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Heightened vulnerabilities and better care for all: Disability and end-of-life care

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ABSTRACT

Objective: The purpose of this study was to assess the extent to which vulnerability was present or heightened as a result of either disability or end-of-life policies, or both, when people with disabilities face end of life.

Method: People with disabilities and policy makers from four Canadian provinces and at the federal level were interviewed or participated in focus groups to identify interactions between disability policies and end-of-life policies. Relevant policy documents in each jurisdiction were also analyzed. Key theme analysis was used on transcripts and policy documents. Fact sheets identifying five key issues were developed and shared in the four provinces with policy makers and people with disabilities.

Results: Examples of heightened vulnerability are evident in discontinuity from formal healthcare providers with knowledge of conditions and impairments, separation from informal care providers and support systems, and lack of coordination with and gaps in disability-related supports. When policies seek to increase the dignity, autonomy, and capacity of all individuals, including those who experience heightened vulnerability, they can mitigate or lessen some of the vulnerability.

Significance of results: Specific policies addressing access to community-based palliative care, coordination between long-standing formal care providers and new care providers, and support and respect for informal care providers, can redress these heightened vulnerabilities. The interactions between disability and end-of-life policies can be used to create inclusive end-of-life policies, resulting in better end-of-life care for all people, including people with disabilities.

KEYWORDS: Palliative care policy, Disability policy, Heightened vulnerability, Coordination of care, Disability supports

INTRODUCTION

Experiences with disability and impairment teach much about a range of human experiences, including those at end of life. In this article we identify some of the key policy-related issues that shape the end-of-life experiences of people with disabilities in Canada. We argue that these issues illustrate two sides of policy impacts. When there is little consideration of or coordination between disability-related policies and palliative and end-of-life policies, people with disabilities can encounter heightened or intensified vulnerability as they face end of life. However, when these interactions are used as the basis to create inclusive end-of-life policies, the result is better end-of-life care for all people, including people with disabilities.

VULNERABILITY AND PALLIATIVE AND END-OF-LIFE CARE

Vulnerability—the possibility of harm to our bodies or our broader selves—shapes all of our lives and is a universal human condition. That universal experience of vulnerability may be especially evident at moments of significant change or illness in our bodies, in major

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life transitions, or changes to our cultural or personal relationships, including at end of life.

For some groups of people, those universal experiences of vulnerability are made more complex and difficult by experiences of exclusion or marginalization that directly and indirectly affect their access to and use of healthcare. Stienstra and Chochinov (2006) argue that this heightened vulnerability is a socially constructed experience. "Marginalization and heightened vulnerability, based on prejudice, bias or faulty assumptions, can find people who are disabled, poor, or disenfranchised further victimized by ever narrowing healthcare options" (Stienstra & Chochinov, 2006, p. 169). These attitudes are widespread and often seen as common sense. They may include the sentiment that it is better to be dead than disabled, as is portrayed in popular movies (Lutfiyya et al., 2009), or the practice of directing questions to the support person rather than to a person with disabilities. They permeate the cultural fabric of society and find their way into our policies and practices (Chochinov, 2007).

Marginalization often has a cascading effect on peoples' experiences of heightened vulnerability. There may be direct effects that shape interactions and care practices and can be addressed by education and increased knowledge and respect. For example, stereotypical attitudes of healthcare providers to groups of people such as the homeless, or those with communication barriers, which come from broader social or cultural values related to differences, may result in treatment or care practices that exclude or discriminate against these people. Assumptions about the relevance of differences may also shape decisions about treatment options. Again, as Chochinov (2007) suggests, these can be redressed by conscious attention to one's own assumptions and a deliberate attempt to ensure dignity and respect in care practices.

However, marginalization also has more subtle, indirect and systemic effects on experiences of heightened vulnerability, including at end of life. For example, in general, people with disabilities have lower employment and income levels than people without disabilities in Canada (Human Resources and Skills Development Canada, 2009). They also rely to a much larger extent on government income programs such as social assistance or Canada or Quebec Pension Plan. The prescription drugs they require to address their disability-related condition are not included in palliative drug care coverage where it exists in Canada. For those with degenerating conditions, their declining health trajectory and increased disability-related costs often lead to impoverishment. They face limited options for care as their need for complex physical care increases. To obtain the care they need, they may be required to live in long-term care settings, often inappropriate to their age group and with an increasing isolation from family and informal supports. In an institutional setting they are not able to continue to manage their own care workers directly, as they may have done in a community setting. Instead they have to rely on the institution to hire, manage, and direct their care. Each of these may heighten the vulnerability they experience. The changes may also diminish both their will and physical capacity to continue to live. They may require palliative care long before they are recognized to be at end of life, but may be deemed ineligible because they do not have an appropriate prognosis.

These more indirect and cascading effects are more difficult to address through education or altered care practices. Rather they require us to look both backward at who was and was not included in palliative and end-of-life care, and explore the gaps that exist. Evidence of heightened vulnerability among marginalized populations can be seen in differential usage and treatment patterns in palliative and end-of-life care (Greiner et al., 2003; Crawley, 2005; Stienstra & Wiebe, 2006; Cohen, 2008; Johnson et al., 2008). "This process [of creating and valuing difference] then uses these differences to establish or explain variations in services, policies or treatment, which, in turn, lead to heightened vulnerability for those whose differences are devalued or understood to be outside the norm. As marginalization increases, curative options tend to be sacrificed earlier; this can segue to palliative or comfort measures consideration" (Stienstra & Chochinov, 2006, p. 169).

It also requires proactive identification of gaps or alternative approaches in care and policies from the viewpoint of those who experience marginalization. For example, developing relationships with those who work most closely with homeless people in shelters as well as with people who are homeless may identify models for delivering palliative care to this population, who are often excluded from mainstream models of palliative care.

Within an understanding of vulnerability as both universal and constant, we recognize that society cannot eradicate vulnerability, but can "and does mediate, compensate, and lessen our vulnerability through programs, institutions and structures" (Fineman, 2008, p. 10), including public services. Fineman and others (Kroes et al., 2009) argue that governments have the responsibility to provide equal access to resources and opportunities in order to enhance resilience. Equality has often been interpreted in policy to mean providing the same treatment to everyone. However, as we recognize that people have different circumstances and that there are systemic inequalities in our societies, we also recognize that equality may require differential treatment to redress these inequalities. In palliative and end-of-life care, this moves to recognition that there are different paths to palliative care, often shaped by circumstances experienced throughout life.

For those who experience heightened vulnerability, the challenge is to identify the ways in which their vulnerability is heightened at end of life, including through policies and care practices. Once these become evident, they can be addressed. Often the changes required will illustrate policies and practices that will benefit many more than the original populations who had been marginalized. For example, in cancer care, when addressing the needs of people with disabilities, providers suggested the changes would benefit all cancer patients (Annable et al., 2010, p. 48).

In this article, we illustrate the impacts that policy assumptions and practices have for people with disabilities at end of life, which heighten vulnerability and undermine their access to healthcare. We demonstrate that when policies seek to increase the dignity, autonomy, and capacity of all individuals, including those who experience heightened vulnerability, they can mitigate or lessen some of the vulnerability.

METHOD

This article draws its analysis from qualitative research and policy analysis conducted from 2005 to 2007 through the policy theme of the Vulnerable Persons and End of Life Care New Emerging Team (VP-NET) based at the University of Manitoba in partnership with the Council of Canadians with Disabilities (CCD). In the summer and fall of 2005, the project undertook 20 key informant interviews with individuals with responsibility for palliative care policies and disability-related policies in the Canadian federal government, and the provincial governments of Alberta, Manitoba, Ontario, and Newfoundland. The four provinces were chosen because they had both palliative care programs and disability programs although the type of each ranged from well-developed programs to modest initiatives. In addition, all four had established networks of people with disabilities. The project collected and analyzed the literature and relevant policies in each of these jurisdictions and developed a policy backgrounder on palliative and end-of-life care policies and people with disabilities for each jurisdiction. Updates of these were developed in 2010. Four areas of policy were addressed: decision making, service provision, symptom management, and informal caregivers.

Member groups of the CCD and local independent living centers organized focus groups in each of the jurisdictions to discuss and identify key issues for people with disabilities in accessing and using palliative and end-of-life care. Between 12 and 15 participants were selected in each of four centers (Edmonton, Winnipeg, Ottawa, and St. John's). Selection criteria ensured a gender balance, inclusion of a range of conditions and impairments, including people who lived with deteriorating conditions and communications barriers, and a diversity in terms of age, and, where possible, rural and urban locations. In total, 48 people with disabilities participated in the focus groups. All had experienced end-of-life care or expected to be experiencing it in the very near future. Some had been diagnosed with conditions such as amyotrophic lateral sclerosis (ALS); therefore, their life expectancy was limited. Others had participated as informal support or care providers to family members at end of life. Participants received the policy backgrounder, a consent form, and the focus group questions prior to the focus group. The focus groups were facilitated by Jim Derksen, who participated in the research team as the representative of CCD. Deborah Stienstra acted as a resource person in the focus groups. Recordings of the focus groups were transcribed and analyzed using key theme analysis.

In April and May 2007, the researchers returned to the four cities to report on the research findings. CCD members groups and an independent living center organized these community forums, where Deborah Stienstra, Jim Derksen, and April D'Aubin, a student research assistant, shared both the findings of the research and five knowledge mobilization flyers, which highlighted key outcomes of the research and suggested possible public policy advocacy strategies that local/provincial groups might want to consider. Researcher notes, from the perspective of participant observers, were taken at these forums and included in this analysis.

HEIGHTENED VULNERABILITY FOR PEOPLE WITH DISABILITIES

Does having a disability mean greater vulnerability in palliative and end-of-life care? The earlier argument about vulnerability suggests that everyone is vulnerable, including at end of life, and that the heightened vulnerability people with disabilities experience may be the result of attitudes, bias, and assumptions that find their way into society's fabric, policies, and care practices.

During the focus groups, participants explored whether there was heightened vulnerability among people with disabilities at end of life. They suggested that having a disability does not necessarily mean that one experiences heightened vulnerability.

People with disabilities have strengths (i.e., attitude, capabilities, knowledge, self-empowerment) and encounter barriers. These barriers, including attitudes or assumptions that marginalize them, physical obstacles that limit their access to services, and lack of knowledge about the trajectory of the end-of-life phase for people with disabilities, may heighten their vulnerability.

Some people with disabilities are perceived as not capable of making decisions throughout their lives. They anticipate that their experiences of marginalization and disempowerment in decision making throughout their lives will be repeated in their end-of-life care. One focus group participant spoke about her fear about end-of-life care.

> A lot of us with disabilities can think for ourselves, can act for ourselves, can make decisions for ourselves, but we're not always validated because of our disability. When we speak about funding because of our disability, we considered not intelligent enough to make decisions . . . For a few years I've had this inner fear about what will happen to my latter days, towards my death . . . I feel we're powerless somehow.

Attitudes about or discomfort with disability among healthcare providers may create barriers in end-of-life care. Making other people comfortable with disability or conditions can be a necessary component of getting services attended to in a manner that it is consistent with one's needs. Doing this when medically stable may become a regular part of life for those living with a disability; however, undertaking these negotiations when their condition is deteriorating may become more difficult. Also with changes to one's condition there may be a need for new negotiations. As one focus group participant noted:

> It doesn't matter whether you're deaf or if you have a mental illness; it's the attitude of the people that you have to cope with. This I find frightening, because I think of myself, and I wonder how I'm going to handle it at the end of life.

Another focus group participant noted that it is the presumption or label of vulnerability that leads to other assumptions about competence or the role of family members in care.

> You are seen as vulnerable and you don't even know it . . . if you are seen as part of a vulnerable population to begin with when you're discussing palliative care, end of life issue, a lot of times if you have a disability then [it is assumed] you must be cognitively impaired too, and, it's an assumption that if you have a disability then maybe we should be discussing things with your parents. I'm thirty-seven years old.

For some people with disabilities communications present a significant barrier in any healthcare setting, including at end of life. Access to sign language interpretation while in a palliative care ward or hospice may not be available as required and provide a barrier for those who are deaf or hard-of-hearing. This is a similar concern to those for whom English or French is not their primary language of communication. One focus group participant in Edmonton outlined some of the barriers people can face at end of life.

> If you have a disability and you need palliative care but you speak a different language, are there people to help you to communicate in your language. It seems to me we don't have those services readily available. Also, do we have signing in palliative care? It makes me wonder if funds would be available for someone to come and sign so that the person could communicate at that important time of their life.

For others, physical barriers limit access to palliative and end-of-life care, including lack of ramps or of accessible access through delivery or “back door” entrances rather front doors, narrow doorways, cluttered hallways, or way-finding signs that are not suitable for those with low or no vision. Each of these barriers can restrict access to palliative and end-of-life care and may play a role in differential patterns of usage in palliative care.

A lack of medical knowledge about the progression of certain disabilities at end of life may create barriers unique to people with disabilities. This may lead to assumptions about the futility of treatment or a lack of attention to the need for palliative care. One key informant in the area of disability programs shared her account of treatment that failed to address her unique situation and could have led to her death without the intervention of her advocates.

> Three years ago I had respiratory arrest which caused my heart to stop. I was resuscitated by the paramedics and brought to the hospital. At the hospital they had given me four hours on the machine [ventilator] and they said then they were going to disconnect me because they figured that would be the chance that they would give me . . . Four hours, yes, four hours. My mom and dad were there. . .and my mom kept insisting that their testing would not register the same with me because I had polio, so part of my body was paralyzed so I wouldn't react the same to the tests.

> They argued and there was no way, this is just the way it is. I'm sure they looked at the size of me—I weigh all of 55 pounds—and figured I had already suffered so much, which is a clinical classical way of the general population to think of someone, right?
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> So, my boss was called . . . My mom and dad told my boss, 'They want to unplug her because she is not reacting the same way that they anticipate she should," and he contacted our lawyer . . . and the lawyer sent a letter saying that my parents had the authority to make this decision and they wanted it [treatment] to be continued. So they [the doctors] extended it to eight hours. They had extended it before they got the letter, and after they got the letter they took off the "Do Not Resuscitate" order.
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> . . . so they made all these assumptions, which I'm sure they would normally make for everyone, but not knowing my condition, not knowing anything about me, they could have made some very critical errors, because three years later I am working full-time, I have an apartment, I'm living my life.

Each of these barriers that people with disabilities experience in end of life care—attitudes and assumptions, physical barriers and lack of knowledge directly affect individuals and their care or support relationships and can be addressed through education and more inclusive and respectful care practices.

INDIRECT AND CASCADING EFFECTS OF MARGINALIZATION

Differences in access to and usage of palliative care among people with disabilities may also come from more subtle or indirect effects of marginalization. Research participants suggested that these cumulating or cascading vulnerabilities included discontinuity from formal healthcare providers with knowledge of conditions and impairments, separation from informal care providers and support systems, and lack of coordination with and gaps in disability-related supports. They also noted that in institutional settings without appropriate knowledge related to the condition or impairment, formal care providers may not recognize changes in a trajectory that indicate the need for palliative care.

Discontinuity in Formal Care Provision

Once in an institutional health setting, patients may be cut off from family physicians familiar with their condition, home care providers and other service providers. This is a concern for all people, but presents significant challenges for people with disabilities who have had to educate and work with their care providers in relation to their disability (McColl et al., 2005; Lutfiyya & Schwartz, 2010; Annable et al., 2010).

A participant at the Edmonton focus group of people with disabilities indicated that, when a person goes into an extended care facility in Alberta, that person is under the care of the facility's doctor and not the individual's primary care doctor.

> I don't know about other provinces, but here in Alberta, when elderly people go into long-term care facilities, their family doctors cease to be involved. Each of the facilities has its own doctor on call which means that when participants are nearing the end of their lives, they're under the medical care of total strangers. Staff turnovers are significant, as are the shift rotations, so even the caregivers to whom the patients are exposed on a daily basis are often virtual strangers. Those who have caring families near at hand are fortunate but there are many who have no one at all to advocate for them.

In Manitoba, entering a long-term care facility also eliminates eligibility for community-based programs such as home care. This can bring an end to some long-term and important relationships that have developed in the life of a person with a disability. As a result, the individual has to develop a level of comfort with new service providers at a time when that individual may be facing a variety of difficult transitions. One key informant from the government identified some of the challenges associated with these transitions.

> If you're on home care in the community and you have a team of staff that support you either through the regular part or if you're on self-management, you hire your own, but the minute you go into an institutional setting you're not allowed to be on the program anymore and so if you had a staff that you're very comfortable with that know your needs and understand you and you work well with them, and then you go into an institution, basically they're taken away from you. So that certainly would have an impact on somebody who is near the end of life stage . . . Suddenly you all of a sudden have to deal with a whole bunch of staff you're not familiar with. If you want to bring the staff you worked with for years maybe, into the institution, you can't . . . Once you start losing all the supports you had in the community, it's got to have an effect on you, your will to live even for that matter.

For some people with disabilities, the relationship with long-term attendant care staff/service providers may be among their most significant relationships and the loss of these relationships is particularly difficult.

Dislocation from Informal Care Providers and Support Systems

Many people with disabilities rely on and contribute to webs of social, emotional and other supports among their peers and in their communities. For some, these include spousal and other family relationships. However, when people with disabilities face moving into an institutionalized care setting or end-of-life care outside of their own homes, they can become dislocated from these informal networks. (Lutfiyya & Schwartz, 2010) Research participants noted the social isolation that occurs for younger people with disabilities when they move into care settings targeted to seniors. They also raised concerns that eligibility for receiving palliative care and/or disability supports that may be based on family income in some provinces may disrupt family relationships.

One Edmonton focus group participant expressed concern that she would face end of life alone without family or an advocate assisting her. She expressed concern about being predeceased by friends and parents and being at the end-of-life stage without anyone who understood intimately her personal needs.

> [My concern] would be that I would be alone, that I would be left alone, or that there would be nobody there if my friends died before me, or they're not able to help. My parents are older and they won't be there, who will be there. Who will advocate? I'm okay to advocate for myself right now but who knows what shape I will be in, whatever the other issues are, you know, that there won't be somebody advocating or somebody speaking on my behalf or hearing what I need to say or that understands me or whatever shape I'm in.

Participants in focus groups had found themselves ineligible for funding and benefits because of program criteria, including family income level. In St. John's one focus group participant was told his family income would affect his eligibility for financial assistance related to his recently diagnosed deteriorating condition.

> The social worker said, "You probably won't qualify for any kind of financial subsidy because your wife is working." And I'm saying well that's great news when we're facing you know all this money [expenses related to the condition] and again I've really at this stage don't know where I'm going or what's going to become of us, so yeah I feel a little vulnerable at the prospects, very vulnerable.

A St. John's focus group participant said that some people with disabilities worry that their end of life costs will bankrupt the families. Some people at end of life even consider divorcing their partners to protect the family assets.

> What do we do? Do you divorce from your wife or from your husband, to get what it is that you need, so that you don't lose everything in the process? I mean, think about it; we're all going to pass away. What do we do to our families? Be separated from them just so that they at least have something when we're gone? I know a divorce would probably only be on paper, but isn't it ridiculous if it has to come to that? We have to lose the loved ones we love so much.

For those who enter institutionalized care settings, there are multiple forms of dislocation and isolation in addition to leaving one's community and neighbourhood. One focus group participant in Edmonton describes the isolation of someone who lives in a long-term care facility, cannot afford to pay for additional support or care in order to participate in activities outside the facility and uses a respirator.

> She has outlived what they thought she'd live, she's thirty-six years old. She can't leave the facility because there is nobody to take her out who knows how to look after the respirator in case something happens. Those who do know how to help her with the respirator are those she can't afford to pay as she lives on an income support program which gives her a very limited amount of money each month. Therefore, she can't get out of the facility; she doesn't have the quality of life that she wishes to have because her activities are limited to the facility. She is not at the end of her life, but then when do you become at end of life?

Another form of isolation comes when younger people are isolated from their peers and placed in living situations with people who are older and in a more serious condition. This concern was raised in different localities and also illustrates links between housing and palliative care.

> I was in a hospital in the city for a year and was in a wing or a room with a lot older individuals than myself. At the time I would have been about 35, 40 years old. The closest age man that was ever

> in my room was 80-something. They were dying around me daily, literally, and I was there for a year. It got to the point I closed off the curtain, and if I was in my room I was hidden behind that curtain or I was never in that room and I was hanging anywhere but that floor . . . I was literally working my way up to a nervous breakdown, because of all these people dying around me, but they [the staff] didn't give a darn. They didn't talk to me about it. They didn't even get the message when I closed off my curtain and hid in my little cubicle. They didn't get the message that there's something wrong.

A participant in a focus group in a different city stated,

> If you're 36 years old and you're put in a situation where you're in a long term facility with 80 and 90 year olds, you don't have anybody your own age to interact with, to communicate with. To me that's a serious issue that—whether she's at end of life or not, or whether she's in a stage where she needs that level of care—she should be in a facility where she can get the care she needs, but where there are other people her own age that she can interact with and get some good, to develop some friendships . . . Maybe she doesn't want to play bridge, you know? Maybe she doesn't want to do what the seniors are doing. Maybe she wants to sit and listen to loud rock music with some friends her own age. I think that that's one of the big problems that we find in service provision: we're not looking at the person and what their needs are in the area of emotional, recreational, psychological. We're looking at physically this is where we can give them their physical needs. Well, maybe she has other needs that aren't just physical.

These cascading effects of marginalization—reduced care options, decreased or limited income, and physical and social isolation—all heighten the vulnerability experienced by people with disabilities. They may have the additional effect of eroding the physical and psychological will to live and precipitating a premature end of life.

Lack of Coordination with and Gaps in Disability-Related Supports

Access to disability support programs such as technical aids and devices can be limited when a person with disabilities moves into an institutional setting such as a hospital at end of life. In some jurisdictions, disability supports programs, including the provision of wheelchairs, were only for those living outside of institutional settings. Once inside a hospital or long-term care institution, providing supports was the responsibility of the institution. A government key informant outlined Manitoba's policies.

> If you live in the community in Manitoba, you have the right to have a wheelchair provided to you free of cost through a program, but if you live in an institution you're not allowed to have a chair through the program, so that's an issue.

Coordination of services is also an issue in the transition from home to palliative care. Generally, to be admitted to an end-of-life or palliative care program a person needs to be referred from some part of the heath system. In some areas, training is being done to improve referral skills for palliative care/end-of-life care. A palliative care key informant stated

> Generally if the referral is initiated by his physician, that comes to us and we take care of everything at that time: the transition, different Home Care structure. Home Care, they can make the referral too. We're continuing to work with Home Care to educate them about when someone might be appropriate for palliative care. We've got a ways to go. Some are very good, some aren't, especially on the non-malignant diseases. As a matter of fact we do regional education sessions every year. Last year it was focused on direct providers. This year we're looking at managers and hospitals and Home Care coordinators and that group, the decision-makers.

Unusual Trajectories at End of Life

During transitions related to disability and to end of life, given the criteria that access to most palliative care is based on prognosis, it is important to know when a person is near the end of their life. A service provider key informant indicated that palliative care has not developed expertise with respect to the end-of-life trajectories for some specific disabilities.

> I think there's this belief that you can't know, so you don't even try to give these people palliative care, and so we are gradually making some inroads in this area, not enough, but I think this will help. The other population with few inroads is the ALS population, we've built a bit of a relationship there. . . Another service provider key informant illustrated the impact that nontraditional paths to palliative care have for the patient and family member's abilities to identify and advocate for resources.
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> As hospice/palliative care focuses on those who are dying, one of its challenges is to be able to identify

> that population. Cancer is disproportionately represented as a diagnosis amongst hospice/palliative care patients at least in part due to a more readily identifiable palliative phase, in comparison with progressive chronic illnesses such as Alzheimer's disease, COPD, and chronic cardiac conditions. In addition, the general public (including those living with illness) more readily identify cancer as an illness which is commonly fatal, and will therefore be in a position to advocate for services/resources to address palliative needs. In contrast, people tend to look upon dementia, COPD, CHF as chronic and potentially debilitating conditions, but not necessarily with the same potential for dying as cancer. This compromises their ability to pursue resources such as hospice/palliative care for themselves or others.

Focus group participants described situations in which healthcare providers lacked familiarity with the atypical (non-cancer) trajectories of some people with disabilities.

> [Person named] died of MS about a year and a half ago. Well he died of whatever it was, I don't honestly know what killed him, but I said after he died, 'Don't you think he was actually in need of palliation prior to this five days where he actually had a steep decline and a noticeable change?' The nurses all said, 'Oh no, we didn't think he was close to death.' I said, 'But you know how you treated him—the stuff you gave him, the care you gave him—were all evidence to me that he was in need of palliative care. You weren't acknowledging that because you didn't know when the end would come until this five day crisis period, when he was in the hospital, that you knew the balance tipped.

The heightened vulnerability that people with disabilities experience as a result of societal and individual attitudes and assumptions about disability may lead to a spiral of cumulating vulnerabilities. These are increased openings for harm for the individuals, including in end-of-life care.

ADDRESSING CUMULATING VULNERABILITIES THROUGH POLICY MEASURES

As we noted earlier, although policies and programs cannot remove the universal condition of vulnerability shared by all humans, they can be used to mediate or reduce the spiral of cumulating vulnerabilities experienced by particular groups of people who have been marginalized. One of the most important policy remedies to address heightened vulnerability is to find ways to increase the dignity, autonomy and capacity of the person who experiences heightened vulnerability. In this section we identify some policy measures that can be used to address the culminating vulnerabilities experienced by people with disabilities at end of life.

Location

As with most Canadians (Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology, 2000), people with disabilities prefer to choose where they die. Many prefer to remain in the community-based setting they consider home, whether that is an independent living housing arrangement; their own house, condo or apartment; or a home with others (Stienstra & Wiebe, 2006). Their hope is to retain the existing disability-related supports they have in that setting and add community or home-based palliative care.

Palliative care that can be delivered in homes, in coordination with existing home care or other supports, can support this choice. One of the challenges for this policy initiative is when a person with disabilities must be in an institutional setting to receive palliative care. A common assumption is that a person who uses a ventilator cannot receive palliative care at home. However, one service provider in our research suggested a different perspective.

> Another patient who had ALS who was on a ventilator at home—now one would think being on life support at home is quite contrary to palliative care—but his goals were that 'I want to stay at home as long as possible but I also want to define the parameters under which I want this withdrawn' . . . we actually withdrew him at home. I think he was the first and, so far in Winnipeg, the only ventilated patient to be withdrawn at home . . .

Community-based palliative care can be more complicated for people who live in transitional housing such as hotels or rooming houses. Those housing arrangements may be linked to living in poverty or other situations of marginalization in society. The interlocking situations of disability, poverty, and inadequate or transitional housing may affect access to palliative care. Stienstra and Wiebe (2006) suggest that half of the research participants in their study of people with disabilities in inner-city Winnipeg had died by the time the work was completed, but not one of those was involved in any hospice or palliative care program (p. 26). Community-based palliative care may be difficult to provide to people who are in unsafe housing or who are transient or homeless.

The policy solution to address location is multifaceted. Stienstra and Wiebe (2006) suggest that one solution is fully accessible, freestanding hospices in all parts of a city, including downtown areas (p. 71). Physical audits of hospice and palliative care units for universal accessibility will identify particular barriers that can then be remedied.

Also, there continue to be insufficient accessible, affordable housing options for people with disabilities in Canada. As a result, many people with disabilities end up in long-term care institutions or transitional housing without access to palliative care. One solution over the longer term is to create more accessible, affordable housing stock, which enables people with disabilities to leave institutional and transitional housing. In turn, this may enable their access to community-based palliative care services at end-of-life. Finally, any palliative care needs to be coordinated with existing and sufficient disability-related supports.

Coordinated Care

As we noted earlier, one of the transitions for people with disabilities at end-of-life is the adaptation to new care or service providers. This discontinuity in formal care provision by a family physician as well as by community-based home care service providers at end of life can be mitigated by transitioning and coordinating formal care providers. Involving family physicians and home care providers in the initial determination of palliative care plans will ensure better coordination and less disruption between home and the new setting. For example, when a person enters or is recognized as being at end of life and makes a transition to an institutional setting whether it is palliative, acute, or intensive care, coordination between the person's primary care physician and the new care team is critical. The primary care physician could brief the institutional care providers on the person's longer-term conditions and trajectory to date. Home care providers could describe the care routines and practices they follow, to the new care providers.

Another critical way to ease end-of-life transitions is to ensure that the person with disabilities or that person's designated support/advocacy person is involved in determining palliative care plans. Many people with disabilities have managed and directed their own care for many years and know how they like to receive care. It is important for the new care providers to recognize and respect these skills and ask how the person would like to be treated or if that person has a preference for care practices. In addition, training for palliative care staff in the goals and values of self-managed care from an independent living perspective would be useful (Wiebe et al., 2009) This type of education would be useful for physicians, nurses, nursing aides, and other staff who provide end-of-life care.

At the provincial government level, coordination is needed between disability-related supports programs and long-term and palliative care programs. An initial review is needed of the eligibility requirements for disability-related supports and provision of these supports during transitions to both long-term and palliative care. If gaps are identified, and our research suggests these gaps exist in long-term care and may exist in some jurisdictions in palliative care, further policy development will be needed to address these.

Informal Care and Support

Support for many people with disabilities comes from sources outside their biological family and in relationships outside the "norm." For example, people who have been institutionalized early in life may have only fragile relationships with their biological families. Instead they may rely on paid support providers as part of their decision making or other support. These paid workers may also provide more informal supports as the relationships deepen. When people with disabilities, and all patients, enter care settings, it is crucial to understand whom they identify as their chief sources of support and who will advocate on their behalf if they are unable to indicate their wishes. Despite common perceptions that people with disabilities are exclusively recipients of care, Fawcett (2009) suggests that men and women with disabilities are significant care providers, especially to relatives, friends, and neighbours.

Disabled people face attitudinal barriers when they act as informal care providers. One focus group participant described her work as a care provider.

> I'm in a position with my mother where she's dealing with a lot of medical issues right now. She's in the hospital. I'm attempting to act as her advocate, but because of my disability, my communication [significant difficulty communicating using verbal speech], I'm not able to do all the things that I want to do. So the medical people are not paying the same kind of attention to what I'm saying, as they would to my able-bodied brother. There should be some training for medical people on how to deal with advocates who are disabled.

To address the attitudinal barriers, education is often the most effective solution, whether education of one's self by reflecting on personally-held assumptions and how they may affect one's interactions with others (Chochinov, 2007), or more formal education (Wiebe et al., 2009).

In addition, informal care providers are an essential part of determining care plans. In the cases of people whose informal support providers are not family members, but may include paid support workers, some flexibility will be needed to include them in the care unit.

Given the prevalence of people with disabilities, especially women with disabilities, among care providers, more consideration is needed of supports for this work (Fawcett, 2009) As well, some analysis needs to be developed of the implications of care providing for disabled care providers on their income and access to special Employment Insurance benefits, including compassionate care benefits.

CONCLUSIONS

All humans experience vulnerability, and some people, including people with disabilities, experience heightened and cumulating vulnerabilities as a result of attitudes, assumptions, and practices that marginalize them. When we recognize these vulnerabilities and their effects on people in our policies and care practices, we can change policies to mitigate the harm.

This research suggests that ensuring that people with disabilities have access to community-based palliative care, that there is coordination between long-standing formal care providers and new care providers, and that there is support and respect for informal care providers, all will help to alleviate some of the heightened vulnerabilities experienced.

Implementing these measures is not simply good policy for people with disabilities at end of life. Coordination and flexibility in policies as well as respect for dignity and autonomy in care practices will benefit all of those who are vulnerable, indeed all facing end of life, and by doing so, create more inclusive palliative and end-of-life care.

REFERENCES

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

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.

Cohen, L.L. (2008). Racial/ethnic disparities in hospice care: A systematic review. *Journal of Palliative Medicine*, *11*, 763–768.

Crawley, L.M. (2005). Racial, cultural, and ethnic factors influencing end-of-life care. *Journal of Palliative Medicine*, *8*, 58–69.

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

Fineman, M.A. (2008). The vulnerable subject: Anchoring equality in the human condition. *Yale Journal of Law and Feminism*, *20*, 1–23.

Greiner, K.A., Perera, S. & Ahluwalia, J.S. (2003). Hospice usage by minorities in the last year of life: Results from the National Mortality Follow Back Survey. *Journal of the American Geriatrics Society*, *51*, 970–978.

Human Resources and Skills Development Canada (HRSDC). (2009). *Advancing the Inclusion of People with Disabilities: 2009 Federal Disability Report*. Ottawa: HRSDC.

Johnson, K.S., Kuchibhatla, M. & Tulsky, J.A. (2008). What explains racial differences in the use of advance directives and attitudes toward hospice care? *Journal of American Geriatrics Society*, *56*, 1953–1958.

Kroes, G., Watling, J. & Policy Research Institute. (2009). *Healthy Transitions to Adulthood: Moving to Integrated Mental Health Care: A Workshop Report*. Ottawa: Policy Research Institute, Government of Canada.

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 (eds.). Washington, DC: American Association on Intellectual and Developmental Disabilities.

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 (ed.), Baltimore: Johns Hopkins University Press.

McColl, M.A., Stienstra, D., Shortt, S.E., et al. (2005). *Reducing Inequities in Access to Primary Care for People with Disabilities*. Final Report to Canadian Institutes for Health Research. Kingston, ON: Queen's University.

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.

Wiebe, R., Stewart, G., Kaufert, J., et al. (2009). *"Introducing Medical Students to Perspectives on Independent Living and the Experiences of Persons with Disabilities."* Poster Presentation, Canadian Conference of Medical Educators, Edmonton, May 3–4, 2009.