

Widening Notions of Personhood: Stories and Identity

Karen D. Schwartz
University of Manitoba

If personhood involves the construction of a narrative identity, then what are we to say of someone who is seriously ill or disabled? How can her life have any narrative when she is unable to write one? In such cases, her personal identity must be written by those who care for her. They form the stories about her that, fitted to the constraints of the circumstances, hold her in personhood. (Nelson, 2002, p. 29)

In the course of my research into media representations of vulnerability and disability at end of life, I came across two very interesting local news stories, both thoroughly reported on by the *Winnipeg Free Press*. In November 1998, doctors at a long term health care facility in Winnipeg, Manitoba insisted on entering a “do not resuscitate” order on the chart of 79 year old Mr. Andrew Sawatzky. In December 2007, doctors in the intensive care unit of a Winnipeg hospital opted to disconnect the ventilator and remove the feeding tube of Mr. Samuel Golubchuk, an 84 year old man. Doctors evaluated both Mr. Sawatzky and Mr. Golubchuk by assessing their levels of awareness and consciousness. Neither man was able to speak, although relatives of both men claimed each was capable of communicating and expressing his wishes. For this reason, both of these medical decisions went against the wishes of their respective families, who then sought judicial intervention to reverse them. At the heart of both these cases was the pivotal debate over the entitlement to the designation of “person” and the moral status that it confers. This debate, and its conflicting narratives, will be the focus of my paper.

Much of my work focuses on people with intellectual disabilities. Their levels of consciousness, and consequent eligibility for personhood, like that of Mr. Sawatzky and Mr. Golubchuk, may also be called into question by our society, which prizes the qualities of intelligence and rationality. These two news stories alerted me to the possibility of

situations where life or death decisions may be made for people with intellectual disabilities based, not on their health, but on their perceived levels of consciousness and awareness. My reading of these two narratives revealed a fascinating juxtaposition: although the majority of these news accounts tended to focus on the more traditional medical definition of personhood, the advocates of Mr. Sawatzky and Mr. Golubchuk, notably their families, told a very different story. While one picture of these gentlemen is drawn with words such as suffering, pain and torment, this is countered by families speaking of love, hope and, above all, humanness. It is this very difference that suggests a break from the traditional societal notion that moral personhood is inexorably linked with a person's perceived level of consciousness or awareness.

My purpose in this paper is to deconstruct the newspaper accounts of the different narratives in the cases of Mr. Sawatzky and Mr. Golubchuk. I will then use the news accounts to demonstrate the implications that such narratives can have on the lives of these two vulnerable people, as well as people with intellectual disabilities. I will begin by describing the law and policy for providing life-sustaining treatments in Manitoba. I will follow this description with a summary of the above-mentioned two cases and continue with a brief review of the literature highlighting the relevant philosophical, ethical and medical concepts which are central to understanding these stories. Using the case study as my qualitative research methodology (Creswell, 2007), I will then "show" how each man is described by different narrators. My analysis will reveal how each narrator sees these individuals in light of the current bioethical debates around personhood and consciousness. I will conclude this paper with a discussion of the implications that these different narratives can have for people with intellectual disabilities.

Setting the Stage

Manitoba is an interesting jurisdiction when considering bioethics and the issue of which patients will receive life-sustaining treatments. In 1997, before Mr. Sawatzky's case was brought to court, the Manitoba Court of Appeal considered the matter of do not resuscitate orders in *Child and Family Services of Manitoba v. R.L. (the Lavallee case)* (1997). The case involved the placing of a DNR order on the chart of an infant *Developmental Disabilities Bulletin, 2009, Vol. 37, No. 1 & 2*

deemed to be in a vegetative state. Mr. Justice Twaddle, in delivering the Court's opinion, noted that "the question of whether a medical doctor can lawfully direct that resuscitation measures be withheld from a patient has not, as far as I am aware, been considered previously by a Canadian court" (p. 413). Although the issue for the Court of Appeal did not require the Court to decide whether or not the child in question should be allowed to die, the Court of Appeal decided that, "there is no legal obligation on a medical doctor to take heroic measures to maintain the life of a patient in an irreversible vegetative state" (p. 412). The justices concluded by ruling that "neither consent nor a court order in lieu is required for a medical doctor to issue a non-resuscitation order where, in his or her judgment, the patient is in an irreversible vegetative state" (p. 413).

Another interesting development occurred in January 2008, during the legal action commenced on behalf of Mr. Golubchuk. The College of Physicians and Surgeons of Manitoba (CPSM) released a Statement (No. 1602) on withholding and withdrawing life-sustaining treatment. The purpose of this Statement is to "assist physicians, their patients and others involved with decisions to withhold or withdraw life-sustaining treatment by establishing a process for physicians to follow when withholding or withdrawing life-sustaining treatment is being considered" (p. 15-S1). In assessing patients to determine whether or not treatment ought to be provided or withheld, the Statement provides a test, referred to as the "minimum goal of life-sustaining treatment." This goal is "clinically" defined as "the maintenance of or recovery to a level of cerebral function that enables the patient to: achieve awareness of self; and achieve awareness of environment; and experience his/her own existence" (p. 15-S3). The relevance of the test's emphasis on awareness is an integral theme that will be considered throughout this paper.

The Cases

Before reviewing the literature, I will briefly review the issues surrounding the medical care of Mr. Sawatzky and Mr. Golubchuk.

4 *Karen D Schwartz*

Mr. Andrew Sawatzky

Andrew Sawatzky was a 79 year old man who had Parkinson's disease and subsequently had a series of strokes. He had been a resident of the Riverview Health Centre since May of 1998. A do not resuscitate (DNR) order was placed on his chart at the end of October 1998. Given his condition and prognosis, doctors did not believe Mr. Sawatzky was a good candidate for resuscitation and felt these attempts would merely prolong his pain and suffering.

The Sawatzkys, dissatisfied with discussions with facility staff, took the matter to court seeking a temporary injunction to have the DNR order lifted until the matter could be fully argued in court. Mrs. Helene Sawatzky felt that her husband would benefit from CPR and expected him to eventually recover and return home.

The court temporarily lifted the DNR order, and asked for independent medical opinions in order to clarify Mr. Sawatzky's condition. There was conflicting evidence as to Mr. Sawatzky's abilities to communicate as well as his level of awareness. It was established that he had had a series of strokes in the past, had Parkinson's disease at the time these stories were circulating, and was apparently unable to speak due to the presence of a tracheotomy tube. How much he understood, was able to process, and communicate was the subject of debate between physicians and lawyers. The merits of this case were never argued in court as Mr. Sawatzky was eventually transferred to another facility. He passed away in the fall of 1999.

Mr. Samuel Golubchuk

Mr. Golubchuk was an 84 year old patient in the intensive care unit of the Grace hospital in October, 2007. He was in hospital as a result of pneumonia and pulmonary hypertension. He was placed on life support at the beginning of November, requiring a ventilator and feeding tube. At the end of November, doctors decided to withdraw life support, concluding these measures to be futile, given Mr. Golubchuk's declining health.

Mr. Golubchuk's adult children, Mrs. Miriam Geller and Mr. Percy Golubchuk, went to court to stop the withdrawal of life support on the grounds that death hastening went against the family's religious beliefs.

The court issued an interim order allowing Mr. Golubchuk to continue on life support until the matter could be tried fully on its merits. Shortly before his death, three intensive care physicians resigned from their shifts at the Grace Hospital in order to avoid treating Mr. Golubchuk, on the grounds that their professional ethics were being compromised in being forced to provide care they considered to be futile. Before the case could be heard, Mr. Golubchuk died in hospital in June 2008.

Issues in Bioethics

In our view, consciousness is the most important characteristic that distinguishes humans from other forms of animal life, going beyond the vegetative functions of heartbeat and respiration. (Cranford & Smith, 1987, p. 233)

I now wish to address a number of related issues that were raised in the cases of Mr. Sawatzky and Mr. Golubchuk and that impact on the lives of all vulnerable people. These issues, which will inform my analysis of the stories later in this paper, include a) what it means to be a person, b) how the notions of consciousness and awareness help define personhood, and c) how the concept of medical futility is used in medicine and bioethics to distinguish between those deemed morally worthy of receiving life-sustaining treatments and those not deemed worthy.

Personhood

Cantor's (2005) point of view holds that to invite an individual into personhood is to evoke a moral status for that individual. That moral status allows for respect and an acknowledgement of rights and duties that we do not owe any other entity not considered a person. "Personhood in our culture carries important consequences" (Cantor, 2005, p. 13). In health care contexts, "a central theme is respect for persons, meaning adherence to certain protections and certain forms of

solicitous treatment associated with human dignity. Implicit in that ethical entitlement to respect is a judgement that all persons have full moral status" (p. 13). Cantor, in discussing "profoundly mentally disabled" people, addresses end of life issues specifically: "If profoundly disabled beings are not persons, then decisions to terminate life-sustaining medical intervention (and thereby precipitate death) are facilitated" (p. 14). I expand upon Cantor's statement by suggesting that an acknowledgement of personhood for any vulnerable individual, including Mr. Sawatzky, Mr. Golubchuk, and people with intellectual disabilities, increases the likelihood of securing moral status.

Koch (2004) suggests that there are two competing paradigms in the field of bioethics. Proponents of one paradigm argue for practices such as eugenics, euthanasia and assisted suicide for people "with severely restricting physical and cognitive attributes" (p. 697). Proponents of the other paradigm favour the idea of "persons of difference" (p. 697). At the heart of the struggle between these competing paradigms "is a debate over the understanding or construction of the notion of *personhood*" (p. 697, emphasis in the original).

In *An Essay Concerning Human Understanding*, Locke (1975) discussed "what a person stands for" (p. 335). He concluded that a person is "a thinking intelligent Being, that has reason and reflection" (p. 335). Locke was not the first to link personhood with intelligence and reason. These ideas can be traced back to the Greek and Roman Stoics (Nussbaum, 2006), to Plato and Aristotle (Parmenter, 2001; Stainton, 2001) and beyond. In the context of her sister, who was born with hydrocephaly, Nelson (2002) reviews the philosophical criteria:

She was incapable of rational reflection, as required by Immanuel Kant's and John Rawls's theories. She probably was not self-aware, as Michael Tooley requires. It was not clear to what extent we could ascribe intentional predicates to her—the criterion advanced by P.F. Strawson. She was not able to treat others as persons, as Rawls and Thomas Nagel demand. She could not communicate with us verbally, as Daniel Dennett says she must. She was not capable of forming second-order desires, as required by Harry Frankfurt. She could not organize her

experiences, acts, or relationships into an autobiographical narrative, as Schechtman believes is necessary (pp. 32-33).

Elliot (2003) says that we know a person is a person by his/her capacities: "intelligence, speech, self-consciousness, abstract thought, the ability to relate to others, and so on" (p. 16).

Consciousness and Awareness

Cranford and Smith (1987) argue that consciousness "is the most critical moral, legal, and constitutional standard, not for human life itself, but for human personhood" (p. 233). As their statement illustrates, for many philosophers, ethicists and doctors, consciousness and awareness constitute the key element to personhood. Williams (1976) traced the word "consciousness" in his volume *Keywords*. The word came into English usage in the first part of the 17th century from the Latin *con* (together) and *scire* (to know). "The word took on a general sense of 'awareness,' with four common specializations: self aware... actively aware and reflecting... 'self-conscious'... active and waking... A further general sense... distinguished a class of beings, as in *thinking* or *rational*" (Williams, p. 270).

The medical focus on consciousness is clearly reflected in the CPSM's concept of minimum goal of treatment. Achieving awareness of self, environment and experiencing existence are all elements of consciousness. For some people, evidence of these elements is clearly discernable. For others, like Mr. Sawatzky and Mr. Golubchuk, this evidence may be less evident, leaving questions of consciousness and personhood open to the interpretation of others.

Futility

In the case of Mr. Sawatzky and Mr. Golubchuk, there arose a disagreement between the families, on the one hand, and the physicians, on the other, as to the efficacy of treatment. One way in which physicians justify withholding or withdrawing life sustaining treatment is to invoke the argument that such treatments are medically futile. In tracing the evolution of the futility concept, Burns and Truog (2007) suggest that it

emerged “in response to concerns about families who demanded life-prolonging treatments for their loved ones that caregivers deemed to be inappropriate” (p. 1987).

Futility describes “any effort to achieve a result that is possible but that reasoning or experience suggests is highly improbable and that cannot be systematically produced” (Schneiderman, Jecker, & Jonsen, 1990, p. 951). Schneiderman, Jecker, and Jonsen (1990) have suggested both a quantitative and qualitative aspect to the futility test. Quantitatively, treatment is considered futile “when physicians conclude...that in the last 100 cases, a medical treatment has been useless” (p. 951). Qualitatively, “any treatment that merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care” is regarded as futile (p. 952).

The Schneiderman, Jecker, and Jonsen (1990) definition seems to imply that decisions about the futility of treatments are exclusively medical in nature. But what if physicians are making values-based judgments? Rubin (2007) asks, “Who should be empowered to decide when to stop and when to go forward? What sort of values, and whose values, ought to be determinative? And probably most significantly, what kind of decision is it after all” (p. 49)? Rubin then goes on to suggest that, once the values of medical professionals enter into the debate, it becomes a significant mistake to impose “our views of a good death, of lives worth living, of battles worth fighting, of risks worth taking, or of suffering worth enduring uniformly across the patient population, a population we know to be profoundly diverse” (p. 50).

A study on how caregivers in intensive care units perceive futile care (Sibbald, Downar, & Hawryluck, 2007) offers an excellent example of Rubin’s point. Based on an analysis of their data, the authors of the study came up with a working definition of medically futile care, which they describe as “the use of considerable resources without a reasonable hope that the patient would recover to a state of relative independence or be interactive with their environment” (p. 1205). What struck me about this definition was its emphasis on morally subjective elements. Some vulnerable people are never “independent,” but are interdependent upon others for care or assistance throughout their lives. Similarly, there *Developmental Disabilities Bulletin, 2009, Vol. 37, No. 1 & 2*

are people who simply do not interact with their environment in an overt way. Given the emphasis on these two qualities, what happens to patients who do not meet these criteria? They may be in danger of being refused treatments based on the values of others.

It is crucial to recognize and acknowledge the role that values play in futility discussions, especially for patients who fall outside of the “normal” expectations. Such patients include those most vulnerable to moral judgements, specifically people with disabilities. Werth (2005), in considering the threat of decision-making based on physician values for people with disabilities, says “...the values of the physician (and the health-care system) lead to decisions to terminate or not offer treatment, even if the person would want treatment and the physician knows this” (p. 33).

Having examined the key notions of personhood, consciousness and futility, I will now turn to a brief overview of the methods I used to analyze the stories. This analysis will illustrate how stories told about people who cannot speak for themselves can encourage exclusion from personhood.

Methods

I have used the qualitative approach of the multi-case study in this work. I rely on Creswell’s (2007) suggestion that this approach is “a methodology, a type of design in qualitative research, or an object of study, as well as a product of inquiry” (p. 73). The case study is “a detailed examination of one setting, or a single subject, a single depository of documents, or one particular event” (Bogdan & Biklen, 2003, p. 54). It is a relevant methodology for studying “clearly definable cases with boundaries” in order to provide a more in-depth look at one or more cases (Creswell, 2007, p. 74). I have chosen to study these two Winnipeg cases involving vulnerable persons who were the subject of withholding or withdrawing life-sustaining treatments. Again referencing Creswell (2007), I am focusing on an analysis of themes, in this instance an analysis of personhood and its differing interpretations by various narrators within each case.

Bogdan and Biklen (2003) suggest that the use of documents as primary data sources in case studies is becoming more common among qualitative researchers and cite specifically the use of “popular culture documents” such as news reports (p. 58). I have chosen to analyze newspaper articles from the *Winnipeg Free Press*, the local daily newspaper in the jurisdiction in which both of these cases took place¹. Rather than examining all of the themes that came up in my analysis, I have purposefully limited this initial examination to focusing on how different people involved in these stories portray the vulnerable person through the stories they tell in the media. The major contributors to the stories told in both these case studies are doctors, lawyers, the court, ethicists, members of the public, and families.

The newspaper articles on Mr. Sawatzky I extracted from the *Winnipeg Free Press* manually during the time period this case was in the news. To locate articles on Mr. Golubchuk, I searched for “Golubchuk” in the electronic database “Virtual News Library,” limiting my search to *Winnipeg Free Press* articles. These searches led me to a combination of news accounts, opinion pieces, editorials and letters to the editor. In Mr. Sawatzky’s case, I analyzed 20 articles and in Mr. Golubchuk’s case I analyzed 32 articles. Both of these cases received national and even international attention in various types of media. However, I chose to limit this research to these local news accounts in order to maintain a manageable amount of data. I also decided to use print media as it generated a sufficient amount of data with a number of contributors from a wide sector of the community.

I read both sets of data over initially to get an understanding of how the stories were presented, looking for possible key themes. Several points struck me, as I continued to peruse the material. First, one of the major themes was an emphasis on consciousness and awareness. Second, neither Mr. Sawatzky nor Mr. Golubchuk told their own stories in these accounts. Third, I realized that different players contributed different

¹ The *Winnipeg Free Press* is independently owned and its political orientation shifts depending upon the issue, the journalist and the editor.

narratives about each gentleman, depending on their perspective. These points encouraged me to re-analyze the data by looking at who told what story and what aspects of each gentleman were emphasized. It is not my intention to enter the debate of the appropriateness of life-sustaining treatments or to dispute their care. Ultimately, I wanted to examine the impact these issues might potentially have on people with intellectual disabilities, whose status of personhood is often brought into question.

I chose to examine the narratives concerning Mr. Sawatzky and Mr. Golubchuk as told through the media by doctors, lawyers, the court, ethicists, the general public, families and the journalists. I am mindful of the problematic nature of attempting to separate the words and opinions of individuals involved with cases from the way the journalists have chosen to frame and write the stories. For example, although the doctors, lawyers and family members talk about these gentlemen in certain ways, I realize journalists writing the articles have sifted through numerous quotations and chosen some over others. Similarly, they have sought to emphasize certain details and chosen specific words with a purpose in mind. I have endeavoured to present the words and details of the stories primarily through the use of direct quotations, in order to try to address this issue.

Stories told by doctors, lawyers, the courts and families were located primarily within the news stories. The versions told by ethicists and, to some extent, doctors, were located in opinion pieces and letters to the editor. I found the accounts told by the general public in letters to the editor. The journalists' own views were embedded within the news stories and in editorial pieces, both in the way they chose to tell the stories and in the stories they chose to tell.

I have divided the accounts told about Mr. Sawatzky and Mr. Golubchuk into three distinct but related categories that tell us something about the way their identities are perceived: a) their contested physical state, b) the contested state of their consciousness and, ultimately, c) their contested personhood. I argue that the way in which the identities of Mr. Sawatzky and Mr. Golubchuk were presented has significant ramifications for how

readers construct and perceive each person as well as others for whom consciousness is less overtly apparent.

The Telling of Stories

Our attitudes toward other beings are built into the language that we use to describe them, and the language is embedded in a way of behaving toward them. (Elliot, 2003, p. 18)

Contested physical identities

The first theme I analyzed about Mr. Sawatzky and Mr. Golubchuk involved their contested physical identities. While it is not surprising that these stories would be told in the medical context, what my analysis demonstrates is the way in which the conditions of these patients are characterized, how these characterizations are taken up by people other than physicians, and the strong language used to justify decisions made about these patients.

Mr. Sawatzky's physical condition is disclosed in the media accounts by journalists relating what the lawyers in the case are purported to have said in court. Three lawyers are involved in this case, the lawyer for the Sawatzky's, the lawyer for the Manitoba League of Persons with Disabilities (MLPD) (who sought and won intervenor status in the case) and the lawyer for the Riverview Health Centre. Although the lawyer for the health centre notes Mr. Sawatzky is "suffering from a variety of health problems including Parkinson's disease" and has had a series of strokes (Wild, 1998a, p. A3), the lawyer for the MLPD makes a point of stressing that he "is walking around... He is not on life support" (Lyons, 1998, p. A2-3). The media describe Mr. Sawatzky as suffering from Parkinson's disease (Lyons, 1998), ailing (Wild, 1998a; Wild, 1998b; McKie, 1999), a "sick old man" (McKie, 1999) and as "so ill" (Janzen, 1998a; Janzen, 1998b). He is also described as having a tracheotomy tube in his throat (Guttormson, 1998).

Mr. Golubchuk's physical condition is described in much greater detail. This condition is discussed by the media and the doctors treating him, although some counter narrative is presented via the family's lawyer.

The media accounts reveal that Mr. Golubchuk had previously suffered from a brain injury (Rollason, 2007), which required the removal of part of his frontal lobe (Mitchell, 2008). He required hospitalization in 2007 for pulmonary hypertension and pneumonia (Rollason, 2007). In the course of treatments, he was placed on a ventilator and provided with a feeding tube (Paraskevas, 2007b). *Free Press* writer Mitchell (2008) provides a particularly vivid description of Mr. Golubchuck's physical health, which focuses solely on deficit and suggests he may not be worth saving.

"He cannot eat, and is fed by a tube surgically inserted into his stomach. He cannot breathe sufficiently; a ventilator was surgically inserted into his throat. He cannot speak. He has a heart condition that cannot support a pacemaker. His kidneys began failing, but 'plateaued'" (p. A13).

Mr. Golubchuk's doctors play a far more active role in revealing his condition than do Mr. Sawatzky's doctors, who remain largely silent in the media. This narrative arose in published accounts by some of Mr. Golubchuk's intensive care unit physicians, who decided their ethics had been compromised by the court order and refused to continue to treat him.

In a resignation letter, Dr. Easton wrote:

"...this individual has had a slow declining level of health, and has what I would consider an insurmountable problem with wound infections and resultant sepsis and renal failure" (Sanders, 2008b, p. A3).

Parts of Dr. Kumar's resignation letter, read aloud in court, are as follows:

"If we honestly attempt to follow the court mandate...we will likely have to continue to hack away at his infected flesh at the bedside in order to keep

the infection at bay...This is grotesque. To inflict this kind of assault on him without reasonable hope of benefit is an abomination" (Skerritt, 2008, p. A5).

The doctor's narrative was dramatic in its description of the treatments physicians were forced to deliver. I argue that words such as "grotesque" and "abomination" become, for the reader, a description of the patient.

Journalists reporting on the case present the position argued by Golubchuk's lawyer, on the other hand, in a more positive light. He is quoted as talking about an independently functioning heart (Paraskevas, 2007a), "improvement and neurological responses" and his eyes following "sound and movement" (Rollason, 2008a, p. A3).

Contested states of consciousness

Mr. Sawatzky's state of consciousness and awareness is contested in different narratives. Riverview's lawyer told the court that "he is not considered competent to handle his own affairs" (Wild, 1998a, p. A3). Doctors who provided the court with information on Mr. Sawatzky's condition described him as not being able to "follow simple commands such as opening his eyes or moving them around" (McKie, 1999, p. A3) or "communicate his wishes in regards to his treatment" (McKie, 1999, p. A3). Another doctor said he did not "have a good grasp of his medical condition and cannot make informed decisions" (McKie, 1999, p. A3).

Using their own words and perspectives, rather than the quotes of others, the journalists tell yet another story. One editorial declares that "Mr. Sawatzky himself is reported to be in command of his mental faculties and opposes the DNR" (1998, p. B4). Another article provides some detail of Mr. Sawatzky. "He sits in a chair, occasionally looking people in the eye, fiddling with his hands" (Guttormson, 1998, p. A9).

Mrs. Sawatzky's story is different again. She adamantly and repeatedly challenges medical opinions about her husband. She claims throughout the ordeal that her husband is capable of making decisions. She tells the media that her husband is aware of his surroundings and knows what a

DNR order means for him (Janzen, 1998b). She is convinced that he knows what is happening.

As was the case with Mr. Sawatzky, Mr. Golubchuk's state of consciousness and awareness was also in dispute. Journalists reported at different times that he had "minimal brain activity" (Rollason, 2008a, p. A3), was "awake" (Rollason, 2008a, p. A3), was in a "minimally conscious state" (Skerritt & Sanders, 2008, p. A1).

One doctor described him as in a "permanent 'minimally conscious state'" (Sanders, 2008b, p. A3) while another, it was reported, suggested he was "above, albeit barely, the vegetative state" (Mitchell, 2008, p. A13).

The Golubchuk lawyer said that "there is no evidence that he is brain dead" (Paraskevas, 2007a, p. B1), his chart says "awake" (Rollason, 2008a, p. A3), and "he is responsive to family" (Rollason, 2008b, p. B2).

The Golubchuk family was indirectly quoted as being "certain their father is alive, that he is not dying and would not want doctors to disconnect the tubes maintaining his organs. They believe his mind is working, that he aware of them. He grasps their hands" (Mitchell, 2008, p. A13).

Contested Personhood

Mr. Sawatzky and Mr. Golubchuk were not only described in terms of their contested medical conditions. They are also described in terms of their contested status as people.

The press reported the lawyer for Riverview Health Centre as saying Mr. Sawatzky "is totally dependent on the Riverview staff for his care" (Wild, 1998a, p. A3). Shafer (1998), the Director of the Centre for Professional and Applied Ethics at the University of Manitoba, wrote a piece on the Sawatzky case in which he alludes to Mr. Sawatzky as being "in a twilight zone between life and death, without personality but perhaps with great pain" (p. A4). In terms of Mr. Sawatzky's prognosis, Shafer (1998) indicates that "the dementing process associated with Parkinson's will continue to rob him of his rationality and personality"

Developmental Disabilities Bulletin, 2009, Vol. 37, No. 1& 2

(p. A4). Finally, Shafer (1998) describes what CPR will do to Mr. Sawatzky, should it be required and should the court so order. "His chest will be crushed, his ribs in all likelihood be cracked, his arteries and lungs perforated, his body electrically shocked" (p. A4). This view of Mr. Sawatzky is traditional from a medical and bio-ethical standpoint, which runs contrary to the view taken by disability rights activists such as Stephen Drake, of Not Dead Yet, Dr. Dick Sobsey, former Director of the JP Das Developmental Disabilities Centre, and Dr. Gregor Wolbring, a bioethicist based out of University of Calgary.

In a letter to the editor, Manishen (1998) (signed as an MD) reiterates Shafer's description of the CPR process, stressing "painful electroshock therapy of the heart, potential rib fractures from vigorous chest compressions and throat discomfort from tubes required for mechanical ventilation of the lungs" (p. A11).

In another letter to the editor, Komar (1998) describes, in great and vivid detail, what I infer to be the potential result for Mr. Sawatzky, should he be resuscitated.

Many who are resuscitated do not live to leave hospital; they live those last days with many tubes emerging from their bodies. When a breathing tube to a ventilator is down your throat, you are unable to speak, so you can't converse with your loved ones even if you are fully conscious. If you need more nourishment than the intravenous fluid is giving you, a feeding tube is passed down your nose into your stomach. This is irritating, so you reach for it or one of the other tubes, and, to prevent you from tugging on them, your hands are restrained. Do you want your last days to be this way? (p. A11)

It is clear from all of these comments that none of the authors can conceptualize that there are people who live meaningful lives even though they require mechanical ventilation to help them breathe or feeding tubes to help them eat. Moreover, preoccupation with "gruesome language" certainly evokes "fear and pity," as Longmore (2005) suggests (p. 38).

Similarly worded stories also emerge in the case of Mr. Golubchuk, with a focus on both his conscious state and his physical deterioration. Mitchell (2008) wonders whether or not he is “any longer of this Earth” (p. A13). She stresses the typical argument about brain function: “Whether he is ‘brain-dead’ or capable of higher cognitive function beyond the ‘brain stem reflexes’ – the so-called persistent vegetative state – is disputed” (p. A13).

Ethicist Shafer (Sanders, 2008a) provides commentary again in the Golubchuk case, emphasizing the cracked ribs, tube feeding and heart electrodes. With his perspective he presents Mr. Golubchuk in this dehumanizing way by insisting that “the person who was Mr. Golubchuk ceased to exist a long time ago, while the body of Mr. Golubchuk is still alive” (p. A3). Shafer concludes by suggesting a discontinuation of treatment on the grounds that Mr. Golubchuk “can’t be cured and he can’t benefit” (Sanders, 2008a, p. A3).

A number of people wrote letters to the editor in response to the ongoing stories appearing about Mr. Golubchuk. One author was an ex-justice of a Manitoba court who weighed in via an opinion piece. Some of the comments made about Mr. Golubchuk are as follows.

“Samual Golubchuk was, and still is, lying in a barely alive state in the intensive care ward of the hospital...he will never recover from the massive medical problems that afflict him, and that have reduced him to near death” (Huband, 2008, p. A15).

An e-mail to the *Winnipeg Free Press* had a reader asking, “Is it natural to have a machine breathe for you because the individual is so brain damaged his own body cannot support life” (Paraskevas, 2007c, p. A12)? Another writer says the doctors “are being forced to breach their professional ethics and bring him back to the torment that is his life now” (Eastveld, 2008, p. A10). The writer continues by linking personhood with consciousness:

“Life is more than a working heart and open eyes. It is self-awareness and the ability to feel joy and to

recognize and interact meaningfully with others”
(Eastveld, 2008, p. A10).

The questions a) who is a person? and b) what is a person? are answered in a very narrow sense in these stories. It seems that the machines, tubes, bed sores and medical problems have literally taken away personhood.

Personhood

The families of Mr. Sawatzky and Mr. Golubchuk and their advocates make efforts to bring the humanity back into the stories about their loved ones. Their narratives move away from the negative and back to words of love, encouragement and humanness.

Mr. Sawatzky, because of the positive narrative, moves for the reader beyond his disease, tracheotomy and inability to speak. He becomes, in one article, a loving husband, “his wedding band glimpsed beneath the band aid wrapped around his finger” (Guttormson, 1998, p. A9). Mrs. Sawatzky remembers that

“in 43 years of marriage we never had any major fights...We had no children so it was always he and I against the world. I want to squeeze out as many more years with him as I can” (Janzen, 1998b, pp. A1-A2). Mr. and Mrs. Sawatzky understand each other. She “peppers him with questions...answering them herself” all the while asserting that “he doesn’t like the attention” his case has brought (Guttormson, 1998, p. A9). In the end “I just want my husband to be safe and I won’t stop until he is” (Janzen, 1998b, pp. A1-A2).

Miriam Geller and Percy Golubchuk, Mr. Golubchuk’s children, are much less vocal in the press about their father and what has happened to him. As I have shown, most of the counter narratives come from their lawyer, who concentrates on Mr. Golubchuk’s health and state of consciousness. His children remain quiet, saying only that their father “would be very proud of us – he would say way to go” (Rollason, 2008c, p. B1) at their success in court. It was not until stories came out in the

press highlighting the resignation letters of his physicians that Mrs. Geller and Mr. Percy Golubchuk began tell a different story. "Hacking off flesh? The doctor put that like a butcher" (Skerritt & Sanders, 2008, p. A1). It is only when the case nears its end that Mrs. Geller says, "He's a World War II veteran and this how we repay him – by trying to kill him?" (Skerritt & Sanders, 2008, p. A1).

In talking about their loved ones in a positive way, in telling a new and different story, in moving away from tubes and cracked ribs, Mrs. Sawatzky, Mrs. Geller and Mr. Percy Golubchuk seem to instinctively re-emphasize the personhood of their loved one. This personhood is worlds away from Cranford and Smith's (1987) notion of consciousness as the "most important characteristic that distinguishes humans from other forms of animal life" (p. 233). It is about relationships. In telling their stories, these family members invite readers to think again. Their tales of personhood are invaluable tools for other vulnerable people, particularly people with intellectual disabilities who may not be able to speak for themselves and who may be perceived of as unworthy of the moral status that personhood evokes.

Implications for People with Intellectual Disabilities

That which we believed we valued, what we – I – thought was at the center of humanity, the capacity for thought, for reason, was not it, not at all. (Kittay, 1999, p. 150)

The analysis of the stories reported in the media about Mr. Sawatzky and Mr. Golubchuk demonstrates how easy it is to perceive these gentlemen solely in terms of their medical conditions and states of consciousness. This perception may lead the reader to forget about the humanness of patients like Mr. Sawatzky and Mr. Golubchuk. Such perceptions can also de-humanize people with intellectual disabilities, who may be in good health, but whose state of consciousness and awareness may be called into question. In medical situations, a failure to recognize the humanness of patients with intellectual disabilities can be even more problematic. Given what we already know about the link between personhood and consciousness and the value-laden concept of medical

futility in denying life-sustaining treatments, would these patients be considered futile and dispensable?

Although there are great risks to people with intellectual disabilities when personhood is articulated within narrow philosophical definitions, there are many people who conceptualize and write about a different kind of personhood. Although I do not claim this paper to be an exhaustive discussion, there are several reconceptualizations of personhood and humanness that I wish to draw upon.

I do not wish to suggest that medical definitions and ethical considerations are inappropriate and have no place in bioethical conversations. What I do wish to emphasize is that there is often more than one way to see someone. And while physicians and other health care professionals, in the practice of their professions, are trained to see patients in certain ways, this does not mean that they are precluded from seeing these same patients in more than one light. Indeed I would argue that they should be encouraged to do so.

Goode (1984; 1992) has written extensively about his research with Bobby, a gentleman of 50 who was labelled as having Down syndrome and as a result had spent the majority of his life at a board and care facility. Goode's first contact with Bobby was through clinical records. These records told a story about Bobby that was entirely clinical:

“Nowhere was Bobby discussed in terms of his having any sort of competence and human value; instead an exclusively fault-finding perspective was employed” (1992, p. 200).

This clinical story reminded me very much of the professional stories told about Mr. Sawatzky and Mr. Golubchuk. When Goode began to get to know Bobby, he saw a very different person, “a man with an unusual countenance, different ways of thinking and evaluating, trying to explore and master his everyday world” (1992, p. 211). Goode suggests that, to see Bobby in a “humanistic” way, focuses on how Bobby was like him and moves away from how Bobby was different.

An examination of “caring and accepting” relationships between nondisabled people and “severely disabled people (people with severe and profound mental retardation or multiple disabilities” (p. 242) was undertaken by Bogdan and Taylor (1998). The authors argue that a person is defined by “the nature of the relationship between the definer and the defined” (p. 243). In examining how the nondisabled people emphasized the humanness of their disabled “partner,” Bogdan and Taylor noted four dimensions: a) attributing thinking to the disabled partner, b) seeing the disabled partner as an individual, c) viewing the relationship as reciprocal, and d) identifying a social place for their disabled partner in their family unit and in their larger social circle. Even though the disabled partners in this study “sometimes drool, soil themselves, or do not talk or walk – traits that most would consider highly undesirable” (p. 242), their nondisabled partners accept them, love them and include them. This is how the Sawatzky and Golubchuk families saw their beloved husband and father. Their families talked to them and knew they can hear and understand. They have not lost their personhood. These gentlemen are presented by their families as human beings.

In an article on bioethics and disability, Koch (2004) looks at different concepts of personhood. He describes McBryde Johnson’s position that personhood is absolute and “by definition relational but not necessarily reciprocal” (p. 703). This echoes the work of Bogdan and Taylor (1998). Humanity and personhood are therefore affirmed by the relationships that people have with one another and both caring and being cared for are ways to demonstrate that humanness. A person is a person by virtue of the loving relationships he or she has, not by virtue of what some consider to be deficits or undesirable and unwanted characteristics.

Kittay (2005) has written about her daughter, who has significant and complex disabilities. Like Bogdan and Taylor, she emphasizes the importance of having families or loving friends because membership in a family is not conditional upon “having certain intrinsic properties” (p. 124). “Families... are critical when we are dependent... At these times, we are generally best served by close personal ties” (p. 124).

One of the reasons why relationships are so important to vulnerable people in critical times, particularly those who cannot speak or communicate in the “usual” ways, is precisely because of the difficulty they have in creating their own identities and communicating those identities to others. Kaufman (2003) explored the creation of identities in patients whose consciousness is “problematic for observers” or when patients live in a “technologically produced border zone between life and death” (p. 2249). She suggests that “family, friends, and health-care personnel become the vehicles through which *the person* is interpreted. *The person* thus emerges and is known through the activities of others” (pp. 2250-2251).

Kaufman’s analysis provides insight into the importance that personal relationships play in maintaining humanness and personhood. Her analysis also emphasizes the critical role health care professionals can play in either ignoring or building upon patient identities, either to the patient’s detriment or benefit. Thus, repeated references in the media to Dr. Kumar’s statement of hacking infected flesh do nothing to encourage readers to respect the humanity and personhood of Mr. Golubchuk. Rather, “the patient-as-person must be invoked, must be made by others” (p. 2255).

Isaacs and Massey (1994) have discussed applied ethics and argue that one of its domains, “appreciative domain,” involves appreciating “the identity of another human being” by “engaging with them – being with them – in a way that recognizes and acknowledges their humanity” (n. p.). This way of thinking parallels the work of Chochinov, Hack, McClement, Kristjanson, and Harlos (2002) and Chochinov (2007) on dignity-conserving models of care. Isaacs and Massey (1994) also suggest that identity emerges from and is shaped by engagement with others, “engagements which often involve the telling of stories to one another” (n. p.). Along the lines of Wolfensberger’s (1998, 2000) discussion of societal tendencies to devalue people with intellectual disabilities and confer on them devalued social roles, these authors note that the narratives people create about one another can be either enabling and confirming, leading to enhanced social identities; or disabling and disconfirming, destroying positive social identities. Quoting Johnston

(1973), Isaac and Massey (1994) emphasize the political nature of this type of engagement: "Identity is who you can say you are in light of what they say you can be" (n. p.). I argue that, for Mr. Sawatzky and Mr. Golubchuk and people with intellectual disabilities, there is a social responsibility to move beyond the limitations of negative narratives, and toward an openness to hearing and accepting new stories.

Conclusion

In analyzing these news stories concerning the dilemma of Mr. Sawatzky and Mr. Golubchuk, I have shown that damage can be done when the value of personhood is ignored. In emphasizing narrow constructions of what it means to be human, society runs the risk of dehumanizing many vulnerable people and, in particular, those with intellectual disabilities. They may not be able to tell their own stories or may not have loved ones to tell those stories for them.

This analysis demonstrates the power of language and the damage that negative narratives cause. It also reminds all of us, as readers, that patients and their loved ones have a story that might be worth listening to. Any time we can perceive likenesses rather than differences, we can expand our ideas of what it means to be human and accept more people into the circle that is humanity.

Acknowledgements

The preparation of this article was supported by the Canadian Institutes of Health Research New Emerging Team Grant on End of Life Care and Vulnerable Populations held by Harvey M. Chochinov, Deborah Stienstra, Joseph M. Kaufert, and Zana M. Lutfiyya.

References

- Bogdan, R. C., & Biklen, S. K. (2003). *Qualitative research for education* (4th ed.). Boston: Allyn and Bacon.
- Bogdan, R., & Taylor, S. J. (1998). The social construction of humanness: Relationships with people with severe retardation. In S. J. Taylor *Developmental Disabilities Bulletin*, 2009, Vol. 37, No. 1& 2

- & R. Bogdan (Eds.), *Introduction to qualitative research methods* (3rd ed.) (pp. 242-258). New York: J. Wiley & Sons, Inc.
- Burns, J. P., & Truog, R. D. (2007). Futility: A concept in evolution. *Chest*, 132(6), 1987-1993.
- Cantor, N. L. (2005). *Making medical decisions for the profoundly mentally disabled*. Cambridge, Massachusetts: The MIT Press.
- Child and Family Services of Manitoba v. R.L.* (1997). 154 D.L.R. (4th) 409 (Man. C.A.).
- Chochinov, H. M. (2007). Dignity and the essence of medicine: The A,B,C, and D of dignity conserving care. *British Medical Journal*, 335, 184-187.
- Chochinov, H. M., Hack, T., McClement, S., Kristjanson, L., & Harlos, M. (2002). Dignity in the terminally ill: A developing empirical model. *Social Sciences & Medicine*, 54, 433-443.
- Cranford, R. E., & Smith, D. R. (1987). Consciousness: The most critical moral (constitutional) standard for human personhood. *American Journal of Law and Medicine*, 13 (2-3), 233-248.
- College of Physicians and Surgeons of Manitoba. (2008). *Withholding and withdrawing life-sustaining treatment*. Retrieved June 25, 2008, from <http://www.cpsm.mb.ca/statements/1602.pdf>
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*(2nd ed.). Thousand Oaks, California: Sage Publications.
- Eastveld, B. (2008, June 19). Show patient respect [Letter to the editor]. *Winnipeg Free Press*, p. A10.
- Elliot, C. (2003). Attitudes, souls, and persons: Children with severe neurological impairment. *Mental Retardation and Developmental Disabilities Research Reviews*, 9, 16-20.
- Goode, D. A. (1984). Socially produced identities, intimacy and the problem of competence among the Retarded. In L. Barton & S. Tomlinson (Eds.), *Special education and social interests* (pp. 228-248). London: Croom Helm.
- Goode, D. A. (1992). Who is Bobby?: Ideology and method in the discovery of a Down syndrome person's competence. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 197-212). New York: Teachers College Press.

- Guttormson, K. (1998, November 24). Sawatzky has become symbol for an issue close to her heart. *Winnipeg Free Press*, p. A9.
- Huband, C. (2008, April 25). Public likely outraged by forced treatment of some patients. *Winnipeg Free Press*, p. A15.
- Isaacs, P., & Massey, D. (1994, February). *Mapping the applied ethics agenda*. Paper presented at the third annual meeting of the Association for Practical and Professional Ethics, Cleveland, Ohio.
- Janzen, L. (1998a, November 14). Keep him alive: Judge. *Winnipeg Free Press*, pp. A1-A2.
- Janzen, L. (1998b, November 14). Devotion to ailing husband puts her in national spotlight. *Winnipeg Free Press*, pp. A1-A2.
- Kaufman, S. R. (2003). Hidden places, uncommon persons. *Social Science & Medicine*, 56, 2249-2261.
- Kittay, E. F. (1999). *Love's labor: Essays on women, equality, and dependency*. New York: Routledge.
- Kittay, E. F. (2005). At the margins of moral personhood. *Ethics*, 116, 100-131.
- Koch, T. (2004). The difference that difference makes: Bioethics and the challenge of "disability." *Journal of Medicine and Philosophy*, 29(6), 697-716.
- Komar, J. (1998, November 23). Sometimes we have to let go [Letter to the editor]. *Winnipeg Free Press*, p. A11.
- Longmore, P. (2005). Policy, prejudice, and reality. *Journal of Disability Policy Studies*, 16(1), 38-45.
- Locke, J. (1975). *An essay concerning human understanding*. (P. H. Nidditch, Ed.). Oxford: Clarendon Press. (Original work published in 1690).
- Lyons, J. (1998, November 8). Do-not-revive order sparks fury of disabled. *Winnipeg Free Press*, pp. A2-A3.
- Manishen, W. J. (1998, November 23). Doctors do not play God (Letter to the editor). *Winnipeg Free Press*, p. A11.
- McKie, P. (1999, May 20). Reviving sick old man bad idea, report says. *Winnipeg Free Press*, p. A3.
- Mitchell, C. (2008, February 15). Thank God for that. *Winnipeg Free Press*, p. A13.

- Nelson, H. L. (2002). What child is this? *Hastings Center Report*, 32(6), 29-38.
- Nussbaum, M. C. (2006). *Frontiers of justice*. Cambridge, Massachusetts: The Bellknap Press.
- Paraskevas, J. (2007a, December 12). Decision reserved in right-to-life case. *Winnipeg Free Press*, p. B1.
- Paraskevas, J. (2007b, December 13). Life and death decisions in courts? *Winnipeg Free Press*, p. A4.
- Paraskevas, J. (2007c, December 14). Right-to-life case sparks widespread debate. *Winnipeg Free Press*, p. A12.
- Parmenter, T. R. (2001). Intellectual disabilities – *Quo vadis?* In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 267-296). Thousand Oaks, California: Sage Publications.
- Rollason, K. (2007, December 11). Jewish kin say pulling plug would be a sin. *Winnipeg Free Press*, p. A4.
- Rollason, K. (2008a, January 12). Senior at centre of life-support battle improving. *Winnipeg Free Press*, p. A3.
- Rollason, K. (2008b, February 12). Judge to rule on removing life support. *Winnipeg Free Press*, p. B2.
- Rollason, K. (2008c, February 14). Maintain life-support: Judge. *Winnipeg Free Press*, p. B1.
- Rubin, S. B. (2007). If we think it's futile, can't we just say no? *HEC Forum*, 19(1), 45-65.
- Sanders, C. (2008a, June 17). Two more MDs quit Grace unit. *Winnipeg Free Press*, p. A3.
- Sanders, C. (2008b, June 18). MD torn over "unethical" care. *Winnipeg Free Press*, p. A3.
- Schneiderman, L. J., Jecker, N. S., & Jonsen, A. R. (1990). Medical futility: Its meaning and ethical implications. *Annals of Internal Medicine*, 112, 949-954.
- Shafer, A. (1998, November 14). Who sets the limits on our health care? *Winnipeg Free Press*, p. A4.
- Sibbald, R., Downar, J., & Hawryluck, L. (2007). Perceptions of "futile care" among caregivers in intensive care units. *CMAJ*, 177(10), 1201-1208.

- Skerritt, J. (2008, June 4). Doctor resigns from Grace over Golubchuk decision. *Winnipeg Free Press*, p. A5.
- Skerritt, J. & Sanders, C. (2008, June21). When doctors say no. *Winnipeg Free Press*, p. A1.
- Stanton, T. (2001). Reason and value: The thought of Plato and Aristotle and the construction of intellectual disability. *Mental Retardation*, 39(6), 452-460.
- Werth, J. L. Jr. (2005). Concerns about decisions related to withholding/withdrawing life- sustaining treatment and futility for persons with disabilities. *Journal of Disability Policy Studies*, 16(1), 31-37.
- When doctors play God (Editorial). (1998, November 15). *Winnipeg Free Press*, p. B4.
- Wild, S. (1998a, November 12). Life or death decision in hands of judge. *Winnipeg Free Press*, p. A3.
- Wild, S. (1998b, November 13). Is MDs' order to let man die ethically right? *Winnipeg Free Press*, p. A3.
- Williams, R. (1976). *Keywords*. New York: Oxford University Press.
- Wolfensberger, W. (1998). A brief introduction to Social Role Valorization: A high-order concept for addressing the plight of societally devalued people, and for structuring human services (3rd ed.). Syracuse : Training Institute for Human Service Planning, Leadership & Change Agency (Syracuse University).
- Wolfensberger, W. (2000). A brief overview of Social Role Valorization. *Mental Retardation*, 38(2), 105-123.

Author Note

Karen D. Schwartz can be reached at kds22@shaw.ca