Palliative and Supportive Care (2013), **11**, 123–133.

doi:10.1017/S1478951512000806

Making "ethical safe space" in the translation of contested knowledge: The role of community debate in defining end-of-life decision ethics

JOSEPH KAUFERT, PH.D.,[1] KAREN SCHWARTZ, PH.D,[2] RHONDA WIEBE, B.A., B.CH.MUS.,[3]
JIM DERKSEN, D. LAW (HON.),[3] ZANA M. LUTFIYYA, PH.D.,[4] AND DEAN RICHERT, M.A., L.L.B.[3]
[1]Department of Community Health Sciences, Faculty of Medicine, University of Manitoba, Winnipeg, Canada
[2]Canadian Centre on Disability Studies, Winnipeg, Canada
[3]Council of Canadians with Disabilities, Winnipeg, Canada
[4]Department of Educational Administration, Foundations and Psychology, Faculty of Education, University of Manitoba, Winnipeg, Canada

(RECEIVED September 19, 2011; ACCEPTED October 27, 2011)

ABSTRACT

Objective: The objectives of this article are, first, to document a unique process of research knowledge translation (KT), which the authors describe as the creation of "ethical safe space," and, second, to document the narratives of forum participants and describe their interaction in a dialogue about vulnerability, the authority of physicians, and the perspective of people with disabilities on the policy.

Method: Narrative data from qualitative interviews with individual key informants and focus groups were used to identify speakers with specific expertise on policy, disability perspectives, and bioethical issues, who were invited to participate in the Forum on Ethical Safe Space. The planning workgroup adopted a model for enabling representative participation in the public forum designed to reduce the impact of physical, sensory, financial, language, and professional status barriers. Using the transcripts and keynote speakers' printed texts, primary themes and patterns of interaction were identified reflecting the alternative perspectives. Through the development of a workshop on ethical, legal, and disability-related implications of professional policy guidelines developed by the College of Physicians and Surgeons of Manitoba, we provided a qualitative analysis of the discourse involving experts and disability community members supporting alternative positions on the impact of the policy statement, and discuss ethical, legal, and disability rights issues identified in the public debate.

Results: Contested policy and ethical frameworks for making decisions about withdrawing and withholding life supporting treatment may influence both the perspectives of palliative care providers and patients referred to palliative care facilities. An innovative model for KT using a public forum that enabled stakeholders with conflicting perspectives to engage with ethical and professional policy issues asserting the physician's authority in contested decisions involving withdrawing or withholding life-supporting treatment, was a successful way to engage stakeholders supporting alternative positions on the impact of the policy statement and to discuss ethical, legal, and disability rights issues identified in the public debate.

Significance of results: Discussion during the forum revealed several benefits of creating ethical safe space. This model of workshop allows space for participation of stakeholders, who might not otherwise be able to interact in the same forum, to articulate their perspectives and debate with other presenters and audience members. Participants at the forum spoke of the creation of ethical safe space as a starting point for more dialogue on the issues raised by the

---

Address correspondence and reprint requests to: Joseph Kaufert, Department of Community Health Sciences, Faculty of Medicine, S113C Medical Services Bldg, University of Manitoba, 750 Bannatyne Ave., Winnipeg, MB. R3E 0W3 Canada. E-mail: kaufertj@cc.umanitoba.ca

policy statement. The forum was, therefore, seen as a potential starting point for building conversation that would facilitate revising the policy with broader consultation on its legal and ethical validity.

KEYWORDS: Ethical safe space, KT, treatment policy

INTRODUCTION

The intent of this article is twofold. The first purpose is to document a unique process of research knowledge translation (KT) (Rogers & Martin, 2009; Straus et al., 2009), which the authors describe as the creation of "ethical safe space" (Ermine, 2007). The second purpose of this article is to document the narratives of forum participants and describe their interaction in a dialogue about vulnerability, the authority of physicians, and the perspective of people with disabilities on the policy (Newell, 2006). The research program that formed the basis for this KT forum was focused on ethical issues and professional policy guidelines that had an impact on decisions about end-of- life care for persons with disabilities. The research was conducted by investigators focusing on ethical issues as part of the wider Vulnerable Persons New Emerging Team Grant (VP-Net) (Stienstra & Chochinov, 2006). The initial goal of the ethics theme research was to collectively build an interdisciplinary framework for understanding the ethical context of decision making from the perspectives of people with longstanding disabilities and chronic illness, and of the elderly who experience barriers in accessing services, information, and community supports. The "Ethical Safe Space" component within the cross-thematic collaboration has focused on ethical dimensions of decision making, and the experiences of people with disabilities, professional care providers, family members, and others who facilitate decisions. The researchers identified diverse, and sometimes conflicting, values and frameworks for advance care decisions (Derksen & Chochinov, 2006).

The research program documented the perspectives of stakeholders and spokespersons for advocacy groups, who asserted diverse and often opposing perspectives on the validity and impact of a policy statement asserting physicians' authority in contested decisions involving withholding or withdrawing life-sustaining treatment.

The 1 day Forum on Ethical Safe Space was planned to provide a safe, inclusive, and accessible forum that brought together a spectrum of individual stakeholders, experts, and representatives of disability organizations to articulate their perspectives on contested policy and contextual issues in ethical treatment of persons with disabilities within a public form that facilitated debate in a safe and enabling environment. The goals were to present a balanced spectrum of perspectives, identify areas of disagreement, and establish areas for potential collaboration in developing more flexible and mutually empowered models for shared end-of- life decision making and mediation in conflict situations. Forum topics selected by the planning work group included: (1) ethical issues in decision making at the end of life, (2) an overview of pan-Canadian case law and related ethical and legal issues impacting end-of-life treatment choice (Sawatzky v. Riverview Health Centre Inc., 1998), and (3) a national overview of provincial health policies defining decision criteria for initiating or withdrawing life-sustaining medical treatments.

Participant narratives were recorded for both designated speakers and discussants in the mediated open forum. These narratives are analyzed to engage contemporary issues in end-of-life decision ethics, and to identify alternative models for mediation involving decision makers with conflicting perspectives. A secondary goal was to elicit from participants proposals for developing more participatory models of end-of-life decision making. This article documents the impacts of using a community forum to define ethical safe space for translating knowledge that is contested by multiple stakeholder communities.

CONFLICTING PERSPECTIVES IN MANITOBA ON WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING TREATMENTS

The policy document that provided the center of the debate at the public forum, is a policy statement developed by the College of Physicians and Surgeons of Manitoba, which asserts the authority of the physician in situations involving contested decisions to initiate or discontinue life-sustaining treatment (College of Physicians and Surgeons of Manitoba, 2008). The law in Canada today has clearly established the principle that a patient has the right to refuse or discontinue medical treatment, notwithstanding that a physician may believe treatment ought to be given or continued (Rodriguez, 1993). However, the law is much less clear on the issue of whether a physician has the right to unilaterally refuse to treat a patient, notwithstanding the wishes of either the patient or his or her family (Golubchuk v. Salvation Army Grace General Hospital and others, 2008). This ambiguity has been particularly visible in Manitoba case law, and continues in the application of the policy statement (Child and Family Services of Manitoba v. R.L., 1997).

In 2008, a revised draft of the policy statement was released by the College of Physicians and Surgeons of Manitoba on withholding and withdrawing life-sustaining treatment. This statement was intended to define a process and set standards and guidelines for physicians to ensure consistency and transparency in making end-of-life treatment decisions. Two particular aspects of the policy statement were at the center of the policy debate. First, the policy asserts that in contested decisions physicians may unilaterally withhold or withdraw treatment if they do not believe the "minimum goals" of life-sustaining treatment can be met. In the policy statement, the minimum goal of such treatment is defined in terms of the patient's capacity for (1) self-awareness, (2) awareness of their own environment, and (3) ability to experience their own existence. The criteria for eligibility for life-supporting treatment defined in the policy statement raised significant objections from both medical legal/bioethics experts and individuals and organizations representing the perspectives of people living with a wide spectrum of disabilities and chronic illnesses in the media and in law and bioethics literature (Downie, 2008a; 2008b; Webster, 2008).

The development and distribution of the initial draft was of the statement criticized by some members of the bioethics/law and disability communities as having been accomplished with very limited public consultation. The subsequent release of the final draft created an even greater public reaction, particularly because the policy was interpreted by some stakeholders as devaluing participation of acutely ill persons and their families in contested treatment decisions.

The impact of the policy in asserting the authority of the physician in decisions about treatment versus non-treatment immediately identified conflicting interpretations of care recipients and attending physicians' interpretations of the person's current and future "quality of life," assessment of the efficacy or "futility" of specific treatment interventions, and risks of unilateral adoption of the statement's definition of "minimal goals" for treatment.

To develop a public forum that would allow both elaboration of the criteria and process defined by the policy statement and, simultaneously, provide space for a critical analysis by experts and community stakeholders, the planners needed to identify new ways of bringing the perspectives of both physicians, medical legal experts and people with disabilities into a public KT process. Our approach involved development and evaluation of an accessible public workshop offering balanced representation to a wide spectrum of stakeholders within a cultural context of "ethical safe space."

ETHICAL SAFE SPACE

A key focus of the forum as a model for translation of contested knowledge was the adoption of the concept of "ethical space," which Ermine developed to create "the analogy of space between two entities. . .initially conceptualized by the unwavering construction of difference and diversity between human communities" (Ermine, 2007, p. 194). Ermine (2007) used the idea of ethical space as a framework to encourage the reconciliation of different world views. This space is described as a "meeting place" or "venue" to "engage" or to "step out of our allegiances, to detach from the cages of our mental worlds and to assume a position where human-to-human dialogue can occur" (Ermine, 2007, p. 202), moving to what Ermine describes as a "partnership model" (Ermine, 2007, p. 203) to create new ways of thinking. The experience of developing and documenting the impacts of a public forum framed as ethical safe space is the focus of this article.

DISABILITY STUDIES PERSPECTIVES ON THE ETHICS OF END-OF-LIFE DECISION MAKING

Although the primary focus of Ermine's (2007) work is on the interplay between Indigenous and Western perspectives, it is suggested here that his work is relevant to our task of developing models of public exchange that may enable stakeholders to understand and engage differences in the perspectives of people with disabilities and health professionals in end-of-life decision making. Ermine writes of "the brick wall of a deeply embedded belief and practice of western universality" (Ermine, 2007, p. 198). Parallel barriers to those identified by Ermine impede communication between persons with disability and their care providers. These barriers to safe and open communication can be influenced by deeply embedded able-ist beliefs about disability. In these constructions, disability is cast, not simply as part of human variation, but as "deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy" (Linton, 1998, p. 11).

Experts from the field of disability studies assert that professionalization and medicalization of disability have been to the detriment of all participants in health communication and ethical decision making (Oliver, 1998). Healthcare professionals and clinical ethicists may not fully appreciate how mass media, professional socialization, and popular language use represent disability in terms of negative quality of life, emphasis on limitations in functional capacity, and perceived experience of suffering (Longmore, 2003). These representations of disability may, therefore, negatively impact how the quality of life of a person living with disability is understood by both health professionals and the general public (Kaufert et al., 2010). Specifically, popular and professional representations of disability may affect people with disabilities and their care providers in crisis situations (Nantais & Kuczewski, 2004). For example, an intensive care specialist's assessment of "futility," "effectiveness," and the perceived quality of life achieved through initiating or continuing to provide mechanical ventilation, may contrast dramatically with the perspective of long-term users of portable ventilators who have lived independently in the community. In the intensive care unit (ICU), a long-term ventilator user experiencing acute respiratory insufficiency may not be able to directly communicate a decision to continue (or discontinue) mechanical ventilation. In crisis situations, the perspective of unconscious persons with long-term respiratory disability may be less adequately represented in their written advance directives, legal designation of proxy decision makers, or their prior conversations about life-preserving treatment options with their personal physicians (Kaufert & Locker, 1990). In these crisis situations, limitations in the attending physicians' wider experience of disability and exposure to community living adaptations to disability may have a profound impact on their role in working with such a person to make informed decisions about present and future treatment (Gill, 2006).

The disability studies literature recognizes the impact of the care provider in ethical decision making and emphasizes the role of formal undergraduate medical education and informal clinical socialization of physicians caring for persons with disability in community practice settings. The ethics theme of VP-Net research documented the teaching approaches and case materials engaging disability perspectives in end-of-life ethics in the pre-clinical curriculum of the University of Manitoba (Kaufert et al., 2010). Our research documented the impact of introducing medical students to an interdisciplinary approach, combining the perspective of disability studies and bioethics perspectives, which emphasizes the social model of disability and involves persons with disability as teachers.

METHOD

The perspectives of physicians, bioethicists, persons with disabilities, and spokespersons for advocacy groups and professional governing bodies were documented by VP-Net investigators (J. Kaufert, R. Wiebe, and L. Labine) through qualitative interviews with individual key informants and focus groups with palliative care providers, medical legal/bioethics experts, persons with disabilities, and representatives of advocacy and professional organizations. The narrative data generated in these interviews were used to identify speakers with specific expertise on policy, disability perspectives, and bioethical issues, who were invited to participate in the Forum on Ethical Safe Space. The primary narrative data used in this article are drawn from verbatim transcripts of the 1 day public forum on June 9, 2008. Summary transcripts were sent to all speakers and participants who consented to have their statements included in the summary of the meetings and posted on the VP-Net website (Wiebe & Neufeld, 2008).

The planning work group adopted a model for enabling representative participation in the public forum designed to reduce the impact of physical, sensory, financial, language, and professional status barriers. The cultural environment and approach to facilitation in the public forum provided "ethical safe space" (Ermine, 2007) in which conflicting ethical, legal, and political perspectives on the specific policy impacting decision making at the end of life could be raised. The forum was designed to provide an ethical safe space, in which Ermine asserted that participants are able to "step out of allegiances and speak with impunity" (Ermine, 2007, p. 202). Of the 212 participants, registration information indicated that 30–40% of the attendees were people identifying with disability perspectives, including individuals who identified need for enabled access. During the forum, disability perspectives were presented by both invited speakers and audience members who identified their affiliation with advocacy and consumer organizations, which included The Council of Canadians with Disabilities, The Manitoba League for Persons with Disabilities, People First, and Community Living Manitoba. In reviewing registration materials, consent forms, and transcripts of the forum proceedings, it was estimated that 30–35% of the speakers and participants from the audience self-identified as clinicians or professionals involved in healthcare delivery.

Using the transcripts and keynote speakers' printed texts, primary themes and patterns of interaction were identified reflecting the alternative perspectives. This analysis identified the significance of alternative interpretations of concepts such as "quality of life" and "efficacy or futility of treatment," and goals of treatment.

Written informed consent agreements were signed by resource speakers and presenters at the "town hall" segment of the forum. All presentations and exchanges between participants were transcribed and coded thematically, and these narratives were used to analyze and compare perspectives of participants and stakeholder organizations. The research protocol and consent agreements for forum participants were reviewed and approved by the University of Manitoba, Health Services Research Ethics Board in 2006 and 2008. In keeping with the provisions of the consent agreement and research ethics board approval, in the narrative data presented in this article, individual speakers and audience members are referred to only in terms of their general role, and names and institutional roles are not identified in the data.

In the Forum for Ethical Safe Space, the need to balance the perspective of participants from the fields of disability studies, law, and ethics with the perspectives supporting the policy from stakeholders from several clinical disciplines and the College of Physicians and Surgeons, was recognized by members of the work group. In planning the policy forum, we, therefore, invited speakers and members of groups with specialist expertise in intensive care medicine, palliative care, and clinical bioethics, as well as representatives of the College of Physicians and Surgeons and Winnipeg Regional Health Authority. The principles and decision criteria defined by the College of Physicians and Surgeons Policy Statement were reviewed in depth by the initial speaker. Clinicians with expertise in intensive care medicine and physicians and lawyers from the group who had drafted the statement were invited to describe the primary elements of the policy statement. Speakers also included physicians with specific expertise in the ethics of resource allocation and conflict resolution in clinical decision making in contested decisions. The forum was, therefore, planned to provide a safe public venue for clinicians to clarify, defend, or suggest modifications to some of the most problematic and publically debated provisions of the policy (Kaufert & Wiebe, 2008).

BUILDING ETHICAL SAFE SPACE

Previous interviews with physicians, ethicists, and people with disability emphasized that intractable disagreement in decisions involving provision or withdrawing of life-sustaining treatment occurred in $<10\%$ of cases involving acute or end-of-life care. The planning group recognized the importance of bringing together physicians and other health professionals with persons with disability in reciprocal KT activities that would build both mutual understanding and identify methods for improving communication and resolving conflicts.

The goal of previous KT events sponsored by the VP-Net grant was to create dialogue-based relationships between end-of-life healthcare providers and people who experience vulnerability because of disability, age, or chronic illness (Stienstra, 2006). Activities at these two prior workshops in 2005 and 2007 focused on the creation of an environment for mutual engagement between people with disabilities and palliative care providers, engaging with the issues of devaluation and resource allocation, and participants' experience of vulnerability in acute and palliative care settings. However, these earlier workshops did not engage specific cases and policies where there was direct conflict between stakeholder communities.

In developing the 2008 Forum on Ethical Safe Space, the decision was made to focus on the policy statement as a contested area of ethical decision making. In planning the event, we received both strong and sustained interest from people with disabilities; advocates; and professionals from the disciplines of medicine, law, bioethics, nursing, spiritual care, and disability studies. The priority throughout all planning stages was to provide an accessible and inclusive forum enabling those groups to present their perspectives on a widely debated professional policy statement asserting the roles of physicians in decisions about provision or withholding treatment. A cultural context of mutual respect and civility for the meeting was established, and a concerted effort was made to avoid over-representing or stereotyping a single perspective.

ASSURING ACCESSIBILITY AND BALANCED REPRESENTATION

The work group implemented a number of measures to ensure fair representation and remove barriers to full participation. All participants were to be assured of adequate time, access to assistive communication technology, and unbiased facilitation. More specifically, the forum made available American Sign Language interpretation and provided amplified sound systems for participants with hearing impairments. Braille programs and other formats for conference background literature were made available on request. We chose an appropriate meeting space with a ramped podium. Summaries of all conference presentations were "translated" in advance into "plain language" for persons with cognitive disabilities or literacy issues. Attendant services were made available for persons requiring physical assistance. Accessible parking spaces were made available, lunch and nutrition break were provided without charge, and registration fees were not charged.

Presenters and panelists represented a wide variety of population sectors, some of whom had developed their expertise in academic settings, and others whose expertise came from life experience.

The planning work group made the decision to forego the use of titles such as "doctor," or "professor," in order to encourage a sense of equality among presenters. A well-respected moderator was engaged. Key speakers were encouraged to present both balanced and critical perspectives on professional practice impacts of the policy, and to comment on parallel legal and policy issues at provincial and national and international levels.

Prior to the conference, print and other media had played a significant role in giving visibility to issues discussed at this event. The planning work group hired a media liaison representative to work with local and national radio, television, Internet, and print media to publicize the meeting and monitor the representation of stakeholder perspectives in local and national media. The media coordinator arranged interviews between conference speakers and local and national news representatives, and documented all news coverage of the event as part of the data collection process.

IMPACT OF THE FORUM AS ETHICAL SAFE SPACE

To establish the context and process for the forum, the elements of ethical safe space and approach to translation of contested knowledge were described in the introduction to the workshop:

> There are a wide range of speakers coming from disciplines representing policy from the College of Physicians and Surgeons perspective, speakers from the community of ethics and law. . . and people from the Winnipeg community that have been involved with this issue. The level of participation reflects a wide range of perspectives I think there are within our community, but the willingness of people to come together in a mutual space to talk about the issues and be clearer about what kinds of perspectives are that are within the community I think represents the ideal of ethics that a friend of mine, Willie Ermine as a Cree ethicist talks about as safe ethical space - that you come, you allow your values to be articulated in a common ground that allows people to talk about it.

During the forum, the arrangements for enabling full participation were introduced. Portable microphones were set up so that people with mobility needs did not have to make their way to standing microphones. All keynote speakers' presentations were "translated" into plain language documents that were included in all participants' registration materials. The issue of using plain language was raised in the initial discussion of the College Policy Statement. One participant commented on the accessibility of the statement: "I find the statement is very difficult for people with intellectual disabilities to understand what it means and everything, especially if they don't have a decision maker." Although the presenter representing the College did acknowledge that this need for translation of the policy into plain language was something to "seriously consider," he added, "I have remarkably good legal counsel who also know how to plain speak." Representatives of disability organizations responded by questioning whether legal interpretations in "plain speak" would actually be appropriate for people with intellectual disabilities or for people for whom English is an alternate language.

Two striking examples of how the use of ethical safe space forum to contribute to the creation of more transparent discussion of policies and practices were documented in exchanges between speakers representing the College of Physicians and Surgeons of Manitoba and other speakers and audience members who challenged the transparency of the process of policy development. For example, the opening speaker representing the College described the composition of a working group whose task it was to "consider the sample policy and propose a statement that addresses physician involvement in these decisions." When this speaker did not describe any process of public consultation or engagement of stakeholder groups, members of the audience emphasized that that people with disabilities were not among the groups consulted. Several other speakers emphasized that people with disabilities have a significant stake in the policy impacting end-of-life decisions. Representatives of disability organizations stated that they were not consulted in the development or dissemination of the document.

The second example of the workshop's impact in encouraging respectful, but mutually empowered, dialogue around contested policy was documented in the interaction among the participants in the question and answer session that followed the summary of the policy statement. Rather than taking questions from the audience, the representative of the College stated that he and his legal team had already anticipated the questions and had prepared a summary of some of the most widely discussed questions, and proceeded to answer them in his presentation . Speakers from disability organizations and presenters with specific expertise in law and ethics responded that none of the 12 questions or responses engaged the specific concerns raised by people with disabilities. They commented that the questions and interpretations of the policy had also not addressed expert criticism of either the legal or the ethical validity of the statement. Experts in law and bioethics also indicated that the speaker explaining the policy had not clarified or justified provisions for asserting the final authority of physicians (Webster, 2008). The exchange in the interactive forum did not resolve the fundamental differences among stakeholders, but it did provide a public venue for contested ethical and policy issues to be articulated and debated.

THE CONTRIBUTION OF THE SAFE SPACE FORUM TO THE DIALOGUE ON END-OF-LIFE POLICY

Both members of the audience and keynote speakers criticized the criteria defining minimal goals for treatment in the policy statement. The profound impact of the College's statement was revealed starkly and powerfully during the forum from the perspective of a person with a disability. The speaker stated:

> Some people are puzzled about why disabled people are particularly concerned about these issues. Well I think that maybe that deserves a bit of explaining… first of all I think one of the important current facts is that many of us are already depending on life-sustaining treatment… We are in a situation naturally threatened by any policy that extends the authority to withdraw these things from us because that would certainly spell the end of our lives very shortly… Secondly, the minimum goal of treatment… I need only think of people with various degrees of Alzheimer's…for whom it would be very difficult to demonstrate they know who they are, where they are, that they experience their own existence, in the way that most people would understand these terms… So many of us would automatically be defined as subject to a doctor determining whether to withhold or withdraw if we were in a crisis situation simply by the very nature of our abilities, so those things make us, make it very dangerous.

Another presenter reflected on the implications of the provisions of the policy defining minimal goals from the perspective of intensive care physicians who were involved in having to make decisions involving clinical assessment of futility based on the physician's assessment of prospects for functional recovery. He stated:

> The doctors actually at the front lines don't like this Statement any better than you folks…only our problems are different with respect to the minimum goal. We tend to be a pragmatic lot. What we are about and what we see in our world is providing life support so that they can get better, so that they can leave the ICU and maybe hospital eventually and go about their lives and enjoy the rest of it.

Several other speakers criticised this presenter's focus on the physician's role in relating decisions to prescribe or discontinue life supporting treatment to the prospects of "returning the patient to normal function." They emphasized that research in disability studies suggested that many physicians in intensive care situations had minimal information about their patients living with a pre-existing disability in terms of either their life in the community, self-defined quality of life, or personal decisions about continuation or discontinuation of life-sustaining measures.

A physician acknowledged the difficulties of the policy defining minimum goals but emphasized the potential value of the statement in situations involving impasse:

> I understand that the issue (minimum goals) is the contentious one, but on the other hand, the Statement consists of many more things besides that so for example, the fact that there is need for dialogue and that is laid out (in provisions) for consultation. Are there things in the Statement that in most instances should involve this kind of contentious impasse?

One speaker with a background in palliative care medicine recognized the extent to which treatment/ non-treatment decisions must integrate the physician's technical medical expertise, but also recognize that this directly overlapped with patient and family's experiential values and perspective on ethical practice. The physician emphasized the need to recognize the overlap between the technical clinical expertise of the physician and the experiential dimension of decisions that required the full participation of the patient and family. He stated:

> The technical/ physiological considerations of medical interventions tend to lend themselves to objective assessment and review… their effectiveness in achieving their intended goals can be measured…The experiential/ value-laden considerations require review through "the eye of the beholder… they are subjective assessments which involve an experience filtered through a "who" influenced by that person's unique life experience, interpersonal connections, value systems, hopes, goals, fears. Considerations such as quality of life, meaning, hope, energy, well-being, and even medical symptoms such as pain or shortness of breath are all experiential, requiring assessment and interpretation by the person experiencing them.

The reaction from members of the audience emphasized that creating a forum that is accessible and safe had enabled the disability community to bring their experience and that of other marginalized groups to the attention of clinicians and other decision makers who may be unfamiliar with these perspectives. A speaker with a background in the field of disability studies affirmed the value of the workshop as a forum for safe dialogue, but also described her personal sense of vulnerability. She stated:

> As other people have stated, I think that the important thing is that it gives space for dialogue, whether or not you agree with what's in the statement is another issue entirely, but at least there is a space to have a dialogue. I would say that the statement as it exists right now, underlies or sort of underscores individual vulnerability in my view, and if you have the ability to articulate the sort of nuances of your particular situation, that's fine, but if you don't and you're relying on a particular physician's knowledge of your disability. I would say that is sort of a dubious situation to be in a lot of times.

THE VALUE OF ETHICAL SAFE SPACE

Discussion during the forum revealed several benefits of creating ethical safe space. This model of workshop allows space for participation of stakeholders, who might not otherwise be able to interact in the same forum, to articulate their perspectives and debate with other presenters and audience members. The participation of physicians from intensive care and palliative care medicine, experts in bioethics and law, and members of the disability community facilitated a more direct conversation than has been observed in forums dominated by one stakeholder group. KT forums are often represented as facilitating dialogue between a dominant group and a nondominant group. However, the narrative data from the workshop suggest that the emphasis on ethical safe space also enabled clinicians, medical legal experts, and disability advocates to express diverse and opposing perspectives. An unanticipated area of diversity in participant perspectives was documented in the expression of diverse perspectives among the physicians participating, and between speakers and audience members representing different health disciplines (Edwards, 2008). A speaker commented on the need for interprofessional dialogue on the implications of the statement for interprofessional practice:

> It's my opinion that nurses' voices has been relatively absent from this discussion to date and I really appreciate the opportunity to be on this panel . . .I think that we as nurses need to talk more about this, but I also think we need to engage our community, our larger broader community in this discussion as well

Other comments following the critical review of the policy from the perspectives of law and bioethics centered on the potential tensions between the interpretation of the statement by physicians and the perspective of the legal system. The individual commented "I think that when you talk about taking medical things into court, there's an unstated (assumption), that there's a lot of resentment by physicians about, towards attorneys."

Some audience members identified the risks of leaving the policy statement as a contested area because of the risk that the conflict would contribute to the breakdown of trust between physicians and their patients. The respondent stated:

> That would be a real concern I'd have living in Manitoba, is the effect of these, of the Statement and the cases on the relationship between the physicians feeling embattled on one side, not the physicians in the case, just physicians generally, and patients and different communities within the patient population, the trust being eroded and you'd have more conflict. . .

Another speaker agreed.

> The thing that struck me today, in listening to people talk is how we have so much work to do on trust. . .we really have to restore that trust somehow, and talk and talk and listen. This forum was a step toward trying to understand different perspectives and moving to clarify positions on the way to trust restoration.

Participants at the forum spoke of the creation of ethical safe space as a starting point for more dialogue on the issues raised by the policy statement. The forum was therefore seen as a potential starting point for building conversation that would facilitate revising the policy with broader consultation on its legal and ethical validity. Other speakers indicated that the safe space forum could form the basis for further dialogue and lead to development of mechanisms for mediation and conflict resolution in disputed cases. For example, one person said, "I would hope that the presence of the College here today is an indication of a willingness to listen to what people have to say on this issue." Another individual described the statement as a "good first step, it's good that it's out there but we have a long way to go and I would welcome the opportunity for the disability community and their allies to be able to dialogue effectively with the College directly." Another emphasized further dialogue, relationship-building is paramount: “I think it is an interchange, it demands a relationship and my hope is that we’re starting to form a relationship as we move forward between different communities that have assembled here.”

Vulnerable and marginalized groups may feel that their perspectives are not known or not acknowledged or engaged in public discourse or policy development. Spokespersons for disability organizations expressed the concern that their views still carry little or no weight in professional discourse and have little impact on policy development. However, other speakers observed that the balanced discussion of conflicting perspectives at the public forum suggests that there is significant common ground between the disability community, the bioethics community, and some clinicians to continue the dialogue. A disability advocate stated,

> We wanted to see a focus on a few of the most critical pieces of the Statement, and I think that today, we have already focused on the two elements that many of us as disabled people felt were the most important parts, and many of the people in the bioethical and other sectors have also agreed are the most important parts

People with disabilities emphasized that their voices were not engaged by medical professionals outside the context of clinical consultation. Participants stated that the forum was “empowering” because it allowed them to express themselves outside the context of professional/client relationship. One speaker noted the general frustration of “being talked down to” and asserted that “. . .some of the doctors need to be educated.” The speaker concluded his statement engaging professional participants stating: “Thank you for listening.”

The creation of a public forum for engaging contested issues within ethical safe space was a new concept to many participants. Notwithstanding the emphasis on dialogue, some participants still considered the context of the workshop to be at least somewhat adversarial in nature. The moderator asked one physician-presenter: “You’ve heard a lot of comments over the course of the day that are contrary to the position of the College of Physicians and Surgeons. Do you feel misunderstood or do you feel ganged up on?” The physician responded: “Uh huh, in this audience, yeah.”

In the final presentation, a palliative care physician reflected on the value of hearing conflicting perspectives in terms of future prospects for and dialogue in future policy development and in potential for mediation of conflicted decision making at the end of life stated:

> Often surrounding controversial issues in health care there are published opinions supporting quite disparate views, and we find ourselves gravitating towards literature that is consistent with our own approach. Unfortunately, this will do little to broaden our understanding of how others feel and why they do so. Arguably, we would become better clinicians. . . and perhaps people. . . if we first selected literature which put forward views to which we held opposing views. We all have ‘lines in the sand’ in our minds representing ‘boundaries of the acceptable’, whether we are health care professionals or not. . ..Being aware of such lines and exploring their foundation is an important step towards being able to articulate views which may be complex and emotionally laden. When such views might influence how we approach patient care, it is particularly important that health care providers be aware of their own “lines in the sand.”

The perception of the workshop as “an adversarial process” may have reflected participants’ prior experience of addressing contested ethical issues in less inclusive venues. Although the concept and process of the workshop emphasized respectful exchange in clinical “safe space,” the diversity of participants’ values and advocacy for alternative frameworks for ethical decision making precluded final consensus on treatment/non-treatment policy. The forum also did not allow time or space to work in small groups to define specific proposals for mediating conflicts and resolving cases in which there was intractable disagreement over initiating or discontinuing life supporting treatment.

MOVING TOWARD THE FUTURE

The diversity of registrants participating in the forum was one indication of the strong ties developed by conference planners with stakeholder groups across the spectrum of policy perspectives. In evaluating the impact of the forum, it is important to determine whether this approach to facilitating KT by defining and enabling participants to communicate in ethical safe space actually contributes to the development of democratic, non-adversarial processes that facilitate discussion between medical professionals and members of wider communities, including people with disabilities. In evaluating the impact of this event and the model for creating ethical safe space for the full spectrum of communities and individual stakeholders, the planning work group posed several follow-up questions in the evaluation form completed by 43 of the participants. In addition to closed format questions evaluating each speaker and public forum on a four point scale, registrants were also asked: What was the impact of the knowledge translation that occurred? Was the creation of safe ethical space an effective model for making public policy accessible? How does the dialogue continue?

Narrative comments from 43 participants who evaluated the workshop included the following statements:

"The (value of the workshop was in) hearing how people define the CPSM guidelines, given their personal life experiences- the perceptions and honesty of the participants was eye-opening."

Another participant stated that the forum was effective in "Provoking thought, far deeper than I experience on a day to day basis working in a large health care institution."

Another said that "the forum opened up future dialogues we need to have. A new thought process around 'quality of life'- whose life, whose choice is it?"

Another commented that there was "Too much information condensed to fit it all in. I truly believe that with these being such controversial and emotionally charged issues there was more time needed for the group to ask questions and share experiences and ideas." Finally, one participant suggested "Perhaps (the forum could have been improved by) more representation from other groups and individuals –rather than just disabilities."

Evidence of the impact of the forum in broadening public discourse about ethics and end-of-life decision making between bioethics and legal experts, healthcare providers, and people with disability was documented in the content analysis of media coverage of the event. The many television, radio, and press articles and sound bites confirmed the high level of media interest and participation in the policy discourse around the statement during and after this conference. The contested policy that served as the centerpiece for the workshop continues to be discussed at the local and national levels. There is currently direct engagement on the part of two different disability rights groups, the Manitoba League of Persons with Disabilities and Community Living Manitoba, with the College of Physicians and Surgeons. These groups have expressed continued concerns about the statement. In addition, the National Human Rights Committee of the Council of Canadians with Disabilities has formed a special task group to monitor healthcare policies dealing with end-of-life decision making and to respond to such policies through public education and political action. All of these groups had sent representatives to attend the 2008 forum. In 2010–2011, a working group including representatives of the College of Physicians and Surgeons and a regional health authority engaged some members of the disability community in an initiative to explore legislation establishing a body that would review, mediate, and provide a forum for resolving contested decisions involving provision or discontinuation of life-supporting treatments.

RELEVANCE FOR PROVIDERS OF PALLIATIVE AND SUPPORTIVE CARE

Using Ermine's (2007) conceptualization of ethical safe space, this forum provided the space required for people of vastly differing views to come together in one place for a respectful and thought-provoking dialogue. The day-long event also allowed for some dismantling of Ermine's "brick wall of deeply embedded belief and practice" (Ermine, 2007, p. 198). It allowed for the perspectives and experiences of people with disabilities to be revealed, where before, these views had remained somewhat hidden from medical professionals. This opportunity served to provide participants who might otherwise have felt vulnerable, to be empowered and heard. Through the ongoing conversations that continue to occur between and among stakeholders and stakeholder groups, the beginning of a partnership model was created over the course of a day.

For palliative care providers, the workshop provided an opportunity to hear and engage the perspectives of people with disability and organizations representing vulnerable populations. It also provided an opportunity to hear the interpretation of the policy from the perspective of the College of Physicians and Surgeons and to contrast this interpretation with the perspectives of experts in disability studies, law, and bioethics. It also provided a venue for articulating and understanding variations in the interpretations of the clinical disciplines such as nursing and intensive care, which in turn influence the delivery of palliative care medicine. Palliative care providers may be able to better interpret patient and family experience of past conflict over treatment choices, and offer equally important information about the risks, costs, and limits of treatment alternatives discussed by specific stakeholder groups. KT workshops may provide one way for care providers to interpret patient and family concerns and address conflicting policy perspectives among stakeholder groups representing both professionals and consumers. These workshops may provide a safe venue in which contested issues can be engaged. Workshops may also offer an alternative to professional conferences that are often represented in the media as focusing primarily on formal and instrumental approaches defining the care providers and institutions in end-of-life decision ethics. Finally, the forum appeared to provide a working model for increasing transparency among stakeholder groups and developing more co-participatory decision models that build in mechanisms for mediation and reconciliation.

ACKNOWLEDGMENT

The research program and public knowledge translation forum were supported by a 5 year New Emerging Team Grant on End-of-Life Care and Vulnerable Populations from the Canadian Institutes of Health Research (C.I.H.R.). The V.P. Net research team included Harvey M. Chochinov (P.I.), Deborah Stienstra (P.I.), Zana Lutfiyya (Co. I.), Joseph Kaufert (C0.I.), and Jim Derksen (Co.I.). We also wish to acknowledge the contributions of George Webster, Patricia Murphy, Dawn Stewart, Paul Graham, Lea Neufeld, Lisa Labine, and Lindsey Troschuk to the research program and knowledge translation forum.

REFERENCES

Child and Family Services of Manitoba v. R.L. (1997). 154 D.L.R. (4th) 409 (Man. C.A.).

College of Physicians and Surgeons of Manitoba. *Withholding and Withdrawing Life-Sustaining Treatment*. http://www.cpsm.mb.ca/statements/st1602.pdf

Derksen, J. & Chochinov, H. M. (2006). Disability and end-of-life care: Let the conversation begin. *Journal of Palliative Care*, *22*, 175–182.

Downie, J. (2008a). The legal status of unilateral withholding and withdrawal of treatment: A National overview. In *End of Life Ethics and Decision-Making: Current Policy Debates about Withholding and Withdrawing Life-Sustaining Treatment*. *Summary of June 9, 2008 Knowledge Translation Forum.* R. Wiebe & L. Neufeld (eds.), pp. 44–51. Winnipeg: Department of Community Health Sciences, University of Manitoba.

Downie, J. (2008b). Whose decision is it anyway? An exploration of unilateral withholding and withdrawal of potentially life-sustaining treatment in Manitoba. In *End of Life Ethics and Decision-Making: Current Policy Debates about Withholding and Withdrawing Life-Sustaining Treatment*. *Summary of June 9, 2008 Knowledge Translation Forum.* R. Wiebe & L. Neufeld (eds.), pp. 37–43. Winnipeg: Department of Community Health Sciences, University of Manitoba.

Edwards, M. (2008). Probing the ethics of minimum goals of life-sustaining treatment and a physician's final authority. In *End of Life Ethics and Decision-Making: Current Policy Debates about Withholding and Withdrawing Life-Sustaining Treatment*. *Summary of June 9, 2008 Knowledge Translation Forum.* R. Wiebe & L. Neufeld (eds.), pp. 67–68. Winnipeg: Department of Community Health Sciences, University of Manitoba.

Ermine, W. (2007). The ethical space of engagement. *Indigenous Law Journal*, *6*, 193-2-3.

Gill, C.J. (2006). Disability, constructed vulnerability, and socially conscious palliative care. *Journal of Palliative Care*, *22*, 183–189.

Golubchuk v. *Salvation Army Grace General Hospital and others* (2008). MBQB 49.

Graham, I. & Tetroe, J. (2009). Implementation of evidence. *International Journal of Evidence-Based Healthcare*, *7*, 157–158.

Kaufert, J. & Wiebe, R. (2008). Conference overview. In *End of Life Ethics and Decision-Making: Current Policy debates about Withholding and Withdrawing Life-Sustaining Treatment*. *Summary of June 9, 2008 Knowledge Translation Forum.* R. Wiebe & L. Neufeld (eds.), pp. 5–8. Winnipeg: Department of Community Health Sciences, University of Manitoba.

Kaufert, J. & Locker, D. (1990) Rehabilitation ideology and respiratory support technology. *Social Science and Medicine*, *29*, 867–877.

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

Linton, S. (1998). *Claiming Disability, Knowledge and Identity.* New York: New York Press, 8.

Longmore, P.K. (2003). *Why I Burned My Book and Other Essays on Disability.* Philadelphia: Temple University Press.

Nantais, D. & Kuczewski, M. (2004). Quality of life: The contested rhetoric of resource allocation and end-of-life decision making. *Journal of Medicine and Philosophy*, *29*, 651–664.

Newell, C. (2006). Disability, bioethics, and rejected knowledge. *Journal of Medicine and Philosophy*, *31*, 269–283.

Oliver, M. (1998). Theories of disability in health practice and research. *British Medical Journal, 312*, 1446–1449.

Rodriguez v. British Columbia (Attorney General) (1993). 3 S.C.R. 519.

Rogers, J.D. & Martin, F.H. (2009). Knowledge translation in disability and rehabilitation research: Lessons from the application of knowledge value. Mapping to the case of accessible currency. *Journal of Disability Policy Studies*, *20*, 110–126.

Sawatzky v. Riverview Health Centre Inc. (1998). 167 Dominion Law Reports (4th) 359 (Man.Q.B.)

Straus, S.E., Tetroe, J. & Graham, I. (2009). Defining knowledge translation. *Canadian Medical Association Journal*, *181*, 165–168.

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

Webster, G. (2008). Between a rock and a hard place: Is the CPSM Statement an ethical remedy. In *End of Life Ethics and Decision-Making: Current Policy Debates about Withholding and Withdrawing Life-Sustaining Treatment*. *Summary of June 9, 2008 Knowledge Translation Forum.* R. Wiebe & L. Neufeld, L. (eds.), Department of Community Health Sciences, Winnipeg, University of Manitoba, 52–58.

Wiebe, R. & Neufeld, L., ed. (2008). *End of Life Ethics and Decision Making: Current Policy Debates about Withholding or Withdrawing Life Sustaining Treatment*. *Summary and Edited Transcript Proceedings of June 9, 2008 Knowledge Translation Forum.* Winnipeg: Department of Community Health Sciences, Faculty of Medicine, University of Manitoba.