

Mental Health and Palliative Care

Literature Review

Mental Health Foundation

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1. Summary

This literature review was carried out to explore the extent and nature of palliative care for people with pre-existing mental health problems. The increased prevalence of terminal illness in those with mental health problems, and the growing number of people with mental health problems living in the community makes research into the palliative care needs of this population especially relevant.

This review initially examines literature on the increased incidence of, and the difficulties associated with treating, physical illness that may require palliative care among those with mental health problems. It then reviews the literature on palliative care for people with severe and enduring mental health problems (such as schizophrenia, bipolar disorder and severe clinical depression). Lastly, literature on anorexia nervosa and palliative care and end-of-life care for people with dementia was reviewed.

While the relationship between mental health problems and poor physical health is well documented and extensively researched there was found to be relatively little literature on the challenges associated with treating people with co-morbidity. There was also found to be an overwhelming lack of literature on the palliative care needs of those with existing mental health problems and very little literature on the appropriateness of palliative care for the treatment of anorexia nervosa. Although there was significantly more literature on the palliative care needs of those with dementia, it was felt a literature review dedicated solely to this group was needed before any definitive conclusions could be made. These gaps in the literature reveal a worrying lack in the provision of palliative care for those with existing mental health problems. The implications of this are discussed with reference to future research, practice and policy.

2. Scope of the Literature Review

2. 1. Introduction

The Mental Health Foundation is an independent UK charity that is working with Help the Hospices to find out more about the provision of palliative support for those with existing mental health problems. This initial scoping exercise includes a literature review and a survey of hospices. Both the survey and the literature review highlight current gaps in the provision of care and recommendations have been proposed to help address this. Due to the relatively few responses to the survey (12 hospices responded out of a total of 184) a separate analysis was not considered appropriate, and key findings will be given at the end of the review.

There are several reasons why it is particularly timely to consider work in this field. First, there have been significant demographic changes, such as an ageing population, which have meant people with severe and enduring mental health problems are living longer and growing older. Secondly, both the Department of Health End of Life Care Strategy and the National Dementia Strategy are to be published later in 2008. Thirdly, there is now full implementation of the Mental Capacity Act 2005, which covers end of life decision-making. Fourthly, public attention on end of life issues appears to be increasing with more media coverage given to standards of care in care homes, and the rights of care home residents. In addition, perhaps there has been a shift in public attitudes towards being more open to talking about dying, and greater demand by people to have more control over their end of life care. Finally, it will be the tenth anniversaries of the National Service Framework (NSF) for Mental

Health in 2009 and the NSF for Older People in 2011. The relationship between palliative care and mental health issues may feature more strongly should these NSFs be “refreshed” or renewed.

Throughout the literature review the term ‘mental health problems’ has been used to describe diagnosed mental health problems where the person has had contact with mental health services. This term does not include mental health problems that have not resulted in contact with mental health services.

2.2. General psychological distress and depression in palliative care

Initially, the purpose of this literature review was to explore the general mental health and psychological support for people receiving palliative care. The original brief included all types of illnesses (physical and mental); depression and psychological distress that arose as a result of a terminal diagnosis; pre-existing mental health problems; all locations of care, stages of illness, therapies and psychological interventions; assessment; models of practice; the different groups of people involved (for example carers, patients and professionals); and mental capacity issues. However, after a preliminary search, this broad scope was deemed inappropriate. Reasons for narrowing the search criteria have been detailed below.

While recognising the importance and range of mental health needs presented by carers the literature review was not intended to focus on this group. This is largely because an extensive literature currently exists for this population.

2.2.1 Depression and palliative care

While there appears to be consensus in the literature that depression resulting from a terminal diagnosis is difficult to assess, under recognised and undertreated (for example Irwin et al, 2008; Noorani et al, 2007; Robinson et al, 2005; Ly et al, 2002), there is a wealth of literature addressing this problem, that covers the effectiveness of different screening tools, therapies and strategies to improve the treatment of depression in palliative care. An initial literature search in this area yielded hundreds of articles concentrating on the prevalence, assessment, and treatment of depression in the terminally ill population. Thus, while there is always a need for further investigation into ways to improve the treatment of depression, an extensive literature review on depression and palliative care was not thought useful.

2.2.2 General mental health and psychological support in palliative care

There is no doubt that there are current gaps in the psychological support for people receiving palliative care, and literature concentrating solely on the provision of mental health support in hospices is somewhat scarce (see section 4). However, literature on mental health and psychological issues in end-of-life care is extensive and covers a plethora of illnesses, therapies, assessment tools, locations of care, and communication issues. Once again, an initial search yielded hundreds of articles on psychological support and mental health issues at the end of life. Due to the wealth and breadth of literature covering these topics a comprehensive review of general psychological support was deemed unnecessary. Moreover, the ongoing interest and research into psychological support for those with terminal illness suggests that this area is currently well covered, and whilst there will always be room for improvement and a need for future research (to identify possible gaps in the provision of care), this is a well documented field.

In conclusion, this review will not be concentrating on depression that has arisen primarily as a result of a terminal diagnosis or general mental health problems associated with end-of-life care.

3. Palliative Care For People With Existing Mental Health Problems

3.1. Introduction

People with pre-existing mental health problems who develop a terminal illness and require end-of-life care are possibly among the most underrepresented and deprived populations in our society (Davie, 2006). Research in this area is scarce, highlighting a distinct lack of knowledge and provision of care for this population. Further, the few studies that do directly address this problem stress the need for further investigation (for example, McCasland, 2007; Kelley & Shanley, 2000; Davie, 2006; Henderson, 2004; Addington-Hall, 2000).

Before an examination of the literature that directly addresses the intersection between chronic mental ill health and palliative care, it is important to consider trends, biases and events that took place prior to a terminal diagnosis that may influence treatment and attitudes at the palliative care stage (Henderson, 2004). Thus, this review will begin by looking at the literature on increased vulnerability to physical illness among those with a psychiatric diagnosis and then go on to look at difficulties around treating physical illness in this population.

Anorexia nervosa and dementia have been considered separately from other mental health problems as they pose some significantly different problems for the treatment of terminal illness. While palliative care for adults with learning disabilities is recognised as an important topic in its own right, literature in this area is not examined in this review.

3.2 Increased vulnerability to physical illness

Literature highlighting the increased incidence of physical health problems in those with mental health problems is extensive. There is good evidence to suggest that the morbidity rate in the psychiatric population far surpasses the expected rate found in the general population with studies finding incidence as high as 88% of chronically mentally ill outpatients having a significant medical illness (Maricle et al, 1987). In addition, there is evidence that people with schizophrenia are twice as likely to have a diagnosis of cardio-vascular disease (CVD) than the general adult population (for example Casey, 2005). Preliminary calculations suggest this could amount to as many as 10,000 people in the UK having both schizophrenia and CVD.

Key reasons for this trend, as outlined by a review of the current literature, are:

- Those with severe mental health problems are less likely to attend screening for cancer or routine check ups for physical symptoms (DRC, 2006)
- Physical complaints in patients with known psychiatric disorder can be ascribed to their underlying mental illness and not given sufficient attention (Henderson, 2004).
- There is evidence that psychiatrists are reluctant to physically examine their patients in situations where the person has a physical complaint or appears physically unwell (McIntyre et al, 1977).
- Those with severe and enduring mental health problems typically lead less healthy lifestyles, take less exercise and participate in more activities damaging to their physical health such as smoking, drinking and poor diets (Koranyi et al, 1979)
- There is a high rate of substance misuse in this population. One explanation for this is that people with mental health problems attempt to self-medicate symptoms of illness and uncomfortable adverse side effects of psychiatric medications (Kasten, 1999).

In summary, it seems that the division between physical and psychiatric medicine has meant that those with both physical and psychiatric pathologies are poorly served. This has not only led to an increased incidence of physical illness but the delay in its diagnosis and treatment has meant that the

likelihood of a terminal diagnosis is potentially increased, making palliative care the first line of treatment for these individuals (Talbot & Linn, 1978).

The breadth of literature in this area has meant that only a small proportion of it has been reviewed. An initial search yielded 29 articles directly relevant, of these there were 10 specifically concentrating on people with a diagnosis of schizophrenia, 5 focusing on excess mortality in this population, and 1 literature review carried out in 1996 (Felker et al) which looked at over 60 papers on medical co-morbidity in the psychiatric population.

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| Adler & Griffith (1991) Concurrent medical illness in the schizophrenic patient. Epidemiology, diagnosis, and management. |
| Bass et al (2002) Referrals to a liaison psychiatry out-patient clinic in a UK general hospital: A report on 900 cases. |
| Brown, S. (1997) Excess mortality of schizophrenia. A meta-analysis. |
| Brown & Birtwhistle(1996) Excess mortality of mental illness. |
| Brown et al. (1999) The unhealthy lifestyle of people with schizophrenia. |
| Brown et al (2000) Causes of the excess mortality of schizophrenia. |
| Casey (2005). Metabolic issues and cardiovascular disease in patients with psychiatric disorders. |
| DRC (2006) Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems |
| Felker et al (1996). Mortality and medical co-morbidity among psychiatric patients: A review. |
| Goldman (1999) Medical illness in patients with schizophrenia. |
| Hahm & Segal (2005) Failure to Seek Health Care Among the Mentally Ill. |
| Harris & Barraclough (1998) Excess mortality of mental disorder. |
| Honig et al (1992) Physical illness in chronic psychiatric patients from a community psychiatric unit revisited. A three-year follow-up study. |
| Jeste et al (1996) Medical co-morbidity in schizophrenia. |
| Kamara et al (1998) Prevalence of physical illness among psychiatric inpatients who die of natural causes. |
| Kasten, B. (1999) Self-Medication with Alcohol and Drugs by Persons with Severe Mental Illness. |
| Koranyi (1979) Morbidity and rate of undiagnosed physical illnesses in a psychiatric clinic population. |
| Kreyenbuhl et al (2006) Extent and management of cardiovascular risk factors in patients with type 2 diabetes and serious mental illness. |
| Madsen et al (1997). Physical health in mentally ill patients |
| Maricle et al (1987) The prevalence and significance of medical illness among chronically mentally ill outpatients. |
| Maricle et al (1989) The coexistence of physical and mental illness among two samples of Oregon's chronically mentally ill. |
| McIntyre & Romano (1977) Is there a stethoscope in the house (and is it used)? |
| Mortensen (1994) The occurrence of cancer in first admitted schizophrenic patients. |
| Mortensen (1989). The incidence of cancer in schizophrenic patients. |
| Munk-Jorgensen et al (2000) The schizophrenic patient in the somatic hospital. |
| Schwartz et al (1998) The medical psychiatrist as physician for the chronically mentally ill. |
| Sheline (1990) High prevalence of physical illness in a geriatric psychiatric inpatient population. |
| Solstad et al (1989) Somatic illness in patients in an acute psychiatric department. |
| Talbot & Linn (1978) Reactions of schizophrenics to life-threatening disease. |

3.3. Treating the physical illnesses of people with mental health problems

Treating physical illness in people with mental health problems can be problematic because people experiencing mental distress may not understand the diagnosis (often because it is not properly explained to them) nor engage with medical practitioners (Inagaki et al, 2006) and the person's existing psychiatric symptoms can be made worse by their physical illness (Kelly & Shanley, 2000). Research into managing and treating this population is scarce, and there are few guidelines for the treatment of physical illness in this group. The lack of knowledge in this area has surely exacerbated the problems met by palliative care practitioners when faced with the same situation. Below are 7 articles that outline the problems associated with treating this population.

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| Hansen et al. (2001) Mental disorders in medical inpatients and the association to severity of illness, self-rated physical disability, and health perception. |
| Inagaki et al. (2006) Factors Disturbing Treatment for Cancer in Patients with Schizophrenia. |
| Kelley & Shanley (2000) Terminal Illness and Schizophrenia. |
| Kemppainen et al. (2004) Antiretroviral Adherence in Persons with HIV/AIDS and Severe Mental Illness. |
| Kunkel et al. (1997) Consultations formaladaptive denial of illness in patients with cancer: psychiatric disorders that result in noncompliance. |
| Talbott & Linn (1978) Reactions of schizophrenics to life-threatening disease. |
| Wagner et al. (2003) Adherence to HIV antiretrovirals among persons with serious mental illness. |

3.4. Types of mental health problems

- **Severe and enduring mental health problems including schizophrenia, bipolar disorder, recurrent depressive disorder, and severe anxiety disorders.**

19 papers were found which covered, in some form, the interface between pre-existing mental health problems and palliative care. Of these only 11 solely concentrated on this issue. There were 4 papers found looking at case studies of people with mental health problems and terminal illnesses: Goldenberg et al (2000) detailed 2 cases, one on end-of-life care for a patient with schizophrenia and the other bipolar disorder. Kelly & Shanley (2000) produced a single case-report of the hospice care delivered to a patient with a diagnosis of schizophrenia. Levin & Feldman (1983) examined the ethical issues of treating a woman with paranoid psychoses and terminal breast cancer and Boyd (1997) presented a case study of the process of care for a hospice patient with a pre-existing condition. Although the prevalence of palliative care patients with severe and enduring mental health problems has not been studied, the literature suggests that terminal illness among the psychiatric population is high thus magnifying concern that there are only 4 case reports in this area.

Of the reviewed literature there is only one paper (McCasland, 2007) that details exactly how this population should be cared for and provides practical guidelines as to how to treat a variety of psychiatric illnesses. Although the National Council for Palliative Care (NCPC) has produced an 'Occasional Paper' that addresses the needs of this population and outlines future directions in this area (Addington-Hall, 2000), these guidelines were published 8 years ago and the NCPC have not addressed the issue since. This leaves us with no indication of current practice or even if these guidelines and recommendations are adhered to in any practical way.

A recent paper, Promoting Excellence in End-of-Life Care (Byock, 2006), aimed at addressing documented deficiencies in the care of patients, did mention those with pre-existing mental health problems as a population that they served. This gives some indication that care for this population might be starting to get the attention it so desperately needs. However, guidelines and initiatives embedded within a framework of general models for palliative care, as this is, are arguably not

sufficient to address the unique palliative needs of persons with severe and enduring mental health problems.

The overall consensus in this literature is that this group of people are not receiving the care they need with the majority of research explicitly stating that there is an urgent need for future research and clearer guidelines. Even in a book that solely concentrates on psychiatry in palliative medicine (Chochinov & Breitbart, 2000) there is only one short chapter on the palliative care needs of those with mental illness. Further, a significant number of the main palliative care journals do not contain a single article on patients with pre-existing mental health problems.

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| Addington-Hall (2000) Positive Partnerships - Palliative Care for Adults with Severe Mental Health Problems |
| Baker (2005) Palliative and End-of-Life Care in the Serious and Persistently Mentally Ill Population. |
| Boyd (1997) When the hospice patient is manipulative. |
| Byock (2006) Promoting excellence in end-of-life care: a report on innovative models of palliative care. Promoting Excellence in End of Life Care. |
| Chochinov & Breitbart (Ed) (2000) <i>Handbook of psychiatry in palliative medicine</i> . |
| Craun (1997) Hospice care of the psychotic patient. |
| Davie (2006) 'A social work perspective on palliative care for people with mental health problems' |
| Durkin et al. (2003) Psychiatric disorder in a palliative care unit. |
| Goldenberg et al. (2000) Palliative care in the chronically mentally ill. |
| Henderson (2004) Mental Health Needs |
| Kelley & Shanley (2000) Terminal Illness and Schizophrenia. |
| Levin & Feldman (1983) Terminal illness in a psychiatric patient--issues and ethics. |
| McCasland (2007) Providing Hospice and Palliative Care to the Seriously and Persistently Mentally Ill. |
| McGrath & Forrester (2006) Ethico-legal issues in relation to end-of-life care and institutional mental health. |
| McGrath & Jarrett (2007). The Problem of Stigma during End-of-life Care at a Psychiatric Institution. |
| Parkes (2000) Hospice: A Psychiatric Perspective |
| Spieß et al. (2002) Palliative care: Something else we can do for our patients. |
| Talbott & Linn (1978) Reactions of schizophrenics to life-threatening disease. |
| Tate (2005) Death and dying: implications for inpatient, psychiatric care. |

Decision-making

Research into end-of-life decision-making in those with severe mental health problems is scant and has been dominated by the work of Foti (2003, 2004, 2005). Only 3 articles were found which specifically researched the problems associated with the ability of those with mental health problems to make end-of-life decisions. While one paper (Foti et al, 2004) does propose a model that will help with decisions at the end of life for a psychiatric population, it was concluded that future research is needed to test advance care planning methods, assess stability of choices over time, and ascertain whether the scenario-based preferences given in a research situation would be representative of real life decisions in this population.

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| Foti (2003) Do it your way: A demonstration on End-of-Life Care for Persons with Serious Mental Illness. |
| Foti et al. (2004) End-of-Life Care and Mental Illness: A Model for Community Psychiatry and Beyond. |
| Foti et al. (2005) End-of-Life Treatment Preferences of Persons with Serious Mental Illness. |

- **Anorexia Nervosa**

Anorexia nervosa is another condition that lies between psychiatry and physical medicine. This is a slightly separate debate from other mental health problems however, as we are not asking ‘Are the palliative care needs of this population met?’ but rather ‘Should they be treated as palliative care patients in the first place?’. Literature on the treatment of anorexia by a palliative care team is scarce and this debate continues to be highly controversial. Nonetheless, there has been media interest in this area indicated by a recent debate on the subject hosted by Radio 4 (Sept 2007).

5 papers were found that addressed this issue, 1 of which was a case study (O’Neill, 1994) and 2 of which only briefly mention palliative care as an option for treatment. In a review of the published books on the treatment of anorexia only 3 were found which mentioned this debate, with the majority detailing the case study reported by O’Neill (1994) highlighting just how little published literature there is to draw on in this field.

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| Giordano (2007) <i>Eating Disorders: Conceptual and Ethical Issues in the Treatment of Anorexia and Bulimia Nervosa</i> |
| Hendrick (2000) <i>Law and ethics in nursing and health care.</i> |
| Manley & Leichner (1998) <i>Treating Eating Disorders: Ethical, Legal and Personal Issues.</i> |
| O’Neill et al (1994) A case study: anorexia nervosa. Palliative care of terminal psychiatric disease. |
| RADIO 4 Programme 2 – Can a patient with Anorexia Nervosa be offered palliative care? |
| Russell (1995) Treating anorexia nervosa |
| Russon & Alison (1998) Does palliative care have a role in treatment of anorexia nervosa? Palliative care does not mean giving up. |
| Treasure & Ramsey (1998) <i>Hard to Swallow: Compulsory treatment in eating disorders</i> |
| Williams et al. (1998) Does palliative care have a role in treatment of anorexia nervosa? We should strive to keep patients alive. |

Decision-making

The mental capacity of people with anorexia to refuse treatment and make decisions about their care is central to the debate about whether anorexia should be considered a terminal psychiatric illness and treated in a palliative care setting.

There is a wealth of literature in this area with a number of books dedicated solely to this discussion, making it interesting that the association between anorexia and palliative care is just becoming a topic of debate and growing concern.

Although literature on anorexia and decision-making is closely linked with the debate around anorexia and palliative care, a more thorough analysis of it was not carried out, as it is not the main focus of the review.

Books

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| Cutter & Shelp (1991) <i>Competency: A Study of Informal Competency Determinations in Primary Care</i> |
| Bruch (1997) <i>The Golden Cage: The Enigma of Anorexia Nervosa.</i> |
| Peveler et al. (2000) <i>Liaison Psychiatry: Planning Services for Specialist Settings.</i> |
| Vandereycken Beumont (1998) <i>Treating Eating Disorders</i> |

Journal Articles

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| Carney et al. (2007) Coercion is coercion? Reflections on trends in the use of compulsion in treating anorexia nervosa. |
| Cavedini et al. (2004) Neuropsychological investigation of decision-making in anorexia nervosa. |
| Cockell et al. (2003) Decisional balance in anorexia nervosa: Capitalizing on ambivalence |
| Cockell et al. (2002) Development of a decisional balance scale for anorexia nervosa. |
| Draper (2000) Anorexia nervosa and respecting a refusal of life-prolonging therapy: a limited justification. |
| Draper (2003) Anorexia nervosa and refusal of naso-gastric treatment: A reply to Simona Giordano. |
| Dresser & Boisubin (1986) Psychiatric patients who refuse nourishment. |
| Gans & Gunn (2003) End stage anorexia: criteria for competence to refuse treatment. |
| Grisso & Appelbaum (2006) Appreciating anorexia: Decisional capacity and the role of values. |
| Kondo et al. (2004) Law Relating to Compulsory Treatment of Patients with Anorexia Nervosa. |
| Laird (2003) Clinical decision analysis and anorexia nervosa. |
| MacDonald. (2002) Treatment Resistance in Anorexia Nervosa and the Pervasiveness of Ethics in Clinical Decision making. |
| Manley et al (2001) Addressing complex ethical issues in the treatment of children and adolescents with eating disorders: application of a framework for ethical decision-making. |
| Richmond (2001) Anorexia and involuntary commitment: A necessary approach? |
| Tan et al. (2003) Competence to refuse treatment in anorexia nervosa. |
| Tan et al. (2006) Competence to make treatment decisions in anorexia nervosa: Thinking and processes and values. |
| Tan et al. (2003) Control and compulsory treatment in anorexia nervosa: the views of patients and parents. |
| Tchanturia et al (2007) An investigation of decision making in anorexia nervosa using the Iowa Gambling Task and skin conductance measurements. |
| Turrell (2005) Capacity to consent to treatment in adolescents with anorexia nervosa. |

▪ Dementia

Although guidelines exist to determine hospice eligibility and palliative care needs for people with dementia, only a small percentage of terminally ill patients with this condition receive hospice care (Mitchell, 2007) and this group is largely excluded from palliative support as a whole (Henderson, 2004). An initial review of the literature revealed that in many respects recipients of care with dementia remain poorly understood and little is known about the standard of their end-of-life care. However, compared to those with other types of mental health problems, there is considerably more research on this group and initiatives are being taken to improve care for this population. For example, The National Council for Palliative Care announced in 2008 that it is committed to improving end of life care for people with dementia and have produced papers detailing how it intends to do this (Creative Partnerships, 2008). There is also evidence of increasing good practice in care for those with dementia. For example, a hospice in Scotland has worked closely with the national dementia research centre to improve palliative care for people with dementia. It has developed joint educational material for mental health and specialist palliative care professionals, and has held joint study days and run short courses on the palliative care approach for mental health workers (Addington-Hall, 2000)

A preliminary search yielded 30 references in palliative care for those with dementia, a few of which were dedicated just to hospice care for this population.

Due to the extensive literature and debate around end-of-life care for patients with dementia, it was felt that an entire literature review dedicated solely to this topic would be needed for this area to be covered sufficiently.

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| Addington-Hall (2000) Positive Partnerships - Palliative Care for Adults with Severe Mental Health Problems . |
| Abbey et al (2006) Palliative care in long-term care: A system in change. |
| Albinsson & Strang (2003) Differences in supporting families of dementia patients and cancer patients: a palliative perspective. |
| Albinsson & Strang (2007) A palliative approach to existential issues and death in end-stage dementia care. |
| Aminoff (2007) The new Israeli Law 'The Dying Patient' and Relief of Suffering Units |
| Aminoff & Adunsky (2005) Dying dementia patients: Too much suffering, too little palliation. American |
| Arie (2006) Review of Ethical Foundations of Palliative Care for Alzheimer Patients. |
| Briggs et al. (2004) Providing Appropriate Care in Advanced Dementia. |
| de Vries (2003) Variant Creutzfeldt-Jakob disease: need for mental health and palliative care team collaboration. |
| Diwan et al. (2004) Strain Experienced by Caregivers of Dementia Patients Receiving Palliative Care: Findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program. |
| Creative Partnerships: Improving Quality of Life at the End of Life for People with Dementia |
| Engel et al. (2006) Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. |
| François et al. (2007) Symptom relief in the last week of life: Is dementia always a limiting factor? |
| Gaugler et al. (2004) The emotional ramifications of unmet need in dementia caregiving. |
| Hanrahan & Luchins (1995) Feasible criteria for enrolling end-stage dementia patients in home hospice care. |
| Henderson (2004) Mental Health Needs |
| Kapo et al (2007) Palliative care for the older adult. |
| Kiely et al (2006) The Validity and Reliability of Scales for the Evaluation of End-of-Life Care in Advanced Dementia. |
| Koopmans et al. (2006) Palliative Care in Patients with Severe Dementia. |
| Kunz & Zeitschrift (2003) Palliative care for patients with advanced dementia: Evidence-based practice replaced by values-based practice. |
| Mitchell et al. (2007) Hospice care for patients with dementia. |
| McCarron & McCallion (2007) End-of-life care challenges for the persons with intellectual disability and dementia: Making decisions about tube feeding. |
| Robinson et al. (2005) End-of-life care and dementia. |
| Sachs et al. (2004) Barriers to Excellent End-of-life Care for Patients with Dementia. |
| Sampson et al. (2005) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. |
| Shega et al (2003) Palliative Excellence in Alzheimer Care Efforts (PEACE): A Program Description. |
| Simard & Baltimore (2007) The End-of-Life Namaste Care Program for people with dementia. |
| Volicer et al. (2001) Scales for evaluation of end-of-life care in dementia. |
| Wilson (1997) Palliative care for late-stage dementia. |

3.5. Multidisciplinary teams and the relationship between mental health experts and palliative care experts

There is an overwhelming consensus in the literature that the development of multidisciplinary teams, good communication and effective partnerships between health care professionals is paramount if palliative care for those with severe mental illness is to be improved. Of the 7 articles found that directly addressed the issue of multidisciplinary teams in palliative care, only 2 were specifically concerned with how to improve palliative care for those with existing mental health problems (Davie, 2006; Baker, 2005).

The majority of this research suggests ways to improve multidisciplinary care and presents evidence for the most appropriate health or social care professional to act as a link person and help bridge the gap between mental health and palliative care services. For example, Baker (2005) argues that mental health nurses are in an ideal position to act in this generic role and have the foundation to become experts in palliative care. Similarly, Davie (2006) suggests that social workers can play an important and central role in bridging the gap between services. This indicates that a successful partnership between disciplines is not yet commonplace, there are at present no dedicated professionals trained to provide care for this population and we urgently need action to incorporate these recommendations into policy and practice.

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| Baker (2005) Palliative and End-of-Life Care in the Serious and Persistently Mentally Ill Population. |
| Black (2001) Palliative care nurses and mental health nurses: sharing common ground? |
| Chochinov (2004) Palliative Care: An Opportunity for Mental Health Professionals |
| Davie (2006) A social work perspective on palliative care for people with mental health problems. |
| de Vries (2003) Variant Creutzfeldt-Jakob disease: need for mental health and palliative care team collaboration. |
| O'Connor (2006) Interdisciplinary teams in palliative care: a critical reflection. |
| Payne (2002) The contribution of psychologists to specialist palliative care. |

3.6. Guidelines

The lack of adequate care for this population is underpinned by an absence of published guidelines in this area. The majority of documentation in palliative care focuses on the physical aspects, and those that do cover the broader spectrum mostly exclude recommendations on people with existing mental health problems. For example, the WHO Interim Guidelines (2003), Advance Care Planning (2007) and the Introductory Guide to End of Life Care (2006) do not make a single reference to care for those with existing mental health problems. The only two documents that acknowledge this group are the current NICE guidelines on improving supportive and palliative care for patients with cancer (2004) and the Addington-Hall (2000) paper on Positive Partnerships published by the National Council for Palliative Care. Further, the section in the NICE guidelines on psychological support concentrates largely on post-diagnosis mental health and although there are recommendations for those with pre-existing mental health problems they are set in a framework of general psychological provision. More alarming still is that a recent survey by Price et al. (2006) found that access to health care professionals is too limited to fulfil the current NICE guidelines. This finding was mirrored in an earlier study by Lloyd-Williams et al. (1999), who concluded that access to psychiatry and psychology is variable and problematic (see section 4 for these last two references).

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| Addington-Hall (2000) Positive Partnerships - Palliative Care for Adults with Severe Mental Health Problems. |
| Advance care planning: A guide for health & social care staff NHS End of Life Care Programme (2007) |

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| Introductory guide to end of life care in care home NHS End of Life Care Programme (2006) |
| Supportive and palliative care. Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual NICE (2004). |
| WHO Interim guidelines for first level facility health workers. Integrated management of adolescent and adult illness. Palliative care: symptom management and end of life care. (December 2003) |

4. Mental Health Provision in a Hospice

Literature directly addressing the provision of general psychological support in a hospice is also scarce. Of the 3 papers found in this area, 2 reported on surveys and one on interviews carried out with doctors and nurses in two hospices. While this literature is too limited to draw any definitive conclusions the general findings were that access to mental health professionals in hospices is too limited to provide adequate psychological care (Price et al. 2006; Lloyd-Williams et al. 1999) and that the majority of staff have very limited experience or training in the field of mental health (Hackett et al. 2007).

There is little doubt that poor care for patients with pre-existing mental health problems is made worse by a general lack of training and professionals with mental health expertise in the palliative care team.

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| Hackett (2007) A qualitative study assessing mental health issues in two hospices in the UK. |
| Lloyd-Williams et al. (1999) A survey of psychological service provision within hospices. |
| Price et al (2006) Psychological services in hospices in the UK and Republic of Ireland. |

5. Conclusions and Future Directions

5.1. Future directions for research, policy and service improvement

The Mental Health Foundation has made a provisional agreement to contribute to a policy briefing with the NCPC to identify key issues in mental health across all palliative care settings and services. The Foundation has suggested to the NCPC that Help the Hospices should be invited to contribute to this briefing.

What needs to be achieved and priorities for future research

- Research is needed to determine exactly how many service users with severe mental health problems require palliative care. There is no data on this or the number of palliative care patients with major mental illness. This will help determine exactly how many service users may have been lost between services, and are not receiving sufficient or appropriate care.
- Exploring the views of service users and working with them to construct appropriate services will assist the development of innovative solutions to this problem and help determine the reasons why and how our health care system fails to provide adequate care for this group.
- If care for this group is to improve, negative attitudes and stigma towards people with mental health problems needs to be overcome (McGrath & Jarret, 2007). This could be done through joint education initiatives between palliative care and mental health professionals. Such initiatives should include experiential training schemes. Research is needed to develop and test the effectiveness of such schemes.

- While the development of such programmes is important, the number of people with severe mental health problems that have a terminal illness will be relatively small and it is therefore unrealistic to expect all palliative care and hospice services to be fully conversant in the management of adults with severe mental health problems (Addington-Hall, 2000). As a result, the development of good partnerships, liaison services and effective multidisciplinary teams is key. Further, there is a need to clarify roles between disciplines so that these individuals do not fall through the gap between care services. Similarly, the appointment of a designated link person to act as a bridge between mental health and palliative care services would greatly enhance the sharing of information and expertise thus facilitating effective communication (Davis, 2006; Baker, 2005). Research is needed to determine who would be best to fill this role and the precise duties that would need to be undertaken.
- Addington-Hall (2000) argued that while palliative care is aware of mental health professionals, mental health specialists are less informed about hospices and specialist palliative care services. Thus, research is needed to determine the pattern of referrals to specialist palliative care teams by the mental health team that the service user is in contact with.
- Wider research is needed with palliative care services in general which would be along the lines of expanding the survey done with hospices. This may be an area of work that the NCPC might be interested in being involved with and might also include an expert advisory group and some focus groups with practitioners to find practical solutions to the challenges identified.
- In addition to the above, which will also improve care for dementia patients, research is needed to determine exactly how many people with dementia are being cared for in a hospice, how the barriers to providing hospice care for people with dementia can be overcome, and the effectiveness of joint training schemes between services currently providing care for dementia patients and palliative care specialists.

Service Improvement & Workforce Development

- Developing training packages for palliative care and/or mental health services
- Evaluating innovative service models (e.g. liaison/link working)

Policy

- Following a meeting with the NCPC a provisional agreement was made to produce a joint policy briefing that identifies the key issues regarding mental health aspects across all palliative care settings and services. The Foundation has suggested to the NCPC that Help the Hospices should be invited to contribute to this briefing.

5.2. Conclusions

Most of the literature to date has primarily concentrated on anxiety and depression that have arisen as a result of a terminal diagnosis, with little attention paid to those with a pre-existing mental illness. The lack of literature in this area reveals a significant unmet need. It is surprising that a population with such a high incidence of physical illness and terminal diagnoses has been almost entirely overlooked in regards to their end-of-life care. As hospice and palliative care becomes increasingly mainstream within the health care system, there is an urgent need for a greater understanding of the specialist palliative care needs of those with mental health problems (Henderson, 2004).

People with severe and enduring mental health problems who require palliative care should have access to the same quality of treatment as the rest of the population. Action needs to be taken to ensure that the appropriate services, training and expertise are available for this goal to be achieved.

6. Survey

Of the 12 respondents to the survey 5 hospices said they had patients with pre-existing severe mental health problems. Incidence was difficult to determine as it was unclear whether hospices understood the definition of severe mental health problems, and it likely that some figures included mental health problems that had developed following a terminal diagnosis. Diagnoses mentioned in the survey were schizophrenia (all hospices said they had patients with schizophrenia), bipolar disorder (1 hospice said they had patients with bipolar) clinical depression, anxiety, OCD, and substance abuse.

In addition, of the 12 respondents 5 hospices had patients with dementia. Prevalence ranged from as low as 0.01% to as high as 50%. With the number of dementia patients reaching as high as 50% it is essential that research is carried out to determine the quality of care they are receiving and ways it can be improved. Further, with such variability in the number of dementia patients receiving hospice care there is an urgent need to determine hospice eligibility for patients with dementia.

Interestingly, the obstacles outlined by hospice staff in the survey mirrored those problems identified in the literature. A primary concern was the lack of effective partnerships between disciplines; with hospices saying that they had difficulty accessing services, there was no joint working and no clear pathway of responsibility. The lack of available resources was also outlined as a concern, with key problems being long waiting lists, and the limited time and availability of psychiatrists and mental health services. The final issue uncovered by the survey was the lack of training. One hospice highlighted that groups of professionals who are excellent at managing, for instance, patients with dementia, may not be so good at pain control. Training issues also involved a lack of resources to fund appropriately trained staff. This emphasises the need for more group training schemes and initiatives and an urgent need for more funding in this area.

In addition, when hospices were asked if they had restrictions to providing mental health support, the principle concern was caring for those with pre-existing mental health problems. For example, one hospice stated that they would not provide support for patients with complex psychiatric needs or a primary diagnosis of mental illness. Similarly, a second hospice said that if close psychiatric monitoring and support was required, it might be deemed more appropriate for the patient to be cared for by mental health services. Overall, it seems that some hospices feel they do not have the necessary skills, experience or access to appropriate services to care for those with pre-existing mental health problems.

When asked about plans for developing mental health support in the future, 6 hospices gave positive responses. These included plans to expand counselling services, to carry out studies on the effectiveness of psychological therapies, to liaise more closely with dementia services, and to look into training and updates for current clinical staff.

The recent National Audit Office survey included a question on general psychological support and assessment. Promisingly, of the 39 respondents only 3 hospices said that psychological assessment was not a formal part of their assessment for patients facing the end of life. In line with Price et al (2006), it appears that although the majority of hospices appear to be providing psychological support, a large proportion of them have insufficient access to qualified professionals to provide the higher levels of support outlined by the current NICE guidelines (See section 4). The main problems identified were lack of available financial resources and long waiting lists when accessing outside counselling and psychological services. Nonetheless, this survey did reveal examples of good practice with a certain number of hospices providing excellent psychological support. However, since this was only a single open-ended question it is impossible to draw any firm conclusions, and a more detailed analysis is required to assess the current provision adequately.

7. References

- Abbey, J., Froggatt, K. & Parker, D. (2006) Palliative care in long-term care: A system in change. *International Journal of Older People Nursing*, 1(1), 56-63
- Addington-Hall, J. (2000) Positive Partnerships - Palliative Care for Adults with Severe Mental Health Problems. The National Council for Palliative Care
- Adler, L. & Griffith, J. (1991) Concurrent medical illness in the schizophrenic patient. Epidemiology, diagnosis, and management. *Schizophrenia. Res*, 91-107
- Advance care planning: A guide for health & social care staff NHS End of Life Care Programme (2007)
(Available from: <http://www.endoflifecareforadults.nhs.uk/eolc/acp.htm>)
- Albinsson L. & Strang, P. (2003) Differences in supporting families of dementia patients and cancer patients: a palliative perspective. *Palliative Medicine*, 17 (4), 359-67
- Albinsson, L. & Strang, P. (2007) A palliative approach to existential issues and death in end-stage dementia care. *Journal of Palliative Care*, 18(3), 168-174
- Aminoff, B. (2007) The new Israeli Law 'The Dying Patient' and Relief of Suffering Units, *American Journal of Hospice & Palliative Medicine*, 24(1), 54-58
- Aminoff, B. & Adunsky, A. (2005) Dying dementia patients: Too much suffering, too little palliation. *American Journal of Hospice & Palliative Medicine*, 22(5), 344-348
- Arie, T. (2006) Review of Ethical Foundations of Palliative Care for Alzheimer Patients. *International Journal of Geriatric Psychiatry*, 21(8), 802
- Baker, A. (2005) Palliative and End-of-Life Care in the Serious and Persistently Mentally Ill Population *Journal of the American Psychiatric Nurses Association*, 11(5), 298-303
- Bass, C., Bolton, J., Wilkinson, P. (2002) Referrals to a liaison psychiatry out-patient clinic in a UK general hospital: A report on 900 cases. *Acta Psychiatrica Scandinavica*, 105(2), 117-125
- Black, C. (2001) Palliative care nurses and mental health nurses: sharing common ground? *Int Journal of Palliative Care*, 7(1), 17
- Boyd, C. (1997) When the hospice patient is manipulative. *The Hospice Journal*, 12 (1), 1-16
- Briggs, H., Rzepnicki, T. & Chicago, I. (2004) Providing Appropriate Care in Advanced Dementia. In Hanrahan, P., Luchins, D. & Murphy, K. (2004) *Using evidence in social work practice: Behavioural perspectives*: US: Lyceum Books: 190-209
- Brown, S. (1997) Excess mortality of schizophrenia. A meta-analysis. *British Journal of Psychiatry*, 171, 502-508
- Brown, S. & Birtwhistle, J. (1996) Excess mortality of mental illness. *British Journal of Psychiatry*, 169(3), 383-384
- Brown, S., Birtwhistle, J. & Roe, L. (1999) The unhealthy lifestyle of people with schizophrenia. *Psychological Medicine*, 29(3), 697-701

- Brown, S., Inskip, H. & Barraclough, B. (2000) Causes of the excess mortality of schizophrenia. *British Journal of Psychiatry*, 177, 212-217
- Bruch, H. (1997) *The Golden Cage: The Enigma of Anorexia Nervosa*. USA: Vintage Books, p104
- Byock, I., Twohig, J., Merriman M. & Collins K. (2006) Promoting excellence in end-of-life care: a report on innovative models of palliative care. Promoting Excellence in End of Life Care. *Palliative Medicine*, 9(1), 137-51
- Casey, D. (2005) Metabolic issues and cardiovascular disease in patients with psychiatric disorders . *American Journal of Medicine Supplement*, 118, 15 – 22
- Carney, T., Tait, D. & Touyz, S. (2007) Coercion is coercion? Reflections on trends in the use of compulsion in treating anorexia nervosa. *Australasian Psychiatry*, 15(5), 390-395
- Cavedini, P., Bassi, T., Ubbiali, A., Casolari, A., Giordani, S., Zorzi, C. & Bellodi, L. (2004) Neuropsychological investigation of decision-making in anorexia nervosa. *Psychiatry Research*, 127(3), 259-266
- Chochinov, H. (2004) Palliative Care: An Opportunity for Mental Health Professionals *Canadian Journal of Psychiatry*, 49(6), 347-349
- Chochinov, H. & Breitbart, W (Ed) (2000) *Handbook of psychiatry in palliative medicine*. New York, US: Oxford University Press
- Cockell, S., Geller, J. & Linden, W. (2003) Decisional balance in anorexia nervosa: Capitalizing on ambivalence. *European Eating Disorders Review*, 11(2), 75-89
- Cockell, S., Geller, J. & Linden, W. (2002) Development of a decisional balance scale for anorexia nervosa. *European Eating Disorders Review*, 10(5), 359-375
- Craun, M. (1997) Hospice care of the psychotic patient. *The American Journal Of Hospice & Palliative Care*, 14 (4), 205-8
- Creative Partnerships: Improving Quality of Life at the End of Life for People with Dementia - A Compendium. January 2008
- Cutter, M. & Shelp, E. (1991) *Competency: A Study of Informal Competency Determinations in Primary Care*: Springer
- Davie, E. (2006) 'A social work perspective on palliative care for people with mental health problems'. *European Journal of Palliative Care*: 13 (1) 26-28
- de Vries, K. (2003) Variant Creutzfeldt-Jakob disease: need for mental health and palliative care team collaboration. *International Journal Of Palliative Nursing*, 9 (12), 512-20
- Diwan, S., Hougham, G. & Sachs, G. (2004) Strain Experienced by Caregivers of Dementia Patients Receiving Palliative Care: Findings from the Palliative Excellence in Alzheimer Care Efforts (PEACE) Program. *Journal of Palliative Medicine*, 7(6), 797-807
- DRC (2006) Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems

- Draper, H. (2000) Anorexia nervosa and respecting a refusal of life prolonging therapy: a limited justification. *Bioethics*, 14(2), 120-133
- Draper, H. (2003) Anorexia nervosa and refusal of naso-gastric treatment: A reply to Simona Giordano. *Bioethics*, 17(3), 279-289
- Dresser R. & Boisaubin E. (1986) Psychiatric patients who refuse nourishment. *General Hospital Psychiatry*, 8(2), 101-106
- Durkin, I., Kearney, M. & O'Siorain, L. (2003) Psychiatric disorder in a palliative care unit. *Palliative Medicine*, 17 (2), 212-218
- Engel, S., Kiely, D. & Mitchell, S. (2006) Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. *Journal of the American Geriatrics Society*, 54(10), 1567-1572
- Felker, B., Yazel, J., & Short, D. (1996). Mortality and medical co-morbidity among psychiatric patients: A review. *Psychiatric Services*, 47, 1356–1363.
- Foti, E. (2003) Do it your way: A demonstration on End-of-Life Care for Persons with Serious Mental Illness. *Journal of Palliative Medicine*, 6(4), 661-669
- Foti, E., Candilis, P. & Holzer, J. (2004) End-of-Life Care and Mental Illness: A Model for Community Psychiatry and Beyond. *Community Mental Health Journal*, 40 (1), 3-16
- Foti, E., Bartels, S. & Van Citters, D. (2005) End-of-Life Treatment Preferences of Persons With Serious Mental Illness. *Psychiatric Services*, 56(5) 585-591
- François, R., Pautex, S. & Herrmann, L. (2007) Symptom relief in the last week of life: Is dementia always a limiting factor? *Journal of the American Geriatrics Society*, 55(8), 1316-1317
- Gans, M. & Gunn, W. (2003) End stage anorexia: criteria for competence to refuse treatment. *International Journal Of Law And Psychiatry*, 26(6), 677-65
- Gaugler, J., Anderson, K., Leach, C., Smith, C., Schmitt, F. & Mendiondo, M. (2004) The emotional ramifications of unmet need in dementia care-giving. *American Journal of Alzheimer's Disease & Other Dementias*, 19(6), 369-380
- Giordano, S. (2007) *Eating Disorders: Conceptual and Ethical Issues in the Treatment of Anorexia and Bulimia Nervosa*, Oxford University Press: chapter 13: 235 (Anorexia nervosa and the refusal of life saving interventions)
- Goldenberg, D., Holland, J., & Schachter, S. (2000) Palliative care in the chronically mentally ill. In: Chochinov, H Breitbart, W. *Handbook of psychiatry in palliative medicine*. New York, US: Oxford University Press: 91-96
- Goldman, L. S. (1999) Medical illness in patients with schizophrenia. *J Clin Psychiatry* 60 (Suppl. 21): 10-15.
- Grisso, T. & Appelbaum, P. (2006) Appreciating anorexia: Decisional capacity and the role of values. *Philosophy, Psychiatry, & Psychology*, 13(4), 293-297
- Hackett, A. (2007) A qualitative study assessing mental health issues in two hospices in the UK. *International Journal Of Palliative Nursing*, 13(6), 273-281

- Hahm, H. & Segal, S. (2005) Failure to Seek Health Care Among the Mentally Ill. *American Journal of Orthopsychiatry*, 75(1), 54-62
- Hansen, M., Fink, P. & Frydenberg, M. (2001) Mental disorders in medical inpatients and the association to severity of illness, self-rated physical disability, and health perception. *Psychosomatics: Journal of Consultation Liaison Psychiatry*, 42(1), 41-47.
- Hanrahan, P. & Luchins, D. (1995) Feasible criteria for enrolling end-stage dementia patients in home hospice care. *Hospice Journal*, 10(3), 47-54
- Harris, E. C., Barraclough, B. (1998) Excess mortality of mental disorder. *Br J Psychiatry* 173: 11-53.
- Henderson, M (2004) Mental Health Needs in Oliviere, D. & Monroe, B. (2004) *Death, Dying and Social Differences*. Oxford University Press: Oxford. Chapter 6: 79-95
- Hendrick, J. (2000) *Law and ethics in nursing and health care*. Cheltenham: Stanley Thomas Ltd
- Honig, A., Pop, P., & de Kemp, E., (1992) Physical illness in chronic psychiatric patients from a community psychiatric unit revisited. A three-year follow-up study. *British Journal of Psychiatry*, 161, 80-83
- Inagaki, T., Yasukawa, R., Okazaki, S., Yasuda, H., Kawamukai, T., Utani, E. Hayashida, M., Mizuno, S., Miyaoka, T., Shinno, H. & Horiguchi, J. (2006) Factors Disturbing Treatment For Cancer In Patients With Schizophrenia. *Psychiatry and Clinical Neurosciences* 60:3, 327–331
- Introductory guide to end of life care in care home NHS End of Life Care Programme (2006)
(Available from: <http://www.endoflifecareforadults.nhs.uk/eolc/>)
- Irwin, S., Rao, Bower, K., Palica, J., Maglione, J., Soskins, M., S. Betterton, A. & Ferris, F. (2008) Psychiatric issues in palliative care: recognition of depression in patients enrolled in hospice care. *Journal Of Palliative Medicine*, 11(2), 158-163
- Jeste, D., Gladsjo. J., Lindamer, A. & Lacro, P. (1996) Medical co-morbidity in schizophrenia. *Schizophr Bull*, 22, 413-430.
- Kamara, S., Peterson, P. & Dennis, J. (1998) Prevalence of physical illness among psychiatric inpatients who die of natural causes. *Psychiatric Services*, 49(6)
- Kapo, J., Morrison, L. & Liao, S. (2007) Palliative care for the older adult. *Journal of Palliative Medicine*, 10(1), 185-209
- Kasten, B. (1999) Self-Medication With Alcohol and Drugs by Persons With Severe Mental Illness. *Journal of the American Psychiatric Nurses Association*, 5(3), 80-80
- Kelly, B. & Shanley, D. (2000) Terminal Illness and Schizophrenia. *Journal of Palliative Care*. 16 (2), 55-57
- Kemppainen, J., Levine, R. & Buffum, M. (2004) Antiretroviral Adherence in Persons With HIV/AIDS and Severe Mental Illness. *Journal of Nervous and Mental Disease*, 192(6), 395-404.
- Kiely, D., Volicer, L. & Teno, J. (2006) The Validity and Reliability of Scales for the Evaluation of End-of-Life Care in Advanced Dementia. *Alzheimer Disease & Associated Disorders*, 20(3), 176-181
- Kondo, T., Takaoka, K. & Ikawa, N. (2004) Law Relating to Compulsory Treatment of Patients with Anorexia Nervosa. *International Medical Journal*, 11(4), 281-284

- Koopmans, R., Pasma, H., Roeline, W. & van der Steen, J. (2006) Palliative Care in Patients with Severe Dementia. In Burns, A. & Winblad, B. (2006) *Severe dementia*: New York, US: John Wiley & Sons Ltd: 205-213
- Koranyi, E. (1979) Morbidity and rate of undiagnosed physical illnesses in a psychiatric clinic population. *Archives of General Psychiatry*, 36(4), 414-419.
- Kreyenbuhl, J., Dickerson, F., Medoff, D., Brown, C., Goldberg, R., Fang, L., Wohlheiter, K., Mittal, L. & Dixon L (2006) Extent and management of cardiovascular risk factors in patients with type 2 diabetes and serious mental illness. *The Journal of Nervous and Mental Disease*, 194 (6) 404-10
- Kunkel, E., Woods, C., Rodgers, C. (1997) Consultations formaladaptive denial of illness in patients with cancer: psychiatric disorders that result in noncompliance. *Psycho-oncology*, 6, 139–149
- Kunz, R. & Zeitschrift, G. (2003) Palliative care for patients with advanced dementia: Evidence-based practice replaced by values-based practice. *Z Gerontol Geriatr*, 36(5), 355-359
- Laird, C. (2003) Clinical decision analysis and anorexia nervosa. *International Journal of Law and Psychiatry*, 26(6), 719-723
- Levin, S. & Feldman, M. (1983) Terminal illness in a psychiatric patient--issues and ethics. *South African Medical Journal*, 63 (13), 492-4
- Lloyd-Williams M., Friedman T. & Rudd N. (1999) A survey of psychological service provision within hospices. *Palliative Medicine*, 13, 431–432
- Ly, K., Chidgey, J. & Addington-Hall, J. (2002) Depression in palliative care: A systematic review. *Palliative Medicine*, 16(4), 279-284
- Madsen, A., Aakerlund, P. & Pedersen, D. (1997). Physical health in mentally ill patients *Ugeskr Læger*, 159, 4508-4511
- MacDonald, C. (2002) Treatment Resistance in Anorexia Nervosa and the Pervasiveness of Ethics in Clinical Decision making. *Canadian Journal of Psychiatry*, 47(3), 267-271
- Manley, R. & Leichner, P. (1998) *Treating Eating Disorders: Ethical, Legal and Personal Issues*. New York: New York University Press: 30-55
- Manley, R., Smye, V. & Srikameswaran, S. (2001) Addressing complex ethical issues in the treatment of children and adolescents with eating disorders: application of a framework for ethical decision-making. *European Eating Disorders Review*, 9(3), 144-166
- Maricle, R., Hoffman, W. & Faulkner, R. (1989) The coexistence of physical and mental illness among two samples of Oregon's chronically mentally ill. *New Directions for Mental Health Services*, 44, 97-110.
- Maricle, R., Hoffman, W. & Joseph D. (1987) The prevalence and significance of medical illness among chronically mentally ill outpatients. *Community Mental Health Journal*, 23(2), 81-90.
- McCarron, M. & McCallion, P. (2007) End-of-life care challenges for the persons with intellectual disability and dementia: Making decisions about tube feeding. *Intellectual and Developmental Disabilities*, 45(2), 128-131

- McCasland, L. (2007) Providing Hospice and Palliative Care to the Seriously and Persistently Mentally Ill. *Journal of Hospice & Palliative Nursing*. 9(6)
- McGrath, P. & Forrester, K. (2006) Ethico-legal issues in relation to end-of-life care and institutional mental health. *Australian Health Review: A Publication Of The Australian Hospital Association*, 30 (3), 286-97
- McGrath, P. & Jarrett, V. (2007). The Problem of Stigma during End-of-life Care at a Psychiatric Institution. *International Journal of Psychosocial Rehabilitation*. 11 (2), 19-30
- McIntyre, J. & Romano, J. (1977) Is there a stethoscope in the house (and is it used)? *Archives of General Psychiatry*, 34(10), 1147-1151
- Mitchell, S., Kiely, D. & Miller, S. (2007) Hospice care for patients with dementia. *Journal of Pain and Symptom Management*, 34(1), 7-16
- Mortensen, P. (1994) The occurrence of cancer in first admitted schizophrenic patients. *Schizophr Res* 12:185-194.
- Mortensen, P. (1989). The incidence of cancer in schizophrenic patients. *J Epidemiol Community Health* 43:43-47
- Munk-Jorgensen, P., Mors, O., & Mortensen, P. (2000) The schizophrenic patient in the somatic hospital. *Acta Psychiatrica Scandinavica*, 102 (Suppl407): 96-99
- Noorani, N. & Montagnini, M. (2007) Recognizing depression in palliative care patients. *Journal of Palliative Medicine*, 10(2), 458-464
- O'Connor, M. (2006) Interdisciplinary teams in palliative care: a critical reflection. *International Journal of Palliative Nursing*. 12 (3), 132-7
- O'Neill, J., Crowther, T. & Sampson, G. (1994) A case study: anorexia nervosa. Palliative care of terminal psychiatric disease. *The American Journal Of Hospice & Palliative Care* 11 (6), 36-8
- Parkes, C. (2000) Hospice: A Psychiatric Perspective In: Chochinov, H. & Breitbart, W. *Handbook of psychiatry in palliative medicine*. New York, US: Oxford University Press: 91-96
- Payne, S. (2002) The contribution of psychologists to specialist palliative care. *International Journal Of Palliative Nursing*, 8(8), 401-6
- Peveler, R, Feldman, E. & Friedman, T. (2000) *Liaison Psychiatry: Planning Services for Specialist Settings*. London: Gaskell: p69
- Price, A., Hotopf, M., Higginson, J., Monroe, B. & Henderson, M. (2006) Psychological services in hospices in the UK and Republic of Ireland. *Journal of the Royal Society of Medicine*, 99, 637-639
- RADIO 4 Programme 2 – Can a patient with Anorexia Nervosa be offered palliative care? (Wednesdays 29 Aug, 05 & 12 Sep 2007 8.00-8.45pm)
- Richmond, J. (2001) Anorexia and involuntary commitment: A necessary approach? *Psychiatry, Psychology and Law*, 8(1), 86-96
- Robinson, J. & Crawford, G. (2005) Identifying palliative care patients with symptoms of depression: an algorithm. *Palliative Medicine*, 19(4), 278-287

- Robinson, L., Hughes, J. & Daley, S. (2005) End-of-life care and dementia. *Reviews in Clinical Gerontology*, 15(2), 135-148
- Russell J. (1995) Treating anorexia nervosa (editorial) *British Medical Journal*. 311:584
- Russon, L. & Alison, D. (1998) Does palliative care have a role in treatment of anorexia nervosa? Palliative care does not mean giving up. *British Medical Journal*, 317 (7152), 196-7
- Sachs, G., Shega, J. & Cox-Hayley, D. (2004) Barriers to Excellent End-of-life Care for Patients with Dementia. *Journal of General Internal Medicine*, 19(10), 1057-1063
- Sampson, E., Ritchie, C. & Lai, R. (2005) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics*, 17(1), 31-40
- Schwartz, C., Steinmuller, R., & Dubler N. (1998) The medical psychiatrist as physician for the chronically mentally ill. *Gen. Hosp. Psychiatry* 20, 52–61.
- Shega, J., Levin, A. & Hougham, G. (2003) Palliative Excellence in Alzheimer Care Efforts (PEACE): A Program Description. *Journal of Palliative Medicine*, 6(2), 315-320
- Sheline, Y. (1990) High prevalence of physical illness in a geriatric psychiatric inpatient population. *General Hospital Psychiatry*, 12(6), 396-400.
- Simard, J. & Baltimore, M. (2007) The End-of-Life Namaste Care Program for people with dementia. *Health Professions Press*, 16, 197
- Solstad, K., Glenthøj, B., Bjérndal, N. & Hemmingsen R. (1989) Somatic illness in patients in an acute psychiatric department. *Ugeskr Læger* 151
- Spiess, J., Northcott, C. & Offsay, J. (2002) Palliative care: Something else we can do for our patients. *Psychiatric Services*, 53(12) 1525-1526
- Supportive and palliative care. Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual NICE (2004). (Available from: <http://www.nice.org.uk/guidance/index.jsp?action=byID&r=true&o=10893>)
- Talbott, J.A. & Linn, L. (1978) Reactions of schizophrenics to life-threatening disease. *Psychiatr Q*. 50(3): 218–227.
- Tan, J., Hope, T. & Stewart, A. (2003) Competence to refuse treatment in anorexia nervosa. *International Journal of Law and Psychiatry* 26(6), 697-707
- Tan, J., Hope, T., Stewart, A. & Fitzpatrick, R. (2003) Control and compulsory treatment in anorexia nervosa: the views of patients and parents. *International Journal Of Law And Psychiatry*, 26(6), 627-645
- Tan, J., Stewart, A. & Fitzpatrick, R. (2006) Competence to make treatment decisions in anorexia nervosa: Thinking and processes and values. *Philosophy, Psychiatry, & Psychology*, 13(4), 267-282
- Tate, F. (2005) Death and dying: implications for inpatient, psychiatric care. *Palliative & Supportive Care* 3 (3), 239-43

- Tchanturia, K., Liao, P. & Uher, R. (2007) An investigation of decision making in anorexia nervosa using the Iowa Gambling Task and skin conductance measurements. *Journal of the International Neuropsychological Society*, 13(4), 635-641
- Treasure, J. & Ramsey, R. (1998) *Hard to Swallow: Compulsory treatment in eating disorders* Maudsley Discussion Paper
- Turrell, S. (2005) Capacity to consent to treatment in adolescents with anorexia nervosa. *The Sciences and Engineering*, 65(10)
- Vandereycken, W. & Beumont, P. (1998) *Treating Eating Disorders: Continuum International Publishing Group*
- Volicer, L., Hurley, A. & Blasi, Z. (2001) Scales for evaluation of end-of-life care in dementia. *Alzheimer Disease & Associated Disorders*, 15(4), 194-200
- Wagner, G., Kanouse, D. & Koegel, P. (2003) Adherence to HIV antiretrovirals among persons with serious mental illness. *AIDS Patient Care and STDs*, 17(4) 179-186.
- WHO Interim guidelines for first level facility health workers. Integrated management of adolescent and adult illness. Palliative care: symptom management and end of life care. (December 2003) (Available from: <http://www.emro.who.int/aiecf/web35.pdf>)
- Williams, C., Pieri, L. & Sims, A. (1998) Does palliative care have a role in treatment of anorexia nervosa? We should strive to keep patients alive. *British Medical Journal* 317 (7152), 195-6
- Wilson, S. (1997) Palliative care for late-stage dementia. In Kovach, C. & Philadelphia, P. (2007) *Late-stage dementia care: A basic guide*. Washington, DC: Taylor & Francis, 13-23

Mental Health Foundation

About the Mental Health Foundation

Founded in 1949, the Mental Health Foundation is the leading UK charity working in mental health and learning disabilities.

We are unique in the way we work. We bring together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. We are keen to tackle difficult issues and try different approaches, many of them led by service users themselves. We use our findings to promote survival, recovery and prevention. We do this by working with statutory and voluntary organisations, from GP practices to primary schools. We enable them to provide better help for people with mental health problems or learning disabilities, and promote mental well-being.

We also work to influence policy, including Government at the highest levels. We use our knowledge to raise awareness and to help tackle stigma attached to mental illness and learning disabilities. We reach millions of people every year through our media work, information booklets and online services. We can only continue our work with the support of many individuals, charitable trusts and companies. If you would like to make a donation, please call us on 020 7803 1121.

If you would like to find out more about our work, please contact us.

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