiatrists (56.6%) agreed with the statement "patients with a diagnosed mental illness have more difficulty accessing palliative care services, this varied with responses from GP's with 69.1% disagreeing with the statement. Again variance was noted between psychiatrists and GP's with regard to utilisation of palliative care services by people with SMI. Thirty percent of psychiatrists agreed that patients with a SMI who were referred to palliative care services were less likely to engage fully with them while 60% of GPs' in the study were of the opinion that people with SMI were less likely to engage fully with services.

Psychiatrists and GP's were also asked to comment on lifestyle issues relating to people with SMI. With regard to physical health care including identification and treatment of serious physical health conditions, the vast majority of psychiatrist (73.8%), and GP's (60%) agreed that people with SMI are less likely to raise concerns about physical health; have difficulty expressing their physical health needs (psychiatrists 81.3%; GP's 80%); less likely to eat healthily (psychiatrists 92.6%; GPs' 88.9%),

more likely to smoke (psychiatrists 96.3%; GPs 94.9%), use alcohol to excess (psychiatrists 78.8%; GPs 75.7%) and to use non-prescribed and or illicit substances excessively (psychiatrists 73.8%; GPs 60.1%). Respondents also overwhelmingly agreed (Psychiatrists 90%; GPs 82%) that people with serious mental illness are more likely to have physical health conditions overlooked than other patients.

Possible reasons for these results may be explained at least in part, by Chacon *et al.* (2011) findings, that patients with SMI presented with higher vulnerability to chronic illnesses due to a decreased likelihood of regularly attending health care services for physical check-ups. A number of factors were considered to explain this disparity in rates of diagnosis, including a lower rate of general health checks for blood pressure, cholesterol and smoking status in those with schizophrenia compared to the general population (Roberts et al. 2007, Mai et al. 2011)

However, the most recognised and important barriers to participation and inclusion including with health services for people with SMI is the stigma associated with their mental illness. The result of the stigma experience is almost always negative. Stigma is considered to act in two ways, directly to exclude individuals with SMI from areas of participation, including work, health, education, travel and decent living conditions; and indirectly, with those experiencing SMI internalising wider societal attitudes resulting in self-stigmatisation. The outcomes of both processes of stigmatisation are perceived powerlessness, lack of control and loss of hope. For many individuals with SMI, the source of discrimination comes from those close to them, including family and friends. In addition, discrimination is experienced when interacting with health professionals including general practitioners, doctors, nurses and other related professional groups and is often related to stereotypes and prejudicial notions about mental illness and quality of life of those with SMI. Importantly, Mental health professionals are not immune to contributing to the stigmatisation of people with SMI and constant vigilance is required of all practitioners. To reduce stigmatisation of vulnerable groups. Thus, the effects of stigma and discrimination work almost like a second illness and the emotion of shame, a common response to stigma, leads to secrecy which, itself, is an obstacle to seeking assistance with health difficulties and their treatment. Thus, stigma can act as a direct barrier to help seeking, lower self-esteem, social isolation and exclusion (Boardman, 2011; Sheridan *et al.*, 2015).

The interviews in this study identified a number of issues relating to stigma which clearly impact the person with SMI in seeking help, having their symptoms recognised as genuine, and being recognised as an equal partner in decision making about their treatment and care. There was a general consensus that people with serious mental illness had reduced access to and received a

lower standard of physical health care than other citizens. This reduced access and poorer quality care had several dimensions. While exceptions certainly exist, Psychiatrists portrayed a physical health care system which is generally resistant to accepting those who are diagnosed with a mental illness. Frequently patient's physical symptoms were ignored, disbelieved or attributed to the persons "mental illness". There was also an unwillingness to admit patients with mental illness to acute care hospitals and barriers to admission were imposed such as requiring the patient to be accompanied and supervised for the duration of their hospital stay by staff from the psychiatric/mental health services.

A further dimension of discrimination and exclusion was identified as a failure to respect the capacity and agency of the individual. Psychiatrists highlighted that decisions about treatments, and in particular treatments which carry high risks such as chemotherapy for cancer, and/ or utilise scarce or restricted resources such as radiation therapy, were often not prescribed for people with mental illness. Such decisions were taken exclusively by the medical team without consultation with the person, their family, or the psychiatrist/mental health team. Psychiatrists felt this approach was justified by the acute care medical team based upon their perception of the quality of life of the person with mental illness, or a perceived lack of capacity to be involved in decisions about their treatment or care and /or on the presumption that they would fail to comply/engage in the treatment.

6.4 THE NEED FOR PALLIATIVE CARE

The risk factors identified above imply that a significant proportion of people with SMI will require palliative care during their life time. Thirty five percent of GPs' and 55% of psychiatrists reported having patients attending their practice/clinic who in addition to their SMI had an identified palliative care need. In addition to GP's and psychiatrists, the palliative care needs of people with SMI were identified by a range of other health care professionals including oncologists, respiratory physicians, cardiologists and nurses. Once identified how palliative care was managed by both group of respondents generally involved some form of combined management approach sharing responsibility with other clinical specialists such as respiratory, oncology and cardiac specialists, involvement of the community palliative care team, referral to specialist palliative services, to hospice, acute hospital or nursing homes.

While referral to appropriate specialist and management of palliative care tended to be coordinated by either GP's or psychiatrists, this study identified serious shortcomings with regard to communication between all clinicians and services about patient's care. The majority of GPs (63.3%) reported rarely or never receiving communication from specialist palliative care services to advise them that their patient had attended their initial appointments and over 43% of GPs reported receiving no feedback at all on their patients from the palliative care services. A total of 22.5% of psychiatrists reported receiving communication from Specialist Palliative Care services to advise them that their patient had attended their initial appointment and received regular updating on the patients' condition. A total of 28.8% of psychiatrists reported rarely or never receiving feedback. While there is no doubt that mental illness acts as barrier to accessing and obtaining effective medical care, is associated with undue medical morbidity; particularly when diagnostic overshadowing results in the misattribution of physical symptoms (Lambert *et al.* 2003; Thornicroft, 2011).; however other barriers which impact on the effective management of health and illness including structural and systemic health disparities also impact on access to and utilisation of health care services.

One of the consequences of experiencing an enduring mental health difficulty is a reduction in the number of social arenas with which the person has contact. For a significant number of people, the only social arenas in which they engage are dominated by others in a similar situation and by health professionals (Eklund & Hansson, 2007). Building, extending and maintaining engagement with friends and social networks is dependent upon the ability to exploit available opportunities. The absence of intimate partnerships and living in restricted environments (such as hostels and supported accommodation) is likely to severely restrict opportunities to develop friendships and build social networks (Sheridan *et al.* 2015; Forrester-Jones *et al.* 2012). There is also evidence to suggest that relying exclusively on mental health service based initiatives may perpetuate difficulties with re-integration for individuals who are reliant solely upon mental health services, as they continue to remain apart from their community, and to feel lonely and isolated from society as a whole, (Catty *et al.*, 2001; Tedstone-Doherty, Moran, & Karatalova-O'Doherty, 2007). Thus the social exclusion experienced by people with SMI is a significant barrier to accessing and utilising health services and will ultimately impact on identification and meeting of palliative care needs

Poor communication between specialities, leading to fragmentation of health care services is a factor contributing heavily to poor outcomes for patients, as they may slip through the net of the healthcare system (Schmutte *et al.* 2009). For those who experience multiple co-morbidity specifically those with mental illness and palliative care needs, these challenges are particularly

significant. The continued organisational separation of mental and physical health care results in confusion as to which division of health services should take responsibility for managing patient's complex health needs and this point was particularly evident in the interviews with psychiatrists undertaken for this study.

Psychiatrists reported a number of difficulties in trying to gain access to physical health and palliative care services and these difficulties existed even where services were co-located. Significant difficulty in communication with and access to other physicians in acute care was identified as a particular difficulty. Some psychiatrists explained they often felt blocked by administrative staff, whom for whatever reason were either unwilling or unable to provide them with required information or direct access to a particular clinician. Furthermore, where multiple comorbidity existed, communication and access was made more complex by the need to communicate with numerous different departments and specialities involved in the care of an individual.

Finally, the absence of a unique patient identifier and an electronic patient record system to which all clinicians involved in the care of a patient have access further compounded communication difficulties relating to management and coordination of treatment and care.

6.5 Conclusion and Recommendations

What is evident from this study is that people with mental illness continue to be disadvantaged as they are less likely to raise concerns about their physical health needs, to have health needs identified, or to access or to be offered, health screening. Consequently, those with a serious mental illness have higher morbidity and mortality rates and live up to 25 years less than the general population. At this point the evidence is clear in that the vast majority of the gap in life expectancy for people with SMI is accounted for by physical illness (Mitchell et al. 2011; Wahlbeck et al. 2011; De Hert et al. 2011)

6.6 RECOMMENDATIONS

6.6.1 PROVISION OF OPPORTUNITIES

On the basis of the evidence presented in this report a number of recommendations are made which relate specifically to supporting patients with SMI and their carers, GP's and Psychiatrists to increase awareness of the health, economic and lifestyle factors contributing to increased morbidity and mortality. In particular increased awareness of the risk resulting from experiencing a SMI and of the pharmacological treatments currently available is required. Equally important however is recognition that addressing these modifiable risks requires interventions at policy, service planning and community levels to reduce the existing health disparities currently impacting the lives of people with SMI and their families. It is important to recognise that to make an impact change is required at the system level rather than focusing exclusively at the level of the individual, and consequently these recommendations are structured to reflect this.

To ensure people experiencing serious mental illness can embark on and sustain their health and wellness, policy, provision and service level interventions are required to provide opportunities for the individual and their families to develop and/or enhance competency to maintain health and wellness. Such opportunities to develop and exercise competency need to be promoted in the following ways:

- Recognition of the individual as an active agent in their own life, and consequent encouragement for individuals to set and pursue their own health and wellness goals
- Adoption of a capabilities approach, encompassing assistance to the individual to identify and build on their strengths and abilities, so as to promote personal agency in relation to health literacy and self management
- Given the difficult financial circumstances of many people with a long term mental health conditions, actions are required to recognise and address economic poverty and the pervading impact this has on health and wellness
- Strengthening relationships between existing community groups such as active retirement clubs, church and other faith groups, and social clubs, with local mental health services to develop socialisation and befriending initiatives to support development of social networks and reduce loneliness and isolation

These recommendations are also societal in that they address the increasing inclusion of people with a long term mental health difficulty into the mainstream of society, by enabling the individuals to develop social competence and interaction, enabled by the provision of supported opportunities and understanding. This requires cross-sectorial commitment and action, ranging from opportunities for local communities to include people with SMI through to changes in service-based support, and consideration of what is considered 'therapeutic'. Other recommendations require action more specifically by health services, as follows.

6.6.2. SERVICE AND PROFESSIONAL PRACTICE

Existing clinical and health service approaches to treatment and service delivery have traditionally focused the primarily role of the treating clinician and while changes are taking place, the complexity of the health system means the pace is exceedingly slow. Current evidence seeks to promote the inclusion and participation of the patient as a partner in their care, however, to a significant extent the health system continues to inculcate passivity and compliance with the wishes of services and or health professionals. The fostering of the attributes in people with SMI to participate as partners in their care is consistent with existing mental health policy both nationally and internationally and therefore recognition is required among all health professional and service based staff including policy makers, service planners and managers, that achieving a person focused service will require fundamental changes within existing structures and processes including:

- Recognition of the importance of the personal autonomy and agency of all patients and respecting their desire and preferences with regard to decisions about their treatment and care
- Training and development of all service staff to re-orient them to the attitudes and skills required for the promotion of inclusion, partnership in care and promotion and support of self management approaches

6.7: CONCLUSIONS

At the outset of this study, there was no empirical evidence originating from within the Irish context as to the need for palliative care services among those individuals who have a diagnosed pre-existing serious mental illness. This study set out to address this deficit, and while not achieving all of its original intentions; it has made a important contribution to identifying that a substantial need for palliative care does indeed exist among those with SMI.

The study also clearly established that the need for palliative care is being recognised and addressed by both general practitioners and psychiatrists. However, given the low response rates in this study, it is very likely that what we have identified represents the 'tip of the iceberg' as we have no way of knowing if the general practitioners and psychiatrists who did not participate in this study are in fact identifying similar or higher rates of palliative care need among their patients.

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