Palliative care for vulnerable populations

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ABSTRACT

Objective: The purpose of this article is to identify how inclusive and accessible palliative care can be achieved for all, including those labelled as vulnerable populations.

Method: Drawing on a review of existing literature as well the research of the Vulnerable Persons and End-of-Life New Emerging Team (VP-NET), this article reflects on what changes can be made within palliative care to make it more inclusive.

Results: Experiences of marginalization often result, intentionally or unintentionally, in differential treatment in healthcare. This increased vulnerability may result from attitudes of healthcare providers or from barriers as a result of "normal" care practices and policies that may exclude or stigmatize certain populations. This may include identifying when palliative care is necessary, who receives palliative care and where, and what is necessary to complement palliative care.

Significance of results: Inclusive and accessible palliative care can become possible through building on the existing strengths in palliative care, as well as addressing existing barriers. This may include treating the whole person and that person's support team, including paid support workers, as part of the unit of care. It involves ensuring physically accessible hospice and palliative care locations, as well as thinking creatively about how to include those excluded in traditional locations. Inclusive palliative care also ensures coordination with other care services. Addressing the barriers to access, and inclusion of those who have been excluded within existing palliative care services, will ensure better palliative and end-of-life care for everyone.

KEYWORDS: Accessibility, Palliative care, Inclusion, Vulnerability, Marginalization

INTRODUCTION

At the end of life, everyone is vulnerable. We all face mortality and thus are susceptible to the experience of vulnerability. However, in the health professions, "vulnerable populations" are often referred to as a separate group of people with unique experiences of palliative care. In this article we argue that vulnerability is a universal human condition and shaped by one's experiences of marginalization and privilege in society. Experiences of marginalization often result, intentionally or unintentionally, in differential treatment in healthcare. We suggest that by addressing the barriers to care among those who have been labelled "vulnerable," we can create palliative care practices and services that are universally inclusive.

WHO IS VULNERABLE?

Vulnerability is a universal human condition, but is experienced differently, depending upon one's life circumstances and other variables including pre-existing impairments or disabilities, homelessness, or being in conflict with the law. Feeling vulnerable comes as a result of being at risk for physical, psychological, or emotional harm. That risk of harm can come from within one's body or psyche as intrinsic vulnerability, or from external sources including poverty, environmental disaster, or discriminatory attitudes.

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Whereas everyone is vulnerable as they near death, or because of illness or changes in their bodies, people can also be made to feel vulnerable, that is, "created vulnerable" (Stienstra & Chochinov, 2006). This may happen when hidden assumptions about the circumstances in which people live, including homelessness or poverty, or about specific groups of people, including people with disabilities or recent immigrants, shape care practices and policies. These assumptions or attitudes may result in differential treatment, or exclusion from what is assumed to be "normal" or standard care practices.

ATTITUDES

Attitudes or assumptions are not always obvious or intentional. Indeed they are learned responses to specific groups of people or ways of understanding life that are hidden parts of the fabric of our societies. They also change over time and across societies. For example, cultural acceptance of smoking as "normal" behavior in North America has shifted to a widespread rejection of smoking and banning of smoke and smokers from public places.

Individual attitudes are often the result of longstanding cultural and societal images related to specific groups of people. For example, one image from some Hollywood movies is that it is better to be dead than to be disabled. Several recent movies, including *Million Dollar Baby*, portray a life with disabilities as not worth living (Lutfiyya et al., 2009; Schwartz & Lutfiyya, 2009). These perceptions become part of public conversations and permeate our individual consciousness. In part, they create the context within which our attitudes emerge.

These attitudes are present in all people in society and shape how we act in relation to others. Our assumptions or attitudes about groups of people may subtly shape how we believe we should provide care for them. Chochinov suggests that the attitudes of healthcare providers may not reflect the patient's reality and may affect the care provided (Chochinov, 2007). "For instance, might an assumption of poor quality of life in a patient with longstanding disabilities lead to the withholding of life sustaining choices? Might ageist assumptions mean that conversations about intimacy are rarely initiated? Is a health worker more likely to assume intoxication in a confused, homeless patient before considering whether they have a metabolic disorder?" To address these often hidden attitudes, Chochinov calls on healthcare providers to ask themselves some basic questions including "Could my attitudes toward the patient be based on something to do with my own experiences, anxieties or fears?"

This self-reflection is an important step and enables a healthcare provider to uncover what may be hidden barriers to effective palliative care for populations perceived to be vulnerable.

BARRIERS

Vulnerability is also created as a result of "normal" care practices and policies that may exclude or stigmatize certain populations. This may include identifying when palliative care is necessary, who receives palliative care and where, and what is necessary to complement palliative care.

Palliative care increasingly recognizes multiple trajectories at the end of life, some of which are quite different from the cancer trajectories that provided impetus for the creation of palliative care. However, palliative care still tends to be prognosis driven, rather than being offered based on the individual needs of people with life-threatening and life-limiting conditions.

In some instances, relinquishing curative options can create vulnerability. Carol Gill argues that people with disabilities may be assumed to be dying when they could and have lived with their condition for many years. "Some disability advocates are concerned that palliative care services, such as hospice, may become the new dumping ground for persons with brain injuries, developmental disabilities, high-level quadriplegia, progressive neuromuscular disease, and other support-intensive disabilities" (Gill, 2006).

Others suggest that people with chronic or fluctuating conditions or impairments may have difficulty accessing palliative care because it is unclear when they are at end of life. One palliative care physician suggested, "I guess palliative care is just 'palliating symptoms' and you can do that through the whole life. So palliative care doesn't mean only end of life." However, he explained that although people may have chronic illnesses, when they have to decide to enter palliative care they no longer expect to live more than 6 months. He used two examples of renal disease and a chronic neurological disability to illustrate the fact that there is a judgment call involved in deciding when end of life, and therefore palliative care, begins (Troschuk et al., 2006).

Palliative care can be difficult to access for some groups. These may include homeless people and people with persistent mental illness (Woods et al., 2008). They may also include poor people and those living in transitional housing. In some cities, these groups include a high proportion of Aboriginal people (Stienstra & Wiebe, 2006; Kaufert et al., 2012).

People with intellectual and developmental disabilities often have difficulty getting access to palliative care (Lutfiyya & Schwartz, 2010). Some of the barriers to access for these populations may be the

location or physical access of hospice or palliative care, lack of family or other supports to facilitate their entry into or retention in the system, unwillingness to enter an institutional setting because of distrust as a result of earlier encounters in institutional settings, or a home considered unsafe or unsuitable for off-site palliative care by care providers. All of these barriers result in exclusion from palliative care.

As stated earlier, individual attitudes are shaped by cultural and media images and portrayals. The barriers that exclude people from end-of-life care may also be part of broader or more systemic stigma, assumptions, or past practices. For example, distrust of care provided in institutional settings may be, for many Aboriginal people, a legacy of the residential school system and the abuse and cultural denial they experienced there. For some people with disabilities, their experiences in healthcare systems have been experiences of vulnerability, with the physicians and other healthcare providers wielding significant power.

> Medical classification, emphasizing abnormality and deficiency, permeates the public's understanding of life with disability. Doctors and other healthcare professionals have served as the primary authorities in public policy affecting us, as well as in our personal life histories. Whether we remember them as kindly paternal or frighteningly austere, medical experts have diagnosed our problems, predicted our potential, and prescribed measures to alter our bodies and our futures. That is an enormous amount of power (Gill, 2006).

For poor people and those who live in some transitional housing settings, perceived safety, of the house or the neighborhood, may preclude their participation in palliative care. Workers may not feel they can provide the required care in a setting that may not meet certain standards of cleanliness, quality, or personal security. For some who live in shelters or on the street, it may be difficult to communicate on a regular basis about tests, results, or medications, limiting their access to palliative care.

Most people who require end-of-life care prefer to die at home or at least surrounded by those who love them (Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology, 2000). However, for some groups of people, vulnerability may preclude being able to die in a place of their choosing. People who live in remote areas, far from palliative care services, may have to come into larger urban settings to receive care. For them, this is not simply a dislocation, but is often a separation from the homes and communities of support, and in some cases, from their cultural communities as well. The

emotional costs may be very high, not only for the dying person but for their communities as well. Stienstra and Wiebe describe the situation of one woman coming into the city from a remote location (Stienstra & Wiebe, 2006). She was only able to bring two children with her. While she was receiving treatment, her other child tried to commit suicide.

For some people with pre-existing disabilities, the complexity of their care requires them to move to institutional settings, including long-term care homes or hospitals. This decision may be one mutually agreed to by the patient and healthcare provider. But it may be a decision predicated on assumptions about what type of impairments can be accommodated within a home-based palliative care practice. For example, in many palliative care settings, those who use ventilators are required to be in hospital. Some palliative care providers have recognized that ventilators can be part of a home-based palliative care regime.

For those who enter institutional settings, their vulnerability is intensified, not only because of the increased exposure to illnesses, but because of their separation from their existing physical and psychological supports.

Many who have lived independently in the community for a long time have managed their own care and support workers. Those support workers are not included in the institutional care structure in that setting unless paid for privately. Those who can afford that option may choose to hire their home-based support workers to provide care in the institutional setting because they have an established relationship and it provides continuity of care. But most cannot afford to bring in privately paid workers. In addition, many of those who provide palliative care have little experience in providing care to people with longstanding disabilities.

> The first day I was brought into the facility, I realized that I'd entered a new stage of my health care. The health aides seemed very jovial—and, very obviously, they had their accustomed ways of doing things. The first thing they wanted to do was to give me a bath. Obviously this was standard operating procedure for a new resident. Five of them had me in a plastic tub chair very quickly and my clothes off. I tried to explain. I had previous experience with bathtubs. People with multiple sclerosis are unlike individuals with conventional neurological systems. When our limbs are immersed in hot water, they immediately become flaccid and weak. I tried to explain to these five smiling, laughing women that I was about to give them a great deal of trouble. But no, they had dealt with reluctant residents before. They were

undeterred. They were bound and determined to give me that bath.

The bathtub was an immense apparatus, with the chair being picked up in a sling and lowered into the tub. The women had wrapped two straps around me that appeared to be sufficient for any difficulties. I knew they weren't. They lowered me into the water. Immediately upon hitting the warmth of the water, my limbs relaxed completely and I became Mr. Jello. I quietly told them that we had a bit of a problem, as I started to slide out of the chair. At first they didn't take me seriously. Two minutes later, I was in the bathtub with five women trying valiantly to stop me from drowning. I wasn't frightened. I'd seen this before. My response was standard and organized: "Ladies, ladies, one at a time. I'm not as young as I used to be. Just promise me, nobody tells my wife." They hoisted me up and got me out and took me to an available bed nearby, where they changed my clothes and then took me back to my own bed. By now they were laughing, but they hadn't been laughing earlier. (Kellerman)

The move to institutional care may mean a loss of accessibility, both for patients and for their support systems. One person with disabilities described his sadness at not being able to say goodbye to a friend in hospice care because it was not accessible to his wheelchair. Informal care providers often experience impairments. One recent study suggests that people with disabilities assume caregiving roles to the same or greater degree as those without disabilities (Fawcett, 2009).

Finally, those who move into institutional settings may have little coordination between their disability-related supports and their end-of-life care. In some provinces in Canada, disability-related supports such as wheelchairs, cannot be provided free of charge in institutional settings because of fiscal decisions about where community is and who provides what. In others, the process of obtaining aids for daily living may be too lengthy to accommodate changes in requirements at end of life. For some people, these gaps in coordination of services effectively limit access to quality palliative care.

The scope of vulnerability extends beyond those disability groups previously mentioned. For example, barriers to information and communications may exist for people who are blind, for deaf people, and for people whose first language is not English or French. Each of these groups requires special accommodation to access information and care. A recent study of disability and cancer care suggests other barriers and challenges. "People who are homeless and people who have substance abuse problems have challenges similar to people with mental health problems. People who are obese may experience some of the barriers faced by people with mobility impairments" (Annable et al., 2010).

Addressing the barriers that create and intensify vulnerability among certain populations will have much broader effects for all those using palliative care. As one oncologist stated, "Ultimately our goal at this institution is to improve care for everybody, and I think looking at people who have more difficulty accessing care would shed light on how to improve care for everybody" (Annable et al., 2010).

INCLUSIVE PALLIATIVE CARE: WHAT IS IT? WHAT DOES IT LOOK LIKE?

For palliative care to be universally accessible and inclusive, it needs to build on the strengths that already exist in palliative care, while concurrently addressing current barriers to access and inclusion for those created vulnerable.

Palliative care emphasizes the care of the whole person: physical, psychosocial, and spiritual care. It also recognizes that people are in relationships and that the unit of care is more than the individual person and extends to the broader family and social support systems. These are important considerations, particularly for those who have been excluded from palliative care and those who have been created vulnerable. For critically ill people who must come from remote areas to receive palliation, their networks of care extend back to their home community. Innovative communications, including video-links, may provide access to and from those communities. For people with intellectual disabilities whose links with family may have been severed as a result of earlier institutionalization, their paid support workers may serve as their broader care unit and need to be included.

One model that looks beyond the physical needs of the patient and includes their whole self and their humanity is dignity-conserving care (Chochinov, 2002; Chochinov et al., 2002). Dignity-conserving approaches address illness-related concerns, the social dignity inventory (i.e., the way in which interactions with others can influence a sense of dignity) as well as dignity-conserving perspectives and practices (i.e., the psychological and spiritual facets of each patient) can help to include those who have been excluded in palliative care. The essence of dignity-conserving care is to provide patients affirmation of their worthiness of honor, respect, and esteem. In this way, people are valued for who they are, in spite of whatever limitations or disabilities they happen to live with.

Lutfiyya and Schwartz (2010) suggest this model may be an effective way to address issues for people

with intellectual disabilities, who have experienced devaluation and exclusion throughout their lives. "Do people for whom dependence is a daily reality mourn a loss of independence at end of life? It is suggested that it is dangerous to believe that people with IDD [intellectual and developmental disabilities] do not have independence simply because they may be dependent on some people to help them with some things. Independence, like competence, may be better understood not as a global construct but as something more specific to particular events or situations. It may be very devastating for a person with IDD to realize that, after having spent considerable time and effort learning a particular skill, they can no longer accomplish the task due to their illness. Thus it is important for palliative care professionals to recognize the demoralizing effects of this type of loss, as they would for any other person" (Lutfiyya & Schwartz, 2010).

Inclusive palliative care also seeks to ensure that the environments within which palliative care is provided are accessible to all. This includes physical access by providing ramps and elevators where necessary, or having all care on one level. It includes information and communications access, including written communications in multiple formats including large print and Braille, and oral communications with access to interpretation as required. It also includes providing palliative care in places considered home and, when possible, making the necessary adaptations. For some this has meant creating a hospice attached to a shelter for homeless people, to enable the required access.

Care providers are also part of the environment of palliative care. Reflection about what they bring to their care practices—including the basics of attitude, behavior, compassion and dialogue that acknowledge personhood—is a necessary piece of creating inclusive palliative care (Chochinov, 2007). Support for this type of work can be developed through education and training for those who provide palliative care. Materials or workshops that bring forward and value the experiences of those who have been created vulnerable are especially effective in raising awareness of hidden assumption (Kaufert et al., 2010). Using novel knowledge translation methods such as theater or humor can also help the process of reflection (Janz, 2006).

Palliative care has understood that curative care options (e.g., treating an infection) do not necessarily end when palliative care begins, but that it is a process of coordinating those two forms of care over the trajectory of a patient's illness. The experiences of those created vulnerable remind us that palliative care may also need to coordinate care with other services and supports. This may involve coordination with rehabilitation or physical therapy, adaptive equipment for activities of daily living, those providing paid support in the community, those involved in ensuring supported decision making, and those providing primary care services.

Everyone has the right to quality end-of-life care. Addressing the barriers to access, and inclusion of those who have been excluded within existing palliative care services, will ensure better palliative and end-of-life care for everyone.

REFERENCES

Annable, G., Stienstra, D. & Chochinov, H.M. (2010). Addressing disability in cancer care. Toronto: Canadian Partnership Against Cancer.

Chochinov, H.M. (2002). Dignity-conserving care — A new model for palliative care. *Journal of the American Medical Association*, *287*, 2253–2260.

Chochinov, H.M. (2007). Dignity and the essence of medicine: The A, B, C and D of dignity conserving care. *British Medical Journal*, *335*, 184–187.

Chochinov, H.M., Hack, T., McClement, S., et al. (2002). Dignity in the terminally ill: A developing empirical model. *Social Science & Medicine*, *54*, 433–443.

Fawcett, G. (2009). Caregivers with disabilities: Debunking the myth. *Policy Research Directorate, Human Resources Skills Development CanadaMay 2009*.

Gill, C.J. (2006). Disability, constructed vulnerability, and socially conscious palliative care. *Journal of Palliative Care*, *22*, 183–191.

Janz, H. (2006). *"Voices at Dying: Dying to be Heard."* 16th International Congress of the Terminally Ill, McGill University, Montreal, Quebec, September, 2006.

Kaufert, J.M., Wiebe, R., Lavallee, M., et al. (Forthcoming). Seeking physical, cultural, ethical and spiritual "safe space" for a "good death": The experience of Indigenous peoples in accessing hospice care. In *Religious Understandings of a 'Good Death' in hospice palliative care*. H. Coward & K. Stajhuhar (eds.). New York: SUNY Press.

Kaufert, J., Wiebe, R., Schwartz, K., et al. (2010). End-of-life ethics and disability: Differing perspectives on case-base teaching. *Medicine, Health Care and Philosophy*, *13*, 115–126.

Kellerman, W.J.P. *Writing on the insides of my eyelids*. http://www.umanitoba.ca/outreach/vpnet/LD-patrick.htm.

Lutfiyya, Z.M. & Schwartz, K.D. (2010). Applying the dignity-conserving model of care to people with intellectual disabilities at end of life. In *End of Life Care for Children and Adults with Intellectual and Developmental Disabilities*. S.L. Friedman & D.T. Helm DT (eds.). Washington, DC: American Association on Intellectual and Developmental Disabilities, pp. 201–218.

Lutfiyya, Z.M., Schwartz, K.D. & Hansen, N. (2009). False images: Reframing the end-of-life portrayal of disability in the film *Million Dollar Baby*. In *Bioethics at the Movies*. S. Shapsay (eds.). Baltimore: Johns Hopkins University Press, pp. 225–241.

Schwartz, K.D. & Lutfiyya, Z.M. (2009). "What lay ahead." A media portrayal of disability and assisted suicide. *Journal of Research in Special Educational Needs*, *9*, 27–38.

Stienstra, D. & Chochinov, H.M. (2006). Vulnerability, disability and palliative end-of-life care. *Journal of Palliative Care*, *22*, 166–174.

Stienstra, D. & Wiebe, R. (2006). Finding our way home: Home and end-of-life transitions for people with disabilities. *Canadian Journal of Urban Research*, *15*, 19–35.

Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology. (2000). *Quality End-of-Life Care: The Right of Every Canadian*. Ottawa: The Senate of Canada.

Troschuk, L., Atherton, C. & Keys, S. (2006). *"A Good Life until the End: Palliative Care and People with Disabilities."* www.vp-net.ca.

Woods, A., Willison, K., Kingston, C., et al. (2008). Palliative care for people with severe persistent mental illness: A review of the literature. *Canadian Journal of Psychiatry*, *53*, 725.