

End of Life Care for People with Mental Illness

Terry Webber RN BSN CHPCN (C)

Clinical Resource Nurse, Hospice Palliative Care Consult Team

Langley, South Delta and White Rock,

Fraser Health Authority, BC, Canada

ABSTRACT

Research shows similar viewpoints on quality of life between persons with severe and persistent mental illness (SPMI) who are experiencing a palliative illness and the general population of people with palliative illness. These commonalities are expressed as hope for control of pain and other symptoms, control over levels of intervention to avoid prolonging the dying phase, and control over maintaining meaningful relationships. Yet the rights of the population of persons with SPMI and palliative illness to achieve these goals of care have not been as well honoured as compared to other members of society. This case study highlights how autonomy has been diminished for persons living with SPMI and palliative illness, and the discussion considers solutions to balance the harms.

Key Words: Autonomy, Severe Persistent Mental Illness (SPMI), Palliative Care, End of Life, Hospice

Joey was diagnosed with paranoid schizophrenia at the age of 21. When he displayed symptoms of fatigue and loss of appetite at the mental health residence where he had lived for the past 10 years, his care providers believed it would be best to transport him to the local hospital. Given the delusions that paralyzed him with fear and prevented him from stepping outside his facility, he was transported under the mental health act for investigation. He was diagnosed with metastatic gastric cancer, given a blood transfusion and sent back to his home facility. Comfort measures within the facility would be the focus of treatment. Unfortunately, the facility's licensing regulations stipulated that he would have to find other housing when he was no longer mobile. The case manager who came to assess Joey for future housing wondered if a hospice residence might fit his palliative care needs.

One in five Canadians have mental illness (Woods, Willison, Kington, & Gavin, 2008). It is unknown what percentage of this group suffer from severe persistent mental illness (SPMI), defined as persons who are "18 years and older who suffer from a prolonged or recurrent mental illness, are impaired in activities of daily living and require long-term treatment" (as cited by Woods et al., p. 725). As well, very little is known about the experience of people with SPMI who have the added burden of terminal illness and who need palliative care. Palliation aims at relieving suffering, while improving quality of life [however the particular

person defines 'quality of life' (Canadian Hospice Palliative Care Association 2002)].

Research shows commonalities in the end of life views between persons with SPMI and terminal illness and the general population of people with terminal illness with respect to what defines quality of life. These commonalities include a wish for: control of pain and other symptoms, control over levels of intervention to avoid prolonging the dying phase, and control over maintaining meaningful relationships (Wood et al, 2008; Zuliani, Plumridge, & Webber, 2004). These are basic goals of palliative care, yet within the population of persons with SPMI and terminal illness these are not always pursued, respected or accomplished.

Control of Pain and Other Symptoms

Little is understood about adequate symptom management for people with SPMI and terminal illness. Research indicates that they may experience pain differently. Two studies showed that persons with schizophrenia had a high pain tolerance and were able to tolerate advanced and non-healing palliative wounds (Talbot & Linn, 1978). Given this high pain tolerance, detection of serious physical diseases may not occur in a timely way and hence late diagnosis occurs (Woods et al., 2008; Baker, 2005).

People with SPMI and terminal illness may also report pain differently or not report pain at all (Talbot et al., 1978). For example, some patients with schizophrenia will not verbalize pain. Instead, they become quieter, or display affective flattening, or more inward symptoms, known as negative symptoms. Some studies have found that pain was incorporated into the delusional system of persons with schizophrenia, thus distorting the experience and reporting of pain and affecting health care providers' normal understanding or interpretation (Goldenberg, Holland, & Schachter, 2000).

Many health care providers (outside of mental health care) do not understand behaviours related to psychiatric illness and lack knowledge on how to deal with these behaviours (McCormack, 2006). When palliative illness is added to the mix of disease presentations, it becomes difficult for health professionals to differentiate which behaviours may be reversible or treatable, and which are chronic (Baker, 2005). For example, a person with schizophrenia will have delusions which do not change in theme, but may become more intense at any particular time as a coping response to a stressful event. An escalation of the delusional

behaviour in a person with SPMI and terminal illness may indicate that there is more suffering going on, yet the health professional may be unable to understand the source of the suffering. In palliative care practice, assessing for symptoms which concern the person involves a gauging of the quality, quantity and the duration of suffering that the person is enduring. In mental health care, instead of acknowledging or assessing symptoms of concern, there can be a tendency to ignore them (McCasland, 2007).

Persons with SPMI may be challenged in keeping appointments, possibly stemming from a lack of skills and knowledge of how to use the health care system. When they do seek support, they may be unable to communicate their symptoms in a way that alerts health care professionals to a palliative illness (Baker, 2005). The result is late referrals, less effective treatments, lack of knowledge on how to care for the person and premature death (Talbot et al., 1978). Sadly, a late diagnosis correlating with an early death rate is considered to be a normal statistic for people living with serious mental illness (McGrath et al., 2004).

Control Over of Levels of Intervention

Autonomy is defined as, “self determination- the right to make independent decisions concerning your own life and well-being” (as cited by Yeo, Moorhouse, Khan, & Rodney, 2010, p. 143). Terminally ill people with SPMI have a right to choose various treatments that they believe will help to achieve their goals of care and quality of life. At the same time, they also have a right to refuse treatment. This autonomy is dependent on the quality of the person’s reasoning process, insofar as the person must be able to exercise their autonomy with some logical deliberation. Autonomy, as expressed through effective deliberation, means that the person must be able to understand and appreciate the health issue that is going on, be able to appreciate the outcomes of the interventions that he or she chooses or does not choose, and be able to demonstrate reasoning showing how this decision supports the goals that he/she hopes to attain (Yeo et al., 2010). When these requisites of reasoning are not present, a delegated substitute decision maker, often a family member who knows the authentic wishes and hopes of the patient, will make those decisions. Sadly, the reality for many people with SPMI is that they are not well connected to their families, and thus a proxy, who may not know the authentic wishes of the person, is assigned the task.

The question of effective deliberation surfaces often in psychiatric illness for a number of reasons. Some patients with psychiatric illness may not realize they are suffering from a disease, which will prevent them from understanding and deciding on intervention options (Sjostrand & Helgeson, 2008). Others may not have the decision making capacity if the illness is affecting their reasoning power. Given a lack of capacity, or variable capacity over time, it can be a real challenge sorting out a person’s wishes, either in advance, or at times of extreme physical or emotional distress. At what point should people with SPMI be asked about their choices for end of life care? When are people at their most optimal competent state to understand and process the information regarding their health matters? (Yeo et al., 2010).

Other threats to the autonomy of the person with SPMI during their palliative phase may be the paternalistic health professional who assumes that the person is not capable of making a decision around end of life issues, and so does not assess the person’s deliberation abilities. Health professionals may lack the knowledge and communication skills to assess what the patient’s wishes are (McGrath, & Holewa, 2004), or believe that people with SPMI will cope poorly with end of life issues (Goldenberg et al., 2000), or fear creating emotional and mental harm by talking about end of life issues (Woods, et al., 2008). Findings, however, show that patients with psychiatric illness who have the greatest degree of physical impairment are the most receptive to talking about end of life advance care directives (Foti, Bartels, Merriman, Fletcher, & Van Citters, 2005). Woods et al. (2008) concludes that despite the difficulty that many people with SPMI face in their understanding and reasoning, as compared to the general population, the end of life information can be tailored to facilitate a simple understanding and discussion.

While end of life planning is recognized as an important and standard element of good health care in many health authorities/services, tragically and unfairly, these advance care directives are often not even discussed with persons with SPMI (Foti et al., 2005).

Control over Maintaining Meaningful Relationships

Woods et al. (2008) identified similarities between palliative care and mental health care, particularly the shared belief that the therapeutic relationship is the core competency of practice. Despite this similarity in philosophical approach, hospice physicians and staff sometimes do not know how to communicate with a person with SPMI. Not surprisingly, health care providers do not want to provide care for a person they view as falling outside of their domain of expertise (Woods et al., 2008).

Closely linked to the theme of who cares for the person with SPMI and terminal illness is the question of where the care should be provided. A study done by McGrath et al. (2004) found that staff in one mental health facility who cared for their own patients with terminal illness showed inherent understanding of the person centered approach, as they had always cared for their patients in this way. The distress for staff came when the patients were moved to another facility for end of life care. Often it is the staff who becomes ‘family’ for the person with SPMI, as there are few other support systems.

Hospice staff may make judgements at first glance if there are issues around lack of hygiene, or behaviours with which they are not familiar. If there are added concerns about safety, staff may feel some hesitancy to care for the patient (Hughes, 2001; McCormack & Sharp, 2006). Hospital wards and hospices may also deny access because of management and behavioural concerns (Woods, 2008). McCasland et al. (2007) note reassuringly that patients who are accepted into hospice care or facilities are usually so ill that they do not have the strength or energy to become threatening.

Choice in therapeutic relationships also means a choice to want to be alone. A person living, and now dying, with schizophrenia

may prefer to be left alone. Some may be unable to tolerate medical attention, or being touched, or having procedures performed, or having restrictions placed on them (Baker, 2005; Talbot et al., 1978, Woods et al, 2008). Avoidance may be the best coping strategy, with no benefit attending the sick role (Baker, 2005).

Outcomes of Lost Autonomy

In working through the challenges of meeting the goals of patients with SPMI who need palliative care, it seems that few strides have been made to support their right to self-determination at this profoundly vulnerable time in their lives. The population with serious mental illness, including those who are poor and homeless, are not included in clinical trials, creating a lack of knowledge around addressing their unique end of life issues (Hughes, 2001; Baker, 2005; Levin, 1983; Davie, 2006, McGrath, 2004). If homeless, accessing care sometimes cannot occur because they do not have a fixed address, which is one of the criteria for referral to many home health (or hospice in the community) programs. "While many will die in institutions, for those who are homeless and poor, dying on the street or in jail [will be] another fact of life" (as cited by Hughes, 2001, p.66).

Lack of Resources

Yeo et al. (2010) point out, "We are not all equal in our health needs. Due to the social and 'genetic lottery,' each of us is born with different opportunities to achieve health and happiness. Some people require more resources than others to meet their health needs and to have more or less equal opportunities in society" (p.302). For purposes of this discussion, the translation is that we are all unequal in our palliative care needs. Hence, there will be unequal resources needed to enable people with SPMI and terminal illness to experience the same level of comfort and dignity in their dying time as the rest of society may experience. Distributive justice in this context might also challenge us to provide fair restitution, in the form of ample palliative care resources, to persons with mental illness in order to compensate for generations of societal neglect.

Restoring Justice for Patients with SPMI and Terminal Illness

A group of American psychiatrists/physicians developed a set of core principles that recognizes the rights of autonomy for people with palliative care needs who also suffer with mental health issues (APA, (2001). The CHPCA (2002) developed a multi-level system framework for the provision of hospice/palliative care based on the unique needs of any population (rooted in values that recognize primacy of the therapeutic relationship as the hallmark of excellent care).

Psychiatric nursing associations should also address palliative care issues for people with mental illness, including a sharing of existing knowledge to identify best practices. Communication tools, such

as advance care planning documents, which are already in place in some health authorities, could be adapted to accommodate the different levels of ability or understanding that might be encountered in the mental health client population.

More research on the unique experience of people with SPMI and terminal illness is needed. Organizations like the APA and CHPCA could then translate this knowledge into a vision and a framework for accessible programs, whether patients are homeless, living at home, in residential or acute care, or in prison.

Development of symptom management guidelines that have sensitivity to multifaceted responses to end of life issues for people with SPMI are needed. Risk assessment tools are also needed, not to shut out people with SPMI and terminal illness from the resources that they need, but as a way to identify safety issues and mitigate harm for both patient and staff.

Innovation

Communities could learn from each other about existing programs that are working, such as the Ontario, Canada outreach program for the homeless who do not tolerate care well. Nurses go out onto the streets to meet people to engage in a therapeutic relationship and provide palliative care to them until such time as the homeless are willing to come to them.

Another innovative care center in Ottawa, Canada is offering 24 hour shelter hospice care using a harm reduction approach of allowing controlled amounts of alcohol, a needle and syringe program and a designated smoking area for the homeless needing palliative care services (Woods et al, 2008).

The director of research in hospice care in Florida, USA, has implemented an innovative, compassionate 'just-do-it' approach to care for homeless people who do not want to move from their living situation; if staff are needed to care for a person living under a bridge, he finds the means to make that happen (McCasland, 2007).

Conclusion

Joey, who was portrayed earlier in this discussion paper, may have experienced a more positive outcome than many of his peers with mental illness, thanks to his care providers. The director of care at the mental health facility welcomed the consult team to provide palliative care education for his staff and develop a plan of care with them for Joey. The staff would continue to provide Joey with his small pleasures, allowing him to rest in bed more, and conserve his energy, which would allow him to stay in the facility for as long as possible with the people that understood him the most. A risk assessment of potential for harm was made with a backup plan (a direct admission to a private room at the local hospital ward which would bypass the need for the emergency department) if required. It was not needed. When transferring to his chair became difficult, Joey was transported to the next hospice room that became available, with the accompaniment of one of the nurses who he knew well, and a promise

that staff and residents would visit him at the hospice. A letter of incompetency was ready in case of his refusal to go to the hospice, but this was not needed. Hospice staff were made aware of his simple likes (such as having tapioca pudding with every meal), which made for a smooth transition and enabled the new therapeutic relationships to become established in short order. When his behaviour changed slightly, the hospice staff used their palliative knowledge base and communication skills to ascertain whether pain was an issue. He died peacefully at the hospice a few days later.

Change begins with the belief and commitment to, “respect the person’s humanity, no matter how they look, what they say and what feelings they evoke, [and] appreciate the person’s unique story as influencing his/her response to illness and death” (Hughes, 2001, p. 68). Let’s begin...

References

- American Psychiatric Association. (2001). *Core principles for end-of-life care: position statement with annotations and additions to the core principles for end of life care for psychiatry*. Washington, D.C.
- 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.
- Canadian Hospice Palliative Care Association. (2002). *A Model to Guide Hospice Palliative Care*. Ottawa, Canada
- 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.
- Foti, M. E. (2003). Do it your way: A demonstration project on end-of-life care for persons with serious mental illness. *Journal of Palliative Care*, 6, (4), 661-669.
- Foti, M.E., Bartels, S.J., Merriman, M.P., Fletcher, K.E. & Van Citters, A.D. (2005). Medical advance care planning for persons with serious mental illness. *Psychiatric Services*, 56(5), 576-584.
- Goldenberg D., Holland J., & Schachter S. (2000). Palliative care in the chronically mentally ill. In: H.M. Chochinov & W. Breitbart (Eds.), *Handbook of Psychiatry in Palliative Medicine* (pp. 91-96). New York: Oxford University Press.
- Hughes, A. (2001). Poor, homeless and underserved populations. In: Coyle, N., Ferrell, B, (Eds). *Palliative Nursing* (pp 661-670). New York: Oxford University Press:
- Levine, S.M., Feldman, M.B. (1983). Terminal issues in a psychiatric patient- issues and ethics. *SA Medical Journal*, 63 (Mar), 492-493.
- McCasland, L.A. (2007). Providing hospice and palliative care to the seriously and persistently mentally ill. *Journal of Hospice and Palliative Nursing*, 9 (6), 305-313.
- McCormack, P., & Sharp, D.M.M. (2006). Palliative care for people with mental healthproblems. *European Journal of Palliative Care*, 13 (5), 198-201.
- McGrath, P. & Holewa, H. (2004). Mental health and palliative care: Exploring the ideological interface. *International Journal of Psychosocial Rehabilitation*, 9 (1), 107-119.
- Sjostrand, M., & Helgeson, G. (2008). Coercive treatment and autonomy in psychiatry. *Bioethics*, 22(2), 113-120.
- Talbott, J. A., & Linn, L. (1978). Reactions of schizophrenics to life threatening disease. *Psychiatric Quarterly*, 50, 218-227.
- Woods, A. Willison, K., Kington, C., Gavin, A. (2008). Palliative care for people with severe persistent mental illness: a review of the literature. *The Canadian Journal of Psychiatry*, 53(11), 725-736.
- Yeo, M., Moorhouse, A., Khan, P., & Rodney, P. (Eds.). (2010). *Concepts and cases in nursing ethics* (3rd ed.). Peterborough, Ont.: Broadview Press.
- Zuliani, M. Plumridge, A., & Webber, T. (2004). *The Gift of Caring: A Palliative Caregiver Education Program*. Mooretown, Ont.: Valley Publishing.

Acknowledgements: none

Competing Interests: none

e-mail: terry.webber@fraserhealth.ca

Date of Publication: November 12, 2012