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"In pain waiting to die": Everyday understandings of suffering

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ABSTRACT

Objective: The notion of "suffering" is understood in very different ways in a variety of contexts. In palliative care, the relief and prevention of suffering is considered to be a fundamental goal (Pastrana et al., 2008). However, the avoidance of suffering has also been used as an argument by those campaigning for the legalization of euthanasia and assisted suicide (Finlay, 2009). In reflecting upon suffering in these two contexts, we were intrigued by Finlay's (2009) contention that to laypeople, the phrase "'unbearable suffering' conjures up images of patients on their deathbeds wracked with uncontrolled pain" (p. 1841).

Method: This article explores how suffering is used and understood in an "everyday" discourse, by analyzing comments posted to a website debating assisted suicide in the context of the Canadian case of Sue Rodriguez.

Results: Using a broad social approach to discourse analysis (Tonkiss, 2004), three themes emerged in our analysis: (1) when people suffer, (2) how people are understood to suffer, and (3) how suffering should be dealt with. We also examined what was not said in this discussion: there was little consideration of the more holistic goals of palliative care and how suffering might be understood and managed in ways other than within the frame of assisted suicide.

Significance of results: Paying attention to the everyday discourse of suffering is important because, as members of society, we all play a role in negotiating the meaning of suffering. Such meaning has a significant impact upon patients and palliative care professionals alike.

KEYWORDS: Suffering, Assisted suicide, Palliative care, Everyday discourse, Discourse analysis

INTRODUCTION

The notion of "suffering" is understood in very different ways in a variety of contexts. In palliative care, the relief and prevention of suffering is considered to be a fundamental goal (Pastrana et al., 2008). It has been suggested that such care allows patients "to maintain a quality of life and prevent and manage physical, psychological, existential, and spiritual suffering" (Strada & Breitbart, 2009, p. 23). However, the avoidance of suffering has also been used as an argument by those campaigning for the legalization of euthanasia and assisted suicide (Finlay, 2009).

In reflecting upon suffering in these two contexts, we were intrigued by Finlay's (2009) contention that to laypeople the phrase "'unbearable suffering' conjures up images of patients on their deathbeds wracked with uncontrolled pain" (p. 1841). We decided to explore how suffering is used and understood in an "everyday" discourse by analyzing comments posted to a website debating the question of assisted suicide in the context of the Canadian case of Sue Rodriguez. Paying attention to the everyday discourse of suffering is important because, as members of society, we all play a role in negotiating the meaning of suffering. Such meaning has a significant impact upon patients and palliative care professionals. In this analysis, we will add to the conversation of how to highlight the more holistic palliative care goals for all patients, and move

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societal conversations of suffering beyond the assisted suicide debate.

ORIGINS AND DEFINITIONS OF SUFFERING

According to the *Online Etymology Dictionary*, the word "suffer" made its appearance in English c. 1225 and was recorded from 1290. It is derived from the Anglo-French word "suffrir", the Old French word "sufrir", and the Vulgar Latin "sufferire" (a variant of the Latin "sufferre"), which mean "to bear, undergo, endure, carry or put under". These words are based on the roots "sub" (up, under) and "ferre" (to carry), and their meaning is "to tolerate, allow".

The *Oxford English Dictionary* indicates that the word "suffer" is used in two basic contexts: (1) "to undergo, endure" and (2) "to tolerate, allow". The first usage is more specifically defined as "to have (something painful, distressing, or injurious) inflicted or imposed upon one; to submit to with pain, distress, or grief"; "to go or pass through, be subjected to, undergo, experience (now usually something evil or painful)"; "to undergo or submit to pain, punishment, or death"; "to be affected by, subjected to, undergo (an operation or process, *esp.* of change)"; or, "to sustain injury, damage, or loss; to be injured or impaired". The second usage ("to tolerate, allow") consists of a number of rare, archaic, and obsolete references.

RELIGIOUS NOTIONS OF SUFFERING

Before the modern age, religious conceptualizations of suffering prevailed in society. In Judaism, Fox (2008) suggests that there are three causes of suffering. First, he discusses suffering as a punishment for those who sin. Garcia (2006) also mentions human suffering stemming from the sin of the parent. Second, Fox says that suffering is "corrective education" (p. 3), which is an attempt by God to "guide humanity through suffering" (Fox, 2008, p. 3). These types of suffering are also known as "merited suffering" (Schumm & Stoltzfus, 2007). Finally, suffering is one way in which people can deepen their relationship with God. This concept is also part of the Christian theology, in which suffering is understood to be "an opportunity of bringing the sufferer closer to God" (Cassell, 1991, p. 35).

In Christianity, suffering is believed to be the result of the original sin with redemption coming through Christ's suffering on the cross and his subsequent death (Garcia, 2006). Van Hooft (1998) suggests that the suffering of Christ is viewed as an example of positive suffering, because salvation can only be achieved through this act. In his discussions of Catholic beliefs of sin and suffering, Garcia (2006) makes reference to the writings of the late Pope John Paul II, who believed that suffering is less about punishment than about purifying our sins.

Buddhist teachings include reference to the term "dukkha", which is "suffering, dissatisfaction or turmoil" (Schumm & Stoltzfus, 2007, pp. 10–11). Suffering, in turn, is defined as something that is difficult to bear (Schumm & Stoltzfus, 2007, referencing Hallisey, 1998). The meaning of suffering "is characterized by selfish attachment" to something associated with "me" or "mine" (Schumm & Stoltzfus, p. 11). Relief from this suffering entails a freeing of oneself from this isolation (Schumm & Stoltzfus, 2007).

This brief discussion shows that suffering, in religious contexts, is something that is explained as a part of life, an "immutable component" of being human (Goldberg & Crespo, 2003, p. 86). Notwithstanding this assertion, people have always been searching for the meaning of suffering (Cassell, 1991) and attempting to reconcile the tension between a benevolent and omnipotent God and suffering as an evil in the world (Morgan, 2002; Schumm & Stoltzfus, 2007). Although religious beliefs continue to influence people's conceptualizations of and explanations for suffering, the modern age brought with it a new paradigm that dominates our thinking today.

MODERN NOTIONS OF SUFFERING

Goldberg and Crespo (2003) argue that the construction of suffering as an unalterable part of life no longer reflects the way we think about the notion. In referencing McGill (1982, p. 159), they suggest that our attitudes today "reveal the pernicious 'conviction that suffering is somehow utterly incompatible with being genuinely human. It is widely believed that no human growth and no human development are possible in suffering" (Goldberg & Crespo, 2003, p. 86). In modernity, it has been suggested that society looks to science to assuage suffering (Morgan, 2002). "The belief that all problems will eventually yield to the ingenuity of science has displaced the irrational and tragic with an epic vision of the *technical* perfectibility of the secular world" (Morgan, p. 319, emphasis in the original).

Cassell (1991) argues that a physician's obligation to relieve a patient's suffering "stretches back into antiquity" (p. 30). He defines suffering as "the state of severe distress associated with events that threaten the intactness of person" (Cassell, 1991, p. 33). Cadwallader (2007) suggests that the promise of a relief from suffering is a goal "one cannot simply reject," therefore establishing the "unshakeable foundation" upon which myriad medical technologies have been developed in order to facilitate this end

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(p. 377). According to Carnevale (2009), three common beliefs about suffering prevail in modern medical contexts: (1) the word "suffering" is used interchangeably with the word "pain"; (2) a patient's suffering can be "accurately assessed" by someone else; and (3) the most important priority is to eliminate suffering (p. 173). Ironically, this third element of eliminating suffering is seen to be even more important than the goal of preserving life (Carnevale, 2009). The importance of the elimination of suffering stands counter to religious ideas, which focus on helping people tolerate, accept, or bear up under suffering. Now there is an underlying notion that eliminating the person is acceptable, if that is the only way to eliminate suffering.

DIMENSIONS OF SUFFERING IN THE PALLIATIVE CARE LITERATURE

In discussions of suffering, it has been suggested that, although the word "pain" tends to accompany the word "suffering," the latter term describes more than physical symptoms. For example, Terry and Olson (2004) argue that "the relief of patients' pain and physical symptoms may be supposed to mean the same thing as the 'relief of the suffering and distress of terminally ill patients'" (p. 604). In fact, they found that sources of suffering were not "clearly related" to patients' "dominant symptoms" (p. 606).

Chochinov (2006) reviews the many facets of suffering. He notes that although it is "tempting" to look at the "alleviation of physical symptom distress" (p. 87), such distress does not tell the whole story. Other dimensions of suffering include existential, spiritual, and psychosocial elements as well (Chochinov, 2006). More specifically, suffering might encompass a number of different reactions. Hopelessness is one such reaction, in which patients may feel that "maintaining hope was intimately connected with a sense that life continued to serve some purpose or held meaning enough to sustain their continued existence" (Chochinov, 2006, p. 90). Another reaction is the feeling of being a burden to others. This feeling relates to notions of quality of life and maintaining autonomy when dependency is seen as "threatening the integrity of personhood itself" (Chochinov, 2006, p. 91). Dignity is another concept that is closely tied to the idea of being a burden, as a patient's perceived inability to continue to be independent may be interpreted as being undeserving of "honor respect, or esteem," which can undermine "the value of life itself" (Chochinov, 2006, p. 92).

In their analysis of suffering, Currow and Hegarty (2006) discuss a number of elements including: (1) physical; (2) social, including isolation when loved ones withdraw; (3) self-image; and (4) existential issues. Similarly to Chochinov (2006), the authors note how suffering can pose a threat to personhood. "It is not just our physical wellbeing but our social, sexual, emotional, financial, or spiritual sense of wellbeing that can contribute to and, at times, drive suffering" (Currow & Hegarty, 2006, p. 128). George (2009) says that the way in which suffering can be envisioned is "an attack on the integrity of, or sense of self, dissociation or otherness, a loss of dignity—the draining of events upon ones sense of worth or value" (George, 2009, p. 386). Kellehear (2009) suggests that "although there is wide agreement that suffering is a significant alteration to a sense of self involving pain, injury, deprivation, or significant social or personal change, the precise prevalence of this experience of suffering changes with the subtleties of its definition" (Kellehear, 2009, p. 389).

THE CASE OF SUE RODRIGUEZ

Notwithstanding that suffering has been described, in the palliative care literature, as multidimensional and complex, the question remains as to how laypeople conceptualize suffering and what connections suffering has with debates about the "right" to assisted suicide. In an effort to shed more light on this issue, we have chosen to look at such a debate within the context of the specific case of Sue Rodriguez.

In 1991, a Canadian woman named Sue Rodriguez was diagnosed with amyotrophic lateral sclerosis (ALS). In 1992 she launched the first of what would become a series of court battles in an attempt to have assisted suicide, which is a criminal offence under Canada's *Criminal Code*, legalized. Knowing that in time ALS would prevent her from being able to end her own life, Rodriguez asked the Court for permission to have a doctor assist her in committing suicide in order to be able to control the time and manner of her death.

In 1993, the case reached the level of the Supreme Court of Canada. The court ruled, by a decision of 5–4, against Rodriguez, suggesting that she did not have a right to assisted suicide. In writing for the majority, Justice Sopinka said:

> Regardless of one's personal views as to whether the distinctions drawn between withdrawal of treatment and palliative care, on the one hand, and assisted suicide on the other are practically compelling, the fact remains that these distinctions are maintained and can be persuasively defended. To the extent that there is a consensus, it is that human life must be respected and we must be careful not to undermine the institutions that protect it (Rodriguez v. British Columbia, 1993, pp. 104–105).

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Sue Rodriguez did commit suicide in 1994, aided by a physician whose identity remains anonymous.

METHODS IN ANALYZING THE EVERYDAY DISCOURSE OF SUFFERING

We conducted our research in connection with a larger project examining vulnerable people at end of life. We define vulnerable people to include: (1) the frail elderly; (2) people whose terminal illness is associated with a long trajectory of decline and cumulative functional limitations; and (3) those with longstanding disabilities, facing comorbid, life-limiting conditions, although we place particular emphasis on the last group. Over the course of this 5-year undertaking, it became evident to us that the use of certain key words plays a significant role in the discourse of disability and end of life. One of these words is "suffering" and its use is the focus of our article.

In designing this study, we were concerned with discovering how laypeople use and understand the word "suffering" in end-of-life contexts. In order to analyze the data, we use discourse analysis as our methodology. Jørgensen and Phillips (2002) describe the word "discourse" as "a particular way of talking about and understanding the world or an aspect of the world" (p. 1). In the context of this work, we are using what Tonkiss (2004) calls "a broad social approach." This allows us to examine the way in which language is used to construct meaning. More specifically, we are looking at how the word "suffering" is used in what we call "everyday discourse" to reveal how members of the general public understand and conceptualize the term.

Our data were taken from a series of postings to the online forum "Staying in School." Called "The fight for the right to die," the discussion raised the following question in connection with the Rodriguez case: "Do you support legislation that legalizes assisted suicide or do you oppose it?" Comments were posted between February 3 and 13, 2008. Of the 155 total comments, we analyzed only those that specifically used the word "suffer" (or a derivative thereof). This narrowed our data set to 63 comments posted between February 4 and 12, inclusive.

Tonkiss (2004) describes three elements involved in discourse analysis. She characterizes them as "devices or tools for opening up the text, rather than a fixed set of analytic strategies" (p. 378). The first element is identifying key themes (Tonkiss, 2004). The second element is looking for variations in the data, with the aim of disrupting "the appearance of a 'smooth' piece of discourse, allowing insights into the text's internal hesitations or inconsistencies, and the way that the discourse aims to combat alternative accounts" (Tonkiss, 2004, p. 379). Finally, we paid close attention to the silences, which required us to read "against the grain", looking for gaps or things that were unspoken (Tonkiss, 2004).

AN ANALYSIS OF HOW LAYPEOPLE UNDERSTAND SUFFERING

In analyzing the data, three key themes emerged. The first theme focused on a discussion of when people suffer. The second theme showed how people are understood to suffer. The third theme that we uncovered considered how suffering should be dealt with. Variations in the data were rare but did reveal a religious understanding of suffering and an acknowledgement of the effects of treatment. We also examined what was not said in this online discussion: there was little consideration of the more holistic goals of palliative care and how suffering might be understood and managed in ways other than within the frame of assisted suicide. We will discuss each theme in turn.

When Do People Suffer?

Our data analysis reveals that people are understood to suffer in a number of circumstances. These include having a particular condition or being in a particular state, having an illness or disease, and being in pain.

State or Condition

Some people posting to the blog indicated that people suffer when they are in a particular state or condition of ill health including: (1) having a permanent disorder (Johnson, 2009), (2) being in a vegetative state (Girl_in_the_Front, 2008), (3) being incapacitated (Lucretia, 2008), and (4) dying. With respect to the latter, people were conceptualized as dying (1) slowly and painfully (wanttobefit, 2008), (2) a painful death (RoxyChic0529, 2008), and (3) from a serious disease (sweetklo020, 2008).

Illness and Disease

Those commenting also saw suffering in people who have an illness or disease. The notions of illness and disease were described by many people who entered the discussion and a number of illnesses and diseases were mentioned specifically in the context of suffering. These included: (1) chronic illness (Aries, 2008; heather, 2008; kortneywithak2, 2008; Lanlande, 2008; Pookie, 2008; superbright, 2008), (2) terminal illness (boolah, 2008; Chris Potts, 2008; chiquita5, 2008; KathleenB, 2008; mdowd, 2008; missmeliss, 2008; Pamber, 2008; the fear, 2008), (3) Alzheimer's disease and dementia (missmeliss, 2008), (4) AIDS (lil_princess86, 2008; missmeliss, 2008), (5) fatal illnesses/

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diseases (kortneywithak2, 2008; sk8rgrl, 2008; twin2, 2008), (6) incurable illnesses/diseases (bklynblog, 2008; EUrban, 2008; Petit Monde, 2008; Pookie, 2008; sunflower, 2008; Tara Johnson, 2008), and (7) being very ill (cali2119, 2008).

Pain

Pain was another central premise in conceptualizing suffering. Unlike the multiple dimensions of suffering mentioned in the palliative care literature, the everyday understanding of suffering centred on the notion of pain. Those who suffer were described as being in (1) so much pain (bb521, 2008; DaisyDown23, 2008; Jackedupballerina, 2008; Petit Monde, 2008), (2) a lot of pain (DivineArtistStevie, 2008; michelleL, 2008), (3) agonizing pain (Kortneywithak2, 2008; Tara Johnson, 2008), (4) severe pain (Reed Cramer, 2008), (5) critical pain (gjones17, 2008), (6) excruciating pain (tlawrence, 2008), (7) unbearable pain (dwtc, 2008), and (8) a great deal of pain (Dave, 2008; sk8rgrl, 2008).

How Are People Understood to Suffer?

After understanding when people suffer, we then turned to the question of how people are understood to suffer. Within this theme, we discovered four sub-themes. People who posted comments believed that people suffer without hope and while waiting to die. Sufferers are also enveloped by pain as they suffer. In expressing how people suffer, those who commented described people who suffer in a way that indicated that they had less value. Many people commenting also felt allowing someone to suffer, and denying them the option of ending their suffering by way of assisted suicide, was unacceptable.

Without Hope and Waiting to Die

Some people posted comments that reflected the notion that people who suffer are without any hope and without the prospect of a cure, recovery, or improvement, and are just waiting to die (bassprodigy, 2008; bb521, 2008; heather, 2008; JC_Lims, 2008; lil_princess86, 2008; M.Gonzalez, 2008; matthew, 2008; Petit Monde, 2008; the fear, 2008; tlawrence, 2008). Phrases in which this sentiment was raised include: (1) "practically gone" (Chris Potts, 2008), (2) waiting around and suffering until they die (JR8, 2008; Kortneywithak2, 2008), and (3) a "prisoner of their disease" (APhilibert, 2008).

Enveloped by Pain

Pain was a common theme when we considered how people are understood to suffer. We offer some illustrative examples. One person commented: "I think 'living' stops when one enters enbearable [sic] pain. 'Living' under these conditions is not really 'living' at all (dwtc, 2008). Another talked about avoiding spending one's "last few days on this earth in pain" (mdowd, 2008). Megan (2008) referred to "living for years in pain", sunflower (2008) discussed escaping from "the abyss of pain", and sunshine (2008) mentioned "living in agony". Finally, superbright (2008) envisioned a scenario in which "every moment of there [sic] life is filled with constant suffering."

Of Lesser Value

A number of people who commented in this blog alluded to people who suffer as having a life less valuable that those who do not suffer. They described this idea in a number of different ways. For example, DaisyDown23 (2008) said, "It is heartbreaking to watch them unable to function on a normal basis and their everyday norm is being physically and socially dependent on an aid." Tara Johnson (2008) wondered, "What is living if you can't actually enjoy Life?" and also lamented a life of not being able to "do anything on my own again." Matthew (2008) asked, "If getting up and just living was a struggle would you wanna [sic] live?" Others mentioned a bedridden life (heather, 2008), just lying in bed and being unable to "open their eyes or even move at times" (chiquita5, 2008), and having a "degenerating body" (Aries, 2008).

If Suffering is Allowed to Happen

A final sub-theme in understanding how people suffer is the idea that allowing people to suffer is wrong. Some people commenting referred to this as "torture" (bassprodigy, 2008), "inhumane" (bklynblog, 2008; sk8rgrl, 2008), and "cruel" (EUrban, 2008; sunshine, 2008).

How Should Suffering Be Dealt With?

The majority of people who posted comments to the blog felt that it was not right to leave people to suffer, and as a result, their suffering should be ended if that was their choice.

Suffering Should be Ended

Most people commenting saw the positive aspect of "ending" suffering through assisted suicide (APhilibert, 2008; Chris Potts, 2008; DaisyDown23, 2008; dwtc, 2008; J_Rambo, 2008; Jackedupballerina, 2008; Kortneywithak2, 2008; Pookie, 2008; Reed Cramer, 2008; Rashera88, 2008; RoxyChic0529, 2008; sunflower, 2008; superbright, 2008; the fear, 2008; twin2, 2008). This was more specifically expressed as: (1) a way of escaping from pain (Megan, 2008; sunflower, 2008), (2) a method of gaining peace

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(JR8, 2008; matthew, 2008; RoxyChic0529, 2008), (3) an end to misery (JC_Lims, 2008; missmeliss, 2008; Pookie, 2008), (4) a way to heal (J_Rambo, 2008), and (5) a way to help the sufferer (bklynblog, 2008; gjones17, 2008; twin2, 2008).

Furthermore, assisted suicide was indicated as providing a method of ending suffering in a manner that is painless (bb521, 2008), dignified (APhilibert, 2008) and humane (Pamber, 2008; Pookie, 2008; sk8rgrl, 2008). It was suggested that forcing people to suffer is wrong (B1ackMesa, 2008; matthew, 2008; Pamber, 2008). Instead, sufferers should be able to "let go" (sweetklo020, 2008).

Ending Suffering is a Right

Another major sub-theme is the notion that making decisions to end suffering is or should be (1) a right (Aries, 2008; bassprodigy, 2008; cali2119, 2008; Dave, 2008; gjones17, 2008; Jackedupballerina, 2008; Kortneywithak2, 2008; M.Gonzalez, 2008; Rashera88, 2008; sk8rgrl, 2008; SocialButterfly, 2008; sunflower, 2008; sunshine, 2008; superbright, 2008; Tara Johnson, 2008; twin2, 2008), (2) a choice (Ashley Marie, 2008; dwtc, 2008; JR8, 2008; lil_princess86, 2008; Megan 2008; mndz05, 2008; Pookie, 2008; RoxyChic0529, 2008) or, (3) an option (APhilibert, 2008; Ashely Marie, 2008; M.Gonzalez, 2008; michelleL, 2008; Tara Johnson, 2008). People are entitled to make such a decision for themselves (Aries, 2008; B1ackMesa, 2008; J_Rambo, 2008; JR8, 2008; Jenna, 2008; KathleenB, 2008; M.Gonzalez, 2008; matthew, 2008; Petit Monde, 2008; Rashera88, 2008; sweetklo020, 2008) and ought to be able to maintain control (RoxyChic0529, 2008) over their lives and their deaths.

Beyond Assisted Suicide

We also point out that several people commenting began their post by stating they were against assisted suicide. However, they held similar conceptualizations of suffering with those people claiming to be in favor of legalized assisted suicide. For example, michelleL (2008) said,

> I think suicide is suicide and I am very opposed to it no matter what! I BELIEVE IN GOD AND IT'S A SIN TO KILL YOURSELF OR ANYONE ELSE UNDER ANY CIRCUMSTANCES!!! I also think its [sic] wrong for a doctor to help you to kill yourself even if you are suffering and in pain. . .I don't how that would feel, *maybe if I was terminally ill and suffering I would want to die probably*- so I cant [sic] say whether I am against it or not! [emphasis added in italics].

Although she begins by denouncing assisted suicide, she continues the assumption found in the larger discourse that sufferers want to die. A similar comment was made by msjessi (2008).

> In my opinion, physician assisted suicide should not be legalized because it defeats the ultimate purpose of a doctor's goal which is to save lives, not take them. . .*Yes, there are some understandable points to these acts like assisted suicide causes suffering patients to be at ease*, but morally and logically it's wrong because doctors are helping patients who desire to kill themselves commit suicide [emphasis added].

Here again, the writer acknowledges the "common sense" opinion that assisted suicide allows the sufferer to be at ease. In a related point, Jackedupballerina (2008) wrote, "As a religious person I dont [sic] believe in suicide. *I can also understand if someone is in so much pain and sufferring* [sic] *that they want to end there* [sic] *life* they should have the right to do so" [emphasis added].

Variations to the Discourse

In our analysis, we did find a few examples of variations to the dominant discourse. These small ruptures suggest that suffering is simply a part of life and can be alleviated in a context other than assisted suicide.

Suffering is Part of Life

People who commented on suffering as part of life professed a religious outlook. One person said,

> I do not believe in any kind of suicide. . . I do think it is very unfortunate that a personwith a painful terminal illness would have to suffer enough to want to take their life. *But things in life happen, like pain, suffering, and dying*. I would not be asking some doctor for assistance in suicide if it were me. I would be praying to God to bring me to peace with Him. If he did so, I would know that was the will he had for my life. If he did not, I would know that it was not my time to return to glory. Suffering and in pain, or not. As odd as it may seem to some, there is a reason for everything [emphasis added] (boolah, 2008).

Lanlande (2008) noted that,

> When we are suffering we suffer for a reason only God knows why we are suffering the way we do. Well we have to let it be sometime because we do not what's God plan is for us. . .*when we're in pain*

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> *we should suffer as much as we can* and wait for our delivrance [sic] from God [emphasis added].

Finally, JC_Lims (2008) suggested that "My personal faith is no matter how suffer we are, there would be a time for us to leave this world in God's will."

Suffering Can be Alleviated

Only one person posting a comment to the blog voiced the opinion that suffering could be alleviated through means other than assisted suicide. Mony88 (2008) said, "Their [sic] are many ways were [sic] treatment helps the people that are teriminally [sic] ill. . ."

WHAT WAS LEFT UNSAID: AN INTERSECTION OF SUFFERING AND PALLIATIVE CARE?

This analysis of the everyday discourse of suffering reinforces Finlay's (2009) contention that "to laypeople the phrase 'unbearable suffering' conjures up images of patients on their death beds wracked with uncontrolled pain" (p. 1841). The vast majority of people who posted comments on the blog in the context of suffering had a very similar understanding of when people suffer, how people suffer, and how suffering should be dealt with.

No alternative conceptualizations of suffering that might concretely address the alleviation of suffering beyond the assisted suicide debate were really explored. In fact, one of the most interesting and obvious things we noted when analyzing the data was a complete disengagement between the everyday discourse and the palliative care literature relating to suffering.

The data confirm that people see pain as an integral component of suffering, although there is little acknowledgement of the role that pain management can play in controlling pain and consequently relieving suffering. There is also little evidence in the data to suggest that people are aware of ways in which suffering can be discussed and ameliorated in a more holistic way. If, as George (2009) suggests, "pain, indignity, hopelessness and agony" are indeed "suffering's acolytes" (p. 385), how can palliative care providers bring an alternative discourse into everyday conversations about suffering?

A number of authors have suggested ways in which suffering can be re-imagined. For example, Currow and Hegarty (2006) suggest that one solution to threats to the integrity of the self is through "connectedness" which "invites a relationship in which the carer's presence is one of humility, honesty, openness, and trust creating a relationship of mutuality and respect for the *wisdom within the suffering person's spirit*" (p. 134, emphasis in the original).

In their work on clinical approaches to cancer care, Lethborg et al. (2008) discuss four goals of care. The first goal is to encourage the person to believe that "life has meaning and purpose" (p. 62). Second, it is important to acknowledge a person's suffering because "suffering exposes the limitation of one's existence, bringing about a greater awareness of the meaning of life" (p. 62). Similarly to Currow and Hegarty (2006), their third goal is to strengthen a person's connections with others. Although people who suffer may initially withdraw from others, Lethborg et al. (2008) suggest that many people "return" and in so doing can share their suffering. The final goal is to ensure the person receives "optimal physical care" (p. 63). The authors see this as a starting point to relieving suffering. From this, the psychological and existential "can be attended to" (p. 63).

Chochinov's (2002) model of dignity-conserving care is another way of understanding and talking about suffering using a new script. This model is based on the notion that the preservation of dignity is paramount in considerations of palliative care and "considers 3 broad areas of influence on individual perceptions of dignity" (p. 2254). The first area is illness-related concerns, or "those things that result from the illness itself, and threaten to, or actually do, impinge on the patient's sense of dignity" (pp. 2254–2255). The second area is the dignity-conserving repertoire, which "incorporates those aspects of patients' psychology and spiritual landscape that influence their sense of dignity" (p. 2256). The final area of influence is the social dignity inventory or the "social issues or relationship dynamics that enhance or detract from a patient's sense of dignity" (p. 2256).

CONCLUSION

Rather than being all inclusive, these examples are meant to represent some of the ways in which wider notions of suffering can be introduced into the everyday discourse. We suggest that such re-conceptualizations can have a real impact upon how we think about suffering and consequently how people who suffer are treated. A move away from automatically assuming that people suffer without hope and with indignity means that we can re-envision these indivudals and what suffering might mean. If we see sufferers as bedridden, degenerating, dependent, and without normal functioning, we cannot possibly imagine a life or death of worth or value. However, if we focus on finding meaning and purpose, connecting through relationships, and promoting dignity on multiple levels, we will see

those who suffer as deserving of the utmost care and respect.

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