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## ACCOUNTS OF SUICIDALITY IN THE HUNTINGTON DISEASE COMMUNITY\*

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### ABSTRACT

Health professionals, researchers, and philosophers have debated extensively about suicide. Some believe suicides result from mental pathology, whereas others argue that individuals are capable of rational suicide. This debate is particularly poignant within illness communities, where individuals may be suffering from chronic and incurable conditions. This article engages with these issues by presenting the accounts of 20 individuals with Huntington disease (HD), a fatal degenerative condition, and 10 informal caregivers (e.g., spouses). Suicide is a leading cause of death amongst people with HD, with an incidence rate many times higher than the general population. In contrast to the majority of the academic literature on HD suicidality, study participants did not connect suicide with mental pathology. Instead, they perceived suicide as a response to the realities of living with HD, such as prolonged physiological degeneration and the need for long-term intensive health care. These findings are subsequently discussed in relation to the rational-pathological suicide binary.

Suicide is one of the leading causes of death in North America, accounting for an estimated 1 to 1.5% of all mortalities and occurring on average every

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17 seconds (Statistics Canada, 2010; Suicide.org, 2011). Suicide rates are often markedly higher amongst people with illnesses, particularly those with terminal illnesses, dementia or neurological conditions (e.g., Paulsen, Hoth, Nehl, & Stierman, 2005a). Some researchers assert that the suicides of ill individuals may be “rational,” emerging from a well-reasoned assessment of their present and future conditions (e.g., Leeman, 2009). However, other medical professionals, particularly psychiatrists, disagree with this perspective and argue that the majority of all suicides result from reversible conditions, such as depression (e.g., Rabins, 2007). This debate over suicide can have serious ramifications for illness communities, as some have argued that ignoring rational suicide may result in inadequately prepared medical staff, paternalism, and hopelessness (Cutecliff & Links, 2008; Hewitt, 2010; Mayo, 1998; Westefeld, 2004).

The rational-reversible suicide dichotomy is particularly poignant in relation to Huntington disease (HD). George Huntington first described HD in 1872, listing suicide as a primary feature and calling it an “insanity which leads to suicide” (1967/1872, p. 35). Suicide is presently the second to fifth leading cause of death amongst people with HD, with rates higher than those of both the general population and other neurodegenerative conditions (e.g., Roos, 2010).

The disease itself is a genetic, degenerative, and fatal condition with symptoms that include mood imbalances, memory loss, personality changes, and chorea (Paulsen, 2004). Disease symptoms typically appear during the late 30s or early 40s, with death resulting from complications from the disease occurring 10 to 15 years later. Although the disease progresses at a different rate for different individuals, the newly diagnosed are typically able to function in a private residence and some are able to maintain employment. As the disease progresses, however, individuals often relinquish their driver’s license and retire early. In the latter years of the disease, advanced motor and cognitive disruptions typically lead to managed care. Since 1993, a genetic test has been available that allows individuals to know whether they will develop the disease within a normal lifespan; thus, people with HD are often fully cognizant of their condition years before symptoms develop. Although there are medications to alleviate some symptoms, there is no cure for HD.

Researchers have investigated the high suicide rate amongst people with HD, primarily in relation to predictive testing. The majority of these studies conclude that suicides result from psychosocial issues (often left undefined), depression, or neurological damage, and that these factors can be addressed through mental health treatment and adherence to testing protocols (e.g., Robins-Whalin, Bäckman, Lundin, Haegermark, Winblad, & Anvret, 2000), which map well onto arguments about the reversibility of suicide. Only a few authors hinted at the concept of rational suicide, with only a single empirical study mentioning it explicitly (Paulsen, Nehl, Hoth, Kanz, Benjamin, Conybeare, et al, 2005b). Indeed, Bird (1999) noted that there is debate in the medical community over

the ability of people with HD to even be capable of rational suicide. This research on suicidality also consists almost exclusively of literature reviews and quantitative studies, with only Kessler's (1987a) mixed-methods study making limited use of qualitative data. While these studies document suicide rates and risk factors, they do not include accounts of the HD community. This article aims to address this literature gap by providing the first completely qualitative study of suicidality in the HD community.

This article's findings present the perspectives of HD community members on suicide, as well as individual accounts of suicidal actions. In contrast to the literature, the HD community did not connect suicide to mental illness but instead situated it as a response to the realities of the disease, such as degeneration and concerns over long term care. The article concludes by highlighting the ramifications of perceiving all HD suicides as reversible, as well as discussing the usefulness of the rational-reversible suicide binary.

### SUICIDE AND HUNTINGTON DISEASE

Researchers across different countries have overwhelmingly concluded that suicide is a leading cause of death amongst people with HD. For instance, a Dutch study observed that 5.6% of all deaths of HD gene carriers were suicides, with suicide being the fourth leading cause of death (Sorensen & Fenger, 1992). American studies suggest that 9.3 to 13% of all deaths in the HD community are suicides, compared to 1 to 1.5% in the general population (Bird, 1999; Di Maio, Squitieri, Napolitano, Campanella, Trofatter, & Conneally, 1993; Paulsen, Hoth, Nehl, & Stierman, 2005a). Other American studies estimate that the suicide rate in the HD population is 3 to 23 times that of the general population, with suicide listed as the second or third leading cause of death (Roos, 2010; Schonfeld et al., 1984). These suicide rates are also higher than those of other neurodegenerative conditions (Arciniegas & Anderson, 2002; Paulsen et al., 2005a).

The majority of studies on HD and suicide focus on the impact of genetic testing. Since the test for HD was developed in 1993, researchers have expressed concerns over its ethical implications, effects on mental health, and impact on suicidality (see Coutasse, Pekar, Sikula, & Lurie, 2009). However, some researchers (e.g., Paulsen et al., 2005a) have suggested that testing actually decreases suicidal ideation, as suicide rates appear to be higher in undiagnosed but symptomatic individuals compared to symptomatic and diagnosed individuals. Additionally, a recent Canadian study on suicide and genetic testing reported zero suicides in a cohort of 181 test-takers over a period of 14 years (Dufranse, Roy, Galvez, & Rosenblatt, 2011). A worldwide study on suicide and predictive testing reported similarly low rates, with only five completed suicides and 21 attempts in a 2-year span following the predictive testing of 4527 participants (Almqvist, Bloch, Brinkman, Craufurd, & Hayden, 1999).

Utilizing this data, another study concluded that initial concerns over genetic testing and suicidality “have not been realized” (Creighton, Almquist, MacGregor, Fernandez, Hogg, Beis, et al., 2003).

In contrast, Bird (1999) has suggested that the impact of genetic testing on suicide is unclear. He specifically questioned the interpretation of the statistics used in both the Almquist et al. (1999) and Creighton et al. (2003) studies, noting that their cohort has a suicide rate 30 times greater than the North American population once their numbers are converted to yearly averages. Meiser and Dunn (2000) also complicated the beneficial influence of genetic testing by observing that suicidal individuals were less likely to volunteer to take the test. Accordingly, Coustasse and colleagues (2009) concluded that the majority of HD researchers are undecided about the ethical ramifications of genetic testing and its potential harms.

Studies have also explored connections between suicidality and symptom onset. Both Schonfeld and colleagues (1984) and Di Maio (1993) documented high suicide rates amongst individuals who had symptoms, particularly those who had not yet received a diagnosis. Almquist and colleagues (1999) also related symptom onset to suicide; however, it is important to note that while all of the individuals in their study who completed suicide ( $n = 5$ ) displayed symptoms, this was the case for only half of the attempted suicides (11/21). More recently, Paulsen et al. (2005a) suggested two “critical periods” of suicide risk, the first occurring when individuals develop “soft” neurological symptoms pre-diagnosis, and the second when diagnosed individuals move from the first to second stage of the disease.

Depression is often listed as a symptom of HD (e.g., Paulsen, 2004) and is thought to be a major component of all suicides. For instance, some studies have estimated that depression was present in 90% of individuals who committed suicide in the general population (e.g., Conwell, Olsen, Caine, & Flannery, 1991). Depression is considered a medically reversible condition that can be treated with psycho-pharmaceuticals and therapy. While it is estimated that 8% of the general population is affected by depression, the prevalence amongst people with HD has been estimated at 9 to 60%, although between 40 and 50% appears to be the most likely range (Paulsen et al., 2005b). Paulsen and colleagues (2005b) also caution that depression is often underestimated in those in the advanced stages of the disease, due to difficulties in assessing those with significant cognitive impairment. Depression has been observed to increase in tandem with suicidality in gene-positive cohorts (Larsson, Luszcz, Bui, & Robins-Wahlin, 2006), but it is not correlated with the number of cytosine-adenine-guanine repeats that cause HD or with cognitive and motor impairment (Paulsen et al., 2005b). Researchers have observed a relationship between suicidality, depression, and HD, particularly amongst those with a history of mental health problems (e.g., Kessler, 1987a). However, several studies also identified cohorts of suicidal but non-depressed individuals (e.g., Paulsen et al., 2005b; Robins-Whalen et al., 2000). Although

depression appears connected to HD suicidality, it does not appear to account for all suicidal behavior.

Researchers have made an unequivocal case about the link between HD and suicide and have also identified key periods of suicide risk. However, there is still ambiguity over the influence of both genetic testing and depression in suicidality. The following section turns from the suicide rates and focuses on the perspectives of HD researchers on the actual act of suicide.

### **RESEARCHERS' AND HEALTH PROFESSIONALS' PERSPECTIVES ON SUICIDE**

A number of studies have suggested that physicians generally hold a negative view of patient suicides, euthanasia, and assisted suicides. For instance, a survey of the general public and physicians determined that 58% of the public believed that a physician should accept patient requests for euthanasia, while only 31% of the physicians concurred (Lindblad, Juth, Fürst, & Lynöe, 2010). It was similarly observed that mental health professionals (particularly psychiatrists) are skeptical about both euthanasia and the possibility of rational suicide, particularly given the connections between mental illness and suicide (e.g., Kleespies, Hughes, & Gallacher, 2000; Knizek, Akotia, & Hjelmeland, 2010; Leeman, 2009).

The reservations that physicians hold vis-à-vis suicide also apply to HD. Bird (1999) noted there is substantial debate over the potential for rational suicide by people facing such “an overwhelming sea of troubles and unbearable life” (p. 1291). This attitude is perhaps captured in some recent surveys of medical professionals. Elger and Harding (2004) found that 44% of medical students thought that a woman with HD who was suicidal, but not terminally ill, should be hospitalized against her will to prevent her suicide. Lindblad and colleagues (2010) also observed that a distinct majority of physicians (57-89%) disapproved of a variety of suicide options for a competent and non-terminal HD patient.

In a similar tone, the vast majority of articles on HD suicidality argued that suicides could be prevented via testing protocols and counseling (e.g., Almqvist et al., 1999; Coutasse et al., 2009; Paulsen et al., 2005a). In fact, Dufranse et al. (2011) credited their team’s adherence to testing protocols for the absence of suicides in their cohort. A plethora of articles advanced a similar argument in reference to psychological counselling (e.g., Meiser & Dunn, 2000). Robins-Wahlin et al. (2000) concluded that HD suicides resulted from psychosocial determinants and thereby suggested that psychologists should take a “central role” in HD care and testing. After connecting suicide to depression, Paulsen and associates (2005b) also observed that suicides might be prevented by clinical intervention, stating that, “unlike Huntington’s disease itself [sic] depression is typically a treatable disorder” (p. 497).

The notion that suicide can be addressed through therapeutic interventions was stated most explicitly in a newsletter available on the Huntington Disease

Society of America's (HDSA) website (2011). The newsletter presents three personal accounts of suicidality, which are followed by a lengthy response from a clinician. The clinician argues that the high HD suicide rate can be addressed by both therapy and communication with loved ones. Although the physician outlines the criteria for rational suicide, he states that HD does not meet these criteria, as the disease is not a "terminal illness" in the necessary sense. The clinician closes by noting that many of his patients "have chosen to live until they succumb to the physical aspects of the disease. And some . . . will with great effort say that they appreciate their lives for the remaining contacts they have with family or caretaker" (p. 3). The physician thereby concludes that suicidality can be reversed, people with HD cannot commit rational suicide, and that individuals who die from the physical symptoms of the disease value their decision.

The overwhelming majority of HD research articles advance an argument of reversibility, with only three authors making explicit reference to rational suicide. In commentaries on suicide, both Bird (1999) and Kessler (1987b) questioned the possibility of rational suicide given the symptoms and difficulties faced by people with HD. The third reference to rational suicide appeared in an article by Paulsen and colleagues (2005a), who briefly suggested that further research is needed to separate rational suicide from the suicides of individuals with major depression.

Discussions of rational suicide in the HD suicide literature are brief and infrequent. Researchers instead emphasized the reversibility of suicidality. This attitude is perhaps unsurprising given the norms and ethics of the medical profession. Having presented the perspectives of researchers, this article will now focus on the accounts of the HD community.

## METHODS

Twenty people with the HD gene were recruited for this study and all but three had confirmed symptom onset. Symptoms ranged extensively, from the three aforementioned asymptomatic individuals, to two participants who required managed care. Ages ranged from 23 to 83 ( $M = 54$ ); 12 of the 20 participants were male. Ten caregivers were also interviewed. Nine of the caregivers were spouses and one was a grandmother. The ages of the caregivers ranged from 37 to 64 ( $M = 54$ ).

After receiving ethics approval, participants were recruited with the aid of a social worker operating a HD center. Potential participants were contacted via e-mail or at a support group. Interested individuals were given the author's contact information and a flyer explaining the nature of the study. Snowball sampling was also used to recruit eligible individuals.

In-depth semi-structured interviews were the primary source of data (Weiss, 1994). Interviews were conducted in person ( $N = 26$ ) or over telephone ( $N = 4$ ) between 2008 and 2009. Interviews occurred in a time and place of the

participant's choosing. All interviews were digitally recorded and ranged from 30 minutes to 2½ hours in duration. The author took detailed fieldnotes upon completion of the interviews (Emerson, Fretz, & Shaw, 1995).

The study was informed by grounded theory. Data analysis utilized line-by-line analysis, thematic analysis and case comparison. Line-by-line analysis was conducted on each transcript to generate large codes to organize the data (Strauss & Corbin, 1998). This structure was then used to code the data using *NVivo8*<sup>TM</sup> software. Coding runs were then read multiple times to develop inductive themes. Case comparison analysis was also conducted to compare each individual case across the entire participant sample (Miles & Huberman, 1994). This technique allowed the data to address both particulars and aggregate trends.

Part of the study focused on death and dying, but participants were not asked about suicide unless they explicitly raised the topic, which occurred often. One participant requested that part of his discussion of suicide be “off the record.” He is not referred to by a pseudonym or demographic information as per his request. This participant has read and approved the portion of the findings that deals with his views.

## FINDINGS

Many participants avoided fatalistic statements about death, were grateful for the support they received from health professionals, and were optimistic about the prospect of a cure for HD; however, participants also frequently discussed suicide during interviews, typically while commenting on death or health services. The vast majority of participants expressed sympathy toward suicidal individuals. Suicide was related to the realities of living with HD, rather than to mental illness. The findings are presented in three sections. The first focuses on the perspective of informal caregivers, the second discusses suicidality in HD families, and the third reviews personal accounts of suicidal behavior.

### The Perspectives of Informal Caregivers

The degenerative aspects of HD particularly distressed informal caregivers. Some referred to HD as a “death sentence” or a “life sentence,” while one person stated that the personality changes made her feel like she had “already lost” her partner. The caregivers expressed notable concern over their loved one's future quality of life and several wished that there were ways to avoid future suffering. For instance, Rose (54), discussed the possible benefits of suicide and euthanasia:

[Husband's] uncle, he was in fetal position for many years, yet they still fed him fluids. My question is, is that quality of life? He has an aunt in [City], she probably weighs eighty pounds and she looks literally like a skeleton and it blows me away that she's still moving around, but she's very demented

and is just a hopeless little piece of human being sitting on the ground just fussing around with a piece of paper or her purse. It's very degrading.

Here Rose argues that the prolongation of life is sometimes inhumane. She contrasted this account to her experience in her home country, where people were much more "open minded" about ending their lives, and, as such, situations like the one she described could be avoided.

While caregivers wished that there were methods to limit their loved one's suffering, most did not endorse suicide, euthanasia, or assisted suicide; however, many of those who did not support these methods still conceptualized suicide as an individual choice. For example, when Natasha (37) first met her partner, he was openly suicidal, due to both his family experience and concerns about the advanced stages of HD. Although Natasha did not endorse suicide, she was still supportive of his right to take his life:

At first when we discussed it I said well, "if you're going to do it then you should have somebody there. I'll be your friend if that's your decision."  
At first, a few years back, I came to that acceptance, "if you want to commit suicide, that's your business."

However, after they decided to get married, Natasha informed him that she did not "want to see him go down that road [suicide]." Although she was still adamant that it was his right to choose, Natasha repeatedly expressed her preference that he not take his life. She stated that her partner now has a renewed vigor for life and no longer has suicidal tendencies. Indeed, she summarized her role in her partner's life by stating that, had they not met, "he would be dead."

Although caregivers refrained from normative judgments and understood the motivations of suicidal individuals, they were not all as "hands off" as Rose and Natasha. One caregiver, Edna (46), encouraged her husband to seek professional help. Edna was her partner's primary support for many issues, including his Obsessive-Compulsive Disorder and childhood abuse. When her partner attempted suicide, she was brought to her limits as a caregiver:

He attempted suicide by taking all of the medication, which was not something I ever dreamed that he would do. I guess he just got into a pretty depressed state and was really missing his sister [who died from HD] and I guess he did not know how to deal with those feelings. And the fact that he was symptomatic now and didn't want to end up in long-term care. And it was to do with, he's afraid of the dying process. I told him, "I can help you with a lot of things, I'm pretty smart and pretty logical, but this I can't." So, I know that [managed care] is coming and this has been so hard so far, and I know that it's just going to get even harder.

This suicide attempt took Edna by surprise, but she interpreted it as a response to fears about the illness and managed care. Edna was the only participant in this study who explicitly connected suicide to mental health issues, and after this attempt she arranged for her and her husband to attend counseling together.



However, she also connected suicide to the realities of the disease, particularly long-term care and witnessing another family member experience the advanced stages. While Edna, like Natasha, depicted suicide as an individual's choice, it is also important to note that they were both vital in ameliorating their partner's suicidality.

Caregivers faced a tension between providing care for their loved one and not wanting to watch them unduly suffer. Several caregivers, like Edna and Natasha, resolved this tension by suggesting that suicide was an individual choice while overtly demonstrating their disapproval of the act. Although Edna connected suicide to mental health issues, suicide was more commonly associated with avoiding undue suffering and the advanced stages of HD.

### Discussions of Familial Suicides

Numerous participants had relatives with HD who had committed suicide. These individuals were typically considered "at-risk" for suicide attempts by health professionals and received additional counseling. For instance, Mark (60, diagnosed in 2009) visited a clinician every 6 weeks post-diagnosis. He explained that this was contextualized by his father's suicide, but stated he would never end his own life. He said, "I told [the doctor], that as a survivor of someone who committed suicide, I would never do it." Although Mark felt depressed after his diagnosis, suicide was not a consideration given the grief he felt over his father's passing.

Like Mark, Samuel (47, diagnosed in 2003) felt depressed post-diagnosis. His father's suicide raised concerns amongst healthcare professionals that he would consider ending his life and he acknowledged during our interview that he was suicidal for a period of time. While neither Mark nor Samuel decided that suicide was an option for them, they both expressed understanding for their father's actions. Samuel discussed this as he detailed his father's suicide, which occurred when he was 12 years old:

We had a farm and, and one day he [father] just kind of brought in the veterinarian and he put all the animals to sleep on the farm. I guess he felt maybe we couldn't take care of them. Another day he took me aside just made sure I knew how to run the farm, and stuff like that. And, of course, what happened was he killed himself. But when you're sick, when you are an adult you suddenly realize how difficult decisions are, when you have Huntington's and stuff like that too. So things that didn't make a lot of sense back then tend to be a little clearer as an adult. I always felt it was a good decision. He had a mum in the hospital for 30 years and I guess it was a big commitment on the family; I'm sure for him. To go visit her all the time and she was quite shaky and things. It wasn't a very bright future for Huntington's at the time. So I can certainly understand why he made that decision and I think he really kind of did it for our family's benefit too.

Samuel's father's actions greatly confused him when he was younger, but now that Samuel also has HD he believes that he understands his father's actions with new clarity. He did not connect his father's suicide to mental health concerns, but did relate it to the bleak prospects for treating HD and his father's knowledge of the advanced stages. Samuel also suggested that there was an altruistic motive to the suicide and that it was partly committed to assist the family.

Although Samuel understood his father's decision, he was still traumatized by the suicide and was visibly emotional during our interview. For another participant<sup>1</sup>, his family member's suicide was free of any traumatizing emotions. Indeed, this participant emphasized that his relative's suicide was an unequivocally positive event:

He had this good evening with his brother. A goodbye evening. He went home and said, "I've had a great evening this evening," he wrote out a little note. He said, "I've decided now to, to end my life and I have the proper medicines and I'll have no pain" and he did it himself. He said, "I would just like you to come and find me" um "or call the authorities" you know, "I'll be at home here" and he mailed the letter. His brother didn't open the letter until the following day of course, then he realized of course his brother was just laying in the bed dead, no problem there. So that's how it went. And then he asked [his brother] to explain it all to the family and it's no problem at all. Nobody was the least bit—everybody was kind of happy about it actually.

In this participant's view, suicide provided his relative with a way to die that was respectful and free from suffering. The suicide was well planned and is portrayed as being in accordance with the wishes of both the individual and his family. Indeed, the participant did not include any accounts of grief or loss that the family members felt at their loved one's passing. This family member's suicide informed this participant's view that suicide was an acceptable option for people with HD and that the choice should not be stigmatized. As will be discussed below, this participant planned to take his own life and he perceived his relative's experience as a strong argument for the benefits of such actions.

Whether or not they themselves were suicidal, participants with a familial history of suicide supported their relative's decision to end their lives. One participant used a relative's suicide to advance the legitimacy of suicide for people with HD, while other participants cited a relative's suicide as a motivating factor for not taking their lives. None of the participants connected a relative's suicide to mental pathology, but did suggest suicide as a way to avoid future suffering and degeneration.

<sup>1</sup> Participant's name and demographic information withheld at his request.

### Accounts of Suicidality

Two study participants explicitly discussed their own suicidal actions. One individual, Phyllis (23, diagnosed in 2008), recounted her past suicide attempts while the other described a potential attempt. As discussed above, the unnamed participant's suicidality was partly informed by the benefits he perceived in a relative's suicide. He further contextualized his perspective by recounting his experiences of growing up in a very religious environment. He rejected many of his childhood teachings and became an atheist. Before the recorders were turned on for our interview, he asked me several vague questions about my religious affiliation. He also asked that the recorders be stopped for conversations about a "particular topic." This topic was revealed to be suicide and he was concerned with how the recording could affect aspects of his future life. These sections of the conversation have been withheld, but he did give permission to present the following:

He [Uncle] was a doctor. We kind of got along well. And one time we were out for a walk and I told him I would, if I got really sick at the end of my life, I would [commit suicide]. By then I had known about HD for five years, so I was talking to him about stuff like that. And he understood. So I told him that if it became a problem for me I would do that. It's not a big deal. Because my attitude is like life is like a gift everyday. Every day is like a free day to me. And not every day is a good day and not every day is equal but in general it's pretty good. So I am not worried about that kind of thing later on. I think as long as I'm physically okay, that's good. But if I start to go mentally, I will probably think that's very depressing. And I'll probably be depressed by that whole idea because my whole being is very mental oriented in a way. That's sort of how I see life, and I've had all these nice mental thinking days of my life. And I regard my religious days as not really fully living I was living in fear of funny things. Superstitious things.

This respondent avidly rejected the religious teachings of his youth and gravitated to an atheistic perspective that he believed did not stigmatize actions like suicide. He connected his perspective on suicide to his personal identity and a lifelong process of intellectual development. Because he believed his mental abilities were so central to his identity, he was not willing to continue living after they began deteriorating; however, in contrast, he did suggest that he would be willing to endure the physical symptoms of HD. This participant also disconnects his ruminations of suicide from a negative mental state by stating that "life is like a gift everyday" and life is "pretty good."

The unnamed participant's logical argument on suicide stands in stark contrast to Phyllis' account of her recent suicide attempt. She stated that she had felt "suicidal depression" her "whole entire life" and that she was often taking anti-depressants. She connected this to watching her mother deteriorate and

pass away from HD when she was a young girl, which she stated was like “watching her die my whole entire life.”

Prior to her own confirmatory genetic test, Phyllis was certain that she would not inherit the gene for HD. To her disappointment, her test came back gene-positive. Phyllis felt depressed and suicidal, despite her attempts to remain optimistic. She moved away from her family to a new city, where she struggled to meet new friends.

During her first winter in the new city, Phyllis attended a party in a nearby town. She became angry and left the party after her friends started to pressure her to consume cocaine. In a decision that echoes the actions of Phebe Hedges walking into the sea (Wexler, 2008), Phyllis decided to remove her winter clothing and lay down in the snow:

And so I went walking to this lake ‘cause I had a plan to fall—just lie down in the snow so I wouldn’t have to get up anymore and deal with anything. Then I was lying there in the snow thinking “what am I doing?” after a bit, “I shouldn’t be doing this; I am such a frickin moron!” And it was really cold out, and I managed to lose my mitts and my toque and everything. So I realized this after a bit of time of lying out there that I was like, “ah, this is stupid” so I got up and I was like stumbling through the snow trying to get back to like the road. I fell a couple of times along the way and then the last time I just couldn’t get up anymore ‘cause my body was like so like cold and frozen. And I was lying there and I could seriously—it was just disgusting—my hands and everything were just like frozen, it was gross. And I was staring up praying like desperately “Oh God, what have I got myself into? I can’t do this, I’m so stupid!” And I’m like saying goodbye and then all of a sudden my hands were instantaneously warm. And I was like—my God! Freaked out, jumped up, ran through the snow and there was a car so I hailed it, and it was a police car and they took me back to the housing place where I was staying.

This was the second time that Phyllis had attempted to commit suicide in this particular town. Although she mentioned several times during our interview that she had bouts of suicidal depression, when asked if her feelings of depression were related to HD, Phyllis stated that “it definitely has a bit of a connection,” but believed that her mother entering a nursing home and her father’s second marriage were what “really changed everything.” Phyllis also did not connect this suicide attempt to her feelings of depression, but instead loosely connected it to a number of issues, including positive feelings toward her mother, anger toward the world, excessive drinking, and her loss of faith in God.

Phyllis and the unnamed participant are both at stages of HD that have been associated with suicidality (Paulsen et al., 2005a), but they experience suicidality in markedly different ways. The unnamed participant’s perspective on suicide has emerged from a lifelong ethos, prior experience with suicide, and the culmination of a rational decision-making process. This participant has clearly

delineated which symptoms he is willing to suffer and which symptoms are too great of burdens. In contrast, Phyllis' perspective on suicide is more ambivalent. She attempted suicide numerous times, but after placing herself in potentially fatal situations decided she had made a mistake. She appears to display hallmarks of reversible suicide, as she stated numerous times that she had "suicidal depression"; however, she did not connect her suicide itself to mental health issues and similarly did not connect her depression to HD, thus raising into question how treatable she perceives her suicidality. While the nuances of Phyllis' account complicate the notion of reversible suicide, the unnamed participant seems to represent a perspective of rational suicide that is largely absent in the literature.

## DISCUSSION

The experiences of these participants are revealing, particularly so given the anticipated increases in both dementia and neurological diseases in subsequent years (e.g., Arciniegas & Anderson, 2002; Haw, Harwood, & Hawton, 2009). Similar to individuals with amyotrophic lateral sclerosis (Achille & Ogloff, 2003), respondents suggested that suicide was a means to avoid prolonged suffering and degeneration. They also expressed sympathy for suicidal individuals and refrained from connecting suicidality to mental pathology, even if they were not suicidal themselves. In contrast, HD researchers have largely overlooked the possibility of rational suicide and instead treated suicide as reversible (e.g., Larsson et al., 2006). Indeed, one HD resource claimed that all suicidal individuals should be considered depressed until proven otherwise (Rosenblatt, Ranen, Nance, & Paulsen 1999). This view is reflective of broader arguments on the reversibility of suicide, which often posit that upwards of 90% of all suicides are connected to mental illness (e.g., Conwell et al., 1991). However, numerous researchers have critiqued studies that equate suicide *ipso facto* with mental health problems (e.g., Shneidman, 2000). Additional research also argues that individuals with mental illnesses are capable of insight and their conditions do not negate rational thought (Cutcliffe & Links, 2008; Hewitt, 2010). This research and the accounts of the present study's participants suggest that there are problems involved in viewing all HD suicides as the result of irrational, mentally ill individuals and considering reversible suicide itself as a clear and concise category.

Researchers frequently suggested that psychological counseling could ameliorate suicidality (e.g., Almqvist et al., 1999; Robins-Wahlin et al., 2000). This is certainly a logical course of action, particularly if individuals are suffering from a psychiatric disorder. However, the majority of this study's participants did not discuss counseling. The absence of counseling from participant accounts is perhaps most poignant when considering Phyllis' experiences, which appear to reflect many features in the HD research (e.g., Paulsen et al., 2005a; Robins-Wahlin et al., 2000).

Instead of relating her suicide attempts to these, or other aspects of HD, Phyllis highlighted the effect of familial changes. Given that she appears to display many of the hallmarks of reversible suicide, it is perhaps troubling that Phyllis did not touch on issues of psychiatric care. Her experience suggests that there are potential problems in mental health messaging in HD care, despite the almost uniform focus on reversible suicide in the literature.

In contrast to counseling, the role of caregivers in suicide amelioration was neglected in the literature (cf. HDSA, 2011). Indeed, Kessler (1987b) argued that caregivers could be detrimental to people with HD, stating that “the affected person is often induced to kill him- or herself to relieve the sense of burden and helplessness from their unaffected caretakers” (p. 317). This statement is echoed in several more recent works on suicide and neurological conditions. For instance, Cooley (2007) argued that individuals with such illnesses are a burden to both their family and society and thereby have a moral duty to commit suicide. Although many caregivers in this study discussed feelings of burden, grief, and loss, there is nothing in their accounts that validates the cynical perspectives advanced by Cooley. Caregivers did not endorse forms of suicide to relieve their own burden, but to prevent what they perceived as their loved one’s unnecessary and prolonged suffering. The majority of participants also noted that caregivers provided irreplaceable psychosocial comfort and two caregivers explicitly stated that their actions were pivotal in decreasing their partners’ suicidality. These aspects of caregiving were predominately omitted from the literature, while counseling was the most commonly advocated solution to suicidality. Ironically, in this study, the benefits of counseling were only raised by a caregiver, who was crucial in facilitating her partner’s entrance into it.

Both caregivers and individuals with HD expressed deep concerns over what they perceived would be a slow, drawn out death from the disease. Particularly vivid was Rose’s description of what she felt were the degrading living conditions of her husband’s parents. These perspectives on the palliation process recall Lawton’s (1999) discussion of “dirty dying” in hospice care. Lawton noted that family members often felt their loved one was dying without “any dignity” and it would have been easier to watch them die quickly, rather than “deteriorate and rot away slowly” (p. 140). A desire to avoid such deaths was consistently emphasized in accounts of suicide in this study. However, this employment of suicide as a means to avoid future suffering or “dirty dying” appears to conflict with medical perspectives that emphasize the utility of continued treatment and the optimism of medical advancements (e.g., HDSA, 2011). This perspective in the HD suicide literature is reminiscent of what Frank (1995) called the “restitution narrative,” which he states is the predominant narrative in modern medicine. This narrative emphasizes a process where individuals fall ill, receive treatment, and then recover. The conceptualization of HD suicides as reversible easily fits this narrative, with researchers suggesting that people become suicidal, receive appropriate care, and are then no longer

suicidal (e.g., Robins-Wahlin et al., 2000). In contrast, the rational suicides of the ill disrupt this narrative both by perceiving medical intervention as no longer relevant and by foregoing continued opportunities for restitution. Frank (1995) suggests that medicine can become “obsessed with cure” and that the restitution narrative can “crowd out any other stories” (p. 83). This appears to be the case for HD, where the tensions between avoidance of “dirty dying” and the “restitution narrative” result in the negation of rational suicide, and where accounts similar to those of Rose, Samuel, and the unnamed participant are therefore not included.

There are also a number of contradictions that become apparent once suicides are exclusively perceived as reversible. For instance, as both Mayo (1998) and Leeman (2009) note, individuals with serious illnesses are typically allowed to refuse life-prolonging treatments without being reviewed by a psychiatrist. These people are often in comparable positions to ill individuals who commit suicide and their decisions have similarly fatal consequences. Yet their actions are not assessed from a mental health standpoint. Despite the resonance between these courses of action, only one seems to be identified with irrationality. The research on HD suicides also contains such connotations between mental illness and rational choice. This is most clearly seen in the HDSA (2011) newsletter where a physician eliminates the possibility of rational suicide, but then advocates that people with the disease choose to die from the physical symptoms. This argument paradoxically depicts irrational suicide as a choice, while also suggesting that it is more appropriate to die from the physical, rather than the psychiatric, symptoms of the disease. Individuals with HD are thereby placed in a double bind. Suicide is depicted as emerging from symptoms of the disease, but one that individuals cannot succumb to, as well as both an uncontrollable affliction and a conscious decision. People with HD are thus accorded all of the responsibility but relieved of the agency that is associated with rational suicide.

Some researchers have argued that the majority of suicides are irrational, and that rational suicides, if such a thing exists, are exceptionally rare (Conwell et al., 1991; Rabins, 2007). Others have stated that not only are rational suicides possible, but that many ill individuals are obligated to complete such acts (e.g., Cooley, 2007). Each of these extreme positions has its shortcomings, as ignoring rational suicide may result in harms (Cutecliff & Links, 2008; Hewitt, 2010; Mayo, 1998; Westefeld, 2004), while some rational arguments describe suicide as a simplistic solution to a heterogeneous set of problems (e.g., Cooley, 2007). Placing this study’s participants in dialogue with such literature suggests that the rational-reversible suicide binary may not be the most helpful paradigm for researchers, health practitioners, or illness communities. Just in reviewing participant accounts reveals aspects of suicide located at either pole of this binary and along the potential spaces in between. Phyllis appears to bear many hallmarks of reversible suicide while the unnamed participant seems to exemplify rational suicide. These poles are blurred when considering Samuel and Edna’s accounts of a family members’ suicide, which appear to contain features of

both rational and reversible suicide. It is not clear which conceptualization of suicide could adequately codify the experiences of all four individuals, yet they all face the same disease. Taking both participant perspectives and HD suicide literature together, it is perhaps more useful to move beyond binary views of HD suicide toward a more ambiguous and productive middle ground. A position that considers suicidality not just in terms of pathology or rationality, but as emerging from complex matrices such as quality of life expectations, predictive testing, familial history, psychiatric symptoms, neurological damage, and personal biographies.

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