# A POLITICS OF HOPE IN THE NARRATIVES OF PEOPLE WITH DEMENTIA

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***Abstract***

The social model of disability challenges the notion of disability as a personal tragedy and reason for despair. Seven autobiographies written by people with dementia are analysed within the social model of disability for evidence of hope and hopelessness. Categories of hope and hopelessness delineated in this research include hope/despair for a cure, hope/despair for social inclusion and involvement, hope/despair related to voice (including being heard and taken seriously), hope/despair related to supports, hope/despair related to personal development, control, and survival, and other evidence of hope and hopelessness. An examination of how political hope expressed within these narratives contributes to the collective hope of people with dementia is included, as well as an exploration of implications for the larger disability rights movement.

***Table of contents***

## *Introduction*

> *Don't assume we are depressed simply because we aren't as active as we once were. People with dementia often say they are not depressed, yet their family thinks they are*. (Bryden, 2005, p. 133)

Dementia is often seen as a hopeless disease, and a diagnosis of dementia as a prediction of a hopeless future. This manner of considering the disease leaves the person with dementia to despair that "life is not worth living" (Harwood & Sultzer, 2002). In contrast to the perception of dementia as a death sentence, people with this disease have begun to speak out about their personal experiences of "living positively with dementia" (Bryden, 2005). These authors infuse the medical label 'dementia' with hope for the future and challenge the idea that their lives are "not worth living" (Harwood & Sultzer, 2002).

The social model of disability reverses the dominant perspective by emphasizing the voices of people with disabilities over that of medical practitioners and others who attempt to relegate people with disabilities into passive roles. This research attempts to prioritize the voices of people with disabilities by concentrating on the narratives of people with dementia.

Wendy Edey (2000) claims that there is a language of hope in all stories that can be recognized by an intentional listener who chooses to hear it from a perspective of hope. Ganzer (1994) claims that literature (fiction and autobiography) can be used to understand how an individual constructs meaning, morality, and their subjective experience. "Such elements are not easily discernible by positivistic research, in which objective measures and empirical studies often conflict with field data"

(Ganzer, 1994, p. 616). Therefore, this study focuses on the subjective experience of living with dementia, and aims to hear the language of hope expressed within narratives.

*Situating the Researcher*

Feminist methodologies, emphasized by researcher Kathryn Church (1995), require the explicit recognition of the researcher in the research. Church shares her experiences of doing research with psychiatric survivors and learning to be more open and passionate in her work. Church also challenges the role between professional/researcher and psychiatric survivors, and emphasizes the importance of personal accounts and reflexive practice in academic work. Her book reminds me to be open and aware of myself in my research.

As a therapeutic professional in two long-term care centres, I have had the opportunity to work with people who are experiencing disabilities linked to the cognitive impairment of dementia. The social model of disability as created by prominent disability activist and scholar Michael Oliver (1990) has been co-opted and adapted by health professionals who have applied these principles within the existing medical model. 'Person-centered care' and the 'social model' were terms that the centres' administrations often used to describe the manner in which staff members were expected to relate to the residents who lived there. However, during the course of my graduate studies, I have come to the understanding that most staff in the two facilities did not truly understand what these terms meant, and I suspect that the administration was at the same loss.

I have also had the opportunity to study hope in the caring relationship, and to immerse myself in literature pertaining to hope. I was overwhelmed with the focus on how a caregiver can encourage hope in people who are very ill or disabled. The role of the professional is central to developing hope in the 'patient' in much of the 'hope' literature (Elliott, Witty, Herrick, & Hoffman, 1991; Fox, 1999; Jevne, 1991; Roessler & Boone, 1978).

To situate myself as researcher within this study, I must recognize that the focal narratives are unfortunately filtered through the researcher, and my background is as a therapeutic professional. However, I was challenged to apply the social model of disability as described by Oliver (1990) to people with dementia through Thomas DeBaggio's autobiography (2002). I began to recognize environmental barriers and attitudes that disabled people with dementia, and began to see disability from the perspective of disabled activists and academics, rather than the therapy professions.

I consider myself an 'ally' of the disability rights movement, a term which has been used to describe people without disabilities who identify strongly with the movement's philosophies and goals (Cory Silverberg, Disability and Imagery Conference, York University, March 15, 2005). As such, I do not view disability as an individual tragedy, but rather as a social failure to accommodate difference.

The results and conclusions contained in this research must therefore be recognized as the product of a health professional who has been educated in the social model philosophy and who identifies as an ally of the disability rights movement. By shifting the focus from the individual impairment to the social barriers that disable people

with dementia, I see possibilities for change to improve the social status of people with dementia. Seeing possibility in a situation and recognizing that things might turn out better than they are right now (Jevne & Miller, 1999), I have hope that people with dementia will be able to lead fulfilling lives in inclusive settings.

*Purpose of the Research*

Broadly, the goal of this major research paper will be to look for evidence of hope in narratives written by people with dementia. This research seeks to provide an academic forum for the hopes of people with dementia, without ignoring the feelings of despair and hopelessness that are experienced as well. By drawing out hopeful language within personal narratives of living with dementia, I hope to call attention to the voices of people who have been labeled as having dementia. The narrative autobiographies examined for this research contain themes of hope and hopelessness that will be discussed within this paper. Finally, this paper will seek to make links between the hopeful language expressed in the narratives and the hope for social change (political hope) of people with dementia that is leading to self-advocacy.

The overall question guiding this research paper asks:

- What evidence of personal hope and hopelessness can be discovered in narratives of people with dementia?

The secondary question that comes forth through the analysis asks:

- How do these individual expressions of hope and hopelessness contribute to a collective political hope by people with dementia?

It is my vision that this research will help to break down exclusionary barriers for people with dementia by exploring the hope/hopelessness of living with dementia. By paying special attention to the hope and hopelessness that exists within the narratives of people with dementia, this research will explore existing barriers to social inclusion which are based on assumptions that people with dementia have no hope and feel that life is not worth living (Harwood & Sultzer, 2002). Secondly, demonstrating collective political hope in people with dementia challenges societal assumptions of passivity, tragedy, and the suffering of people with dementia.

I also hope that this research on the hope contained in narratives helps to open new areas for investigation into the self-advocacy movement of people with dementia. By seeing people with dementia as *active* and *hopeful* participants in life, those of us without dementia disabilities will give the voices of dementia advocates the respect they are due.

## ***Literature Review***

### *The Social Model of Disability*

A diagnosis of dementia is often seen to be a personal tragedy and reason for despair (Harwood & Sultzer, 2002). However, the social model of disability challenges the notion of disability as a personal tragedy and looks instead at the social factors that contribute to the exclusion of people with impairments from mainstream society. The social model differentiates between impairment as the biological condition, and disability

as the social conditions that result from physical, social, institutional, political, and attitudinal barriers.

According to Colin Barnes, the social model is:

> nothing more or less dramatic than a concerted shift **away** from an emphasis on individual impairments as the cause of disability, but rather **onto** the way in which physical, cultural and social environments exclude or disadvantage certain categories of people; namely, people labeled disabled. (Emphasis in original, 2001, p. 3)

Barnes, Mercer, and Shakespeare (1999) compare the social and the medical models of disability by describing the social model as one of social oppression over personal tragedy, of a social problem over a personal problem, and of social change over individual adjustment. In other words, the social model challenges the traditional, medical definitions of disability and recognizes the socially constructed barriers that exist for people with impairments.

The underlying philosophy from which this paper emerges is the social model of disability. People with dementia are seen as the experts on living with dementia. In approaching social inclusion, societal deficits are recognized over individual deficits.

Innes, Archibald, and Murphy (2004) have problematized this exclusion of people with dementia and attempted to address the socio-cultural aspects of the disease, including stigma and institutionalization. In this way, the authors argued for an inclusive society for people with dementia and shared the belief that disability is a social construction.

*Voice and Narrative*

There has been increasing attention within academic literature to the voices of people with dementia (Harwood & Sultzer, 2002; Proctor, 2001; Snyder, 1999). Within this movement that recognizes the voices of people with dementia as credible sources of information, people with dementia themselves are beginning to write their own stories of living with the disease (Boden, 1998; Bryden, 2005; Davis, 1989; DeBaggio, 2003; DeBaggio, 2002; Henderson, 1998; McGowin, 1993; Rose, 1996).

Ganzer (1994) argues that narratives are an important research tool because they contain conflict, histories, and traditions that are not discernible through traditional positivistic research methods. Interpretation of research data is relative and subjective, depending on context. Narrative helps the researcher to understand the social context within which a person lives. She claims that literature serves not only as a rich data source, but also as a healing tool. Ganzer (1994) claims that telling stories is part of a healing process and is a way for one to perceive oneself. This is similar to Edey's (2000) contention that telling stories elicits hope in the teller because it allows the teller to open up to available options. Ganzer's (1994) article lays the foundation for an exploration of the subjective, contextual construct of hope in narratives.

Snyder's (1999) collection of seven narratives from people with dementia is the most ethnically diverse I have yet found. Hope is a central theme in many of the narratives, as the storytellers focus on looking ahead towards the future and some discuss the importance of maintaining hope in their lives. Snyder (1999) facilitated a support group's discussion of hope and includes the responses by people with Alzheimer's disease. Although the narratives are filtered through someone who does not have

dementia, this book is a seminal piece because of its clear and concise inclusion of seven diverse narratives of people with Alzheimer's. It also begins to address the idea – originating from people with Alzheimer's themselves – that dementia does not only lead to hopelessness and despair.

Proctor (2001) examines the power differentials present when researchers attempt to represent the voices of people with dementia. She endeavors to represent the voices of four women with dementia because they are voices that are traditionally not represented by the dominant cultural voice, and she discusses her concerns with representing the Other. Proctor (2001) employs feminist methodology and pays particular attention to power issues, especially those between the women with dementia and the medical staff. Her open approach to the subjective experiences and her manner of judging responses to be valid and valuable is important to note in research that attempts to be re-present narratives through secondary research.

Davis (2002) argues that social movements are dominated and guided by narratives, both as movement discourse and as analytical tools. He posits that these narratives provide the cultural and symbolic base of a social movement, much as Barton (2001) claims a politics of hope can do for the disability movement. Davis claims that narrative is the primary form by which human experience is made meaningful, leading to the speculation that a person's hopes would be conveyed through narratives. Davis provides valuable perspective on the role of narrative in establishing a collective identity.

Fine (2002) claims that narratives play a key role in social movements because they elicit emotional, intellectual, and behavioral responses. While recognizing the

importance of individual narratives to social movements, he goes beyond this to examine shared discourses that emerge from individual narratives. Group members can refer to these shared discourses, and the shared discourses become metanarratives, acting to socialize new members into the culture of the social movement. Fine is careful to state that narratives exist within a social context, and stories are constrained by the previous experience of the participants. Thus, narratives act to create a shared identity among members of a social movement.

Narratives open space for subjective, contextual experiences in research. This type of research prioritizes marginalized voices of people with dementia and is keenly aware of the power relationship between the researcher and the people being studied. Narratives play a key role in deciding what type of knowledge becomes the dominant discourse in a given area, and who identifies with this discourse.

*Hope*

In order to address the central research question, the manner in which hope and hopelessness are expressed in the narratives needs to be addressed. There have been a variety of tools created to measure hope in language (Gottschalk, 1974; Herth, 1991; Herth, 1992; Miller & Powers, 1988; Nurmi & Lainekivi, 1991; Obayuwana et al., 1982). Rather than analyzing the ways in which hope is conveyed solely through discourse (Eliot & Olver, 2002) or purely through metaphors (Averill, Catlin, & Chon, 1990), this research will endeavor to recognize implicitly *and* explicitly expressed hope. In other words, this research will analyze times where derivatives of the words hope and

hopelessness are used, but also times when the authors write hopeful/hopeless reflections that do not expressly employ those words. So there is a need to determine first and foremost how implicitly and explicitly expressed hope can be recognized.

The meaning of hope is the most important concept to explore and discuss in this paper, in part because it is such an abstract concept, and in part because it claims such a central role in this exploratory study. A solid foundation of "hopeful language" and "hope in narratives" must be established in order to give the reader a clear idea of how the topic of hope in narratives of people with dementia is being approached.

Jevne and Miller, for example, describe hope as variable:

> Hope can go down or go away for various reasons. Demanding or depressing situations that continue for a long time can fatigue our hope. Times of illness or unwanted change are particularly hard on it (1999, p. 13).

Following Augustine's conception of hope as a virtue, the philosopher Barbara V. Nunn also claims hope is a virtue, an attribute that is considered inherently and morally good (2005). Hope is oriented towards the future, and is therefore uncertain (Nunn, 2005). Nunn (2005) theorizes hope to be uncertain, possible, desirable, and good.

For the purposes of this research, hope is defined as all of the above. More precisely, hope is a way of looking positively towards a desired but uncertain future, where something that may once have been considered impossible now becomes possible, and where something may turn out differently than one wanted but will still be okay. Ronna Jevne cites the example of a man who continues to hope despite the hopelessness of his situation and says, "There's no hope for my condition. But I am not only my

condition" (2005, p. 269). Jevne describes hope as "a small voice in the heart of each of us that yearns to say 'yes' to life" (2005, p. 267).

Jevne and Miller (1999) define hope as actively looking forward towards something good with the belief that although unlikely, it is still possible. They state that hoping remains open to all possibilities, even that situations may turn out different than one envisages and still be okay. They offer 22 strategies to foster hope within oneself, including the act of storytelling and the practice of looking at circumstances from a slightly different perspective in order to consider new possibilities. The authors' perspective is valuable when examining hope in an area that is not often perceived as hopeful, such as living with dementia.

According to Cousins (1989, in Farran, Herth, & Popovich, 1995), hope offers emotional reassurance, and involves the act of looking within to discover that perseverance exists within oneself.

According to Dufault and Martocchio's multidimensional model (1985), hope can be generalized or particularized. Generalized hope is more vague, such as hope for a good future; particularized hope encompasses more immediate goals. This difference is illustrated in the contrast between the "*look[ing] with hope to a new future*" (Bryden, 2005, p. 55) and "*I hope a bright researcher will create a cure soon enough to benefit me*" (DeBaggio, 2002, p. 68).

Dufault and Martocchio's (1985) model also comprises six dimensions in which hope may be expressed. These are: affective, cognitive, behavioral, affiliative, temporal, and contextual. Contextual hope allows for fluctuations in our level of hope depending

on circumstances. For example, at the time of initial diagnosis, hope might be very low. However, hope and hopelessness exist side by side. As time goes on, there may be hopeful incidents that are expressed within the narratives. The affective dimension of hope, including emotions and feelings, is witnessed in the narratives when they express feelings of confidence about the future, feelings of personal importance in the outcome (for example, McGowin's feelings of pride in creating support groups for people with dementia), and feelings of purpose in life. The cognitive dimension is evidenced in beliefs that the future contains positive possibilities, that it might turn out better than expected. The behavioral dimension of Dufault and Martocchio's (1985) model deals with actions that are motivated by hopes, such as Bryden's (2005) advocacy with the Alzheimer's Associations to "*challenge the idea of being the 'patient' or 'sufferer'*" (Bryden, 2005, p. 51). Recognizing life achievements and experiences in the past addresses the temporal dimension by recognizing that there have been difficult times before, and they have been overcome. Extending this hope into the future by hoping for a cure or hoping that a memoir might help others with dementia feel less alone addresses the temporal aspect of hope as well. David SteidlRast (in Hafen, Karren, Frandsen, & Smith, 1996) refers to hoping as "looking at things with a passion for the possible."

The affiliative dimension of Dufault and Martocchio's (1985) model addresses the individual's relationships and sense of involvement beyond themselves. Support groups for people with dementia, support by family and friends, and involvement in advocacy groups are examples of this affiliative dimension of hope.

If one examines the literature pertaining to hope and disability, one discovers that there is an overwhelming focus on the medical construction of disability. The literature implies that disability is tragic; one needs hope in the face of tragedy. If one does not hope, then one despairs over the disability/impairment. For example, Jacoby (1993) wrote, '[t]he miserable hath no other medicine, but only hope.' It is interesting to observe that even the research that aims to investigate the perspective (hope) of those with a disability is framed in the researcher's point of view of disability as tragedy.

Farran, Herth, and Popovich (1995) address the dialectics of hope and hopelessness, giving equal attention to each concept. Although the authors study hope from an individualized and clinical point of view, their attempts to clearly define, describe, and measure hope as a construct provide a solid framework for other studies of hope. They define hope as a way of relating to the world, and as being fluid, so that even if the desired outcome does not occur, hope can still be present. In this way, these authors support the social construction of hope and hopelessness.

*Hopelessness*. As important as it is to be clear on the concept of hope, it is equally important to discuss its opposite, hopelessness/despair. Being hopeless is often seen as being the same as having no hope (hope-less). However, some researchers have challenged this idea and have described hope and hopelessness in more of a dialectical relationship, where one cannot exist without the other (Farran, Herth, & Popovich, 1995; Pruyser, 1963).

As stated by Farran, Herth and Popovich, "*hopelessness* expresses a way of feeling (affective component), a way of thinking (cognitive component), and a way of

acting (behavioral component)" (1995, p. 24). Hopeless individuals feel they have lost control over their lives (Farran, Herth, & Popovich, 1995; Hafen, Karren, Frandsen, & Smith, 1996). In the presence of deep despair and hopelessness, we find the seed of hope (Farran, Herth, & Popovich, 1995; Pruyser, 1963).

Harwood and Sultzer (2002) measured hopelessness among ninety-one people with Alzheimer's. They used a depression rating scale, and classified people who felt "life was not worth living" as evidencing thoughts of hopelessness. The authors found that 10% of the sample evidenced feelings of hopelessness, and concluded that hopelessness is prevalent in people with dementia. A critical (and hopeful) examination of the findings would show that 90% of the sample does *not* evidence feelings of hopelessness, providing grounds for the argument that people with dementia experience hope. Although the authors make some assumptions concerning the probable hopelessness of people with dementia, their study is unique in its application of hope/hopelessness research to people with dementia.

*Hope and Story.* The act of storytelling in order to make one's own story of hope more tangible is supported by various hope researchers (Jevne & Miller, 1999; McDermott & Snyder, 1999; Rappaport, 1993). Edey (2000) addresses hopeful language used between storyteller and active listener in the counseling relationship. Edey also states that hope is contextual, depending on the circumstances of the story. She argues that a purposeful listener can find hope in stories that may seem to lack it at first impression. The challenge of finding hope can be remedied in part by focusing on the existence of possible courses of action and alternative options. Although presented

within a clinical setting, Edey's focus on the language of hope in stories is valuable for a discussion of hope found in narratives of people with dementia because it provides examples of hopeful language. She also claims that hope is contagious and can be exchanged among people.

Two components are important to recognizing the language of hope in a narrative: the expectation of a good future, and the willingness of the teller to participate in this future (Edey, 2000). The expectation of a good future is something that may challenge the view of dementia as a personal tragedy (see, for example, Harwood & Sultzer, 2002), but there are many other aspects of hope that may be expressed in narratives.

Eliot and Olver (2002) give an overview of the dominant theories of hope and their properties. It also supposes that language is not neutral and analyzes the speech of cancer patients. The authors specifically consider whether the patients present medical constructions of hope, and what other constructions are present in their narratives. Hope as a noun was often used in relation to hope for a cure, but the authors point out that to equate the two serves to isolate the patient who has reached the limits of medical help. This is a useful observation in a discussion of hope for people with dementia that challenges prevailing medical ideas. Hope as a verb most often positions the patients as actively engaged in doing something, rather than being helpless victims of circumstance.

In a study of hope and hopelessness in narratives, it is important to remember that language is not neutral and that a purposeful listener (the researcher) can find hope in

stories that may seen to lack it at first impression. This is where a challenge of dominant perspectives must be acknowledged, but subverted in the hopeful reading of narratives.

*Collective Hope.* Barton (2001) argues that there is a need to encourage collective hope, rather than just personal hope, within a social and political context and that organizations of disabled people are very important in this struggle for personal and collective empowerment because they articulate grand narratives. Grand narratives are those narratives that provide a collective identity and purpose for a group of people. Collective hope is also important to meta-narratives because the power of many people hoping for the same thing has the potential to effect social change.

Averill, Catlin, and Chon (1990) understand hope to be a socially constructed emotion, and explore it through four studies published in their book. They explore the ways in which people experience and interpret episodes of hope in their lives, how hope differs from similar emotions such as anger and love, and how hope is expressed through metaphors. They also compared hope between two cultures, the United States and Korea. The authors believe that hope is structured according to social norms and rules, and thus would concur with Zournazi's (2002) argument that political hope emerges as a product of social conditions. This is useful in a discussion of personal and political hope because of its emphasis on the influence of social condition.

Although Snyder and Feldman's (2000) equation of hope to goal-oriented thinking does not encompass all aspects of hope, they theorize how collective hope emerges on a societal level. The authors postulate that social movements are created when groups of people recognize that they are blocked in achieving what they hope for,

and hope for a new system emerges. This is similar to Zournazi's definition of a politics of hope that arises out of our current lives and struggles, and is valuable in a discussion that emphasizes political hope, or hope for transformative change. In this way, hope for transformative change becomes hope for radical or revolutionary change – hope as a form of political activism. When people with dementia hope for social inclusion, voice, and dignity, they are challenging the status quo. Their narratives are challenging the commonly held assumption of dementia being seen as a hopeless disease.

Mary Zournazi defines a politics of hope as "a hope that comes out of our present lives and struggles" (2002, p. 17). For people with dementia who struggle every day with social barriers that prevent their full participation, the politics of hope have real significance. Bryden's (2005) narrative is an important tool of political activism and resistance because it advocates political change in the wider population for people with dementia.

It is very important to note that political hope may arise out of social conditions that provide few options for citizens. Where discrimination and inequality exist, political hope emerges when citizens desire a more just society.

According to Zournazi (2002), hope lies in looking towards the future and envisioning a more just world. Zournazi's hope is a distinctly political sort of hope that springs from our current lives and struggles, where one's vision of the world includes a form of social change. Philosophical discussions on the elements of hope, a politics of hope, and revolutionary hope are grounded in real-world events and times of political and social change. Though she sometimes becomes confused with similar terms such as joy

and passion, her discussion of a 'politics of hope' in a social sense – similar to Davis' (2002) use of narratives as the cultural and symbolic base of a social movement – is useful.

Collective hope is important to social change because it moves the emphasis from personal hopes to group hopes, and articulates the hopes and desires of a number of people. Zournazi (2002) describes hope as a social construction, and Averill, Catlin, and Chon (1990) would concur. However, Averill, Catlin, and Chon (1990) believe hope is far more susceptible to social norms and rules than does Zournazi, who believes hope is a product of restrictive social conditions (2002). According to her ideas, political and collective hope involves a vision of a more just and equal world. This is the type of collective hope that will be discussed within this paper.

### *Narratives by people with dementia*

The narratives of people with dementia that were analyzed in this research have many similarities as well as many differences. The individual authors express many varying attitudes and perspectives about living with dementia, ranging from DeBaggio's (2002, 2003) bittersweet focus on the tragic aspects of dementia, to Bryden's (2005) political advocacy. The seven narratives described below are those that have been examined in this research.

Christine Bryden (2005) wrote her memoir with a distinctly positive attitude about her diagnosis of dementia. As one of the key self-advocates in the movement of people with dementia and the first person with dementia to be elected to Alzheimer's

Disease International, Bryden also provides an overview of Dementia Advocacy and Support Network International. She describes actively living with dementia, and articulates her hopes that people with dementia will be treated with dignity and respect (p. 60), will challenge current attitudes (p. 55) by educating others about what it is like to live with dementia (p. 97), and will remain full participants in cultural life (p. 56). Bryden's account is valuable because she expresses her hopes for the future and actively pursues them through political advocacy.

As a pastor in Miami's largest church when he began experiencing moments of confusion, Robert Davis (1989) wrote his memoir in order to continue his spiritual work and show others that his god had not forsaken him. Davis felt that even though his god had the power to heal the disease, that there was ultimately a reason that his god chose not to do so. Davis' memoir deals repeatedly with the difficulties he encounters as someone with Alzheimer's disease, but does not dwell for too long on the negative aspects before emphasizing the positive aspects that are present in his life. Although Davis had help from his wife to complete the book, he is upfront with the extent to which this help influenced the final memoir, and which chapters were completed entirely by his wife. Throughout the book, Davis emphasized faith in the will of his god.

Thomas DeBaggio (2002) began writing his memoir at fifty-seven years of age when he was diagnosed with Alzheimer's disease. Although DeBaggio (2002) does not mince words when it comes to describing his devastation about his disease, his memoir is interspersed with positive, uplifting, and hopeful reflections. Hope and hopelessness are both given due attention in this memoir, illustrated in what DeBaggio (2002) calls the

three streams of his narrative: 1) memories from his childhood, 2) the disappointment and loss of living with Alzheimer's, and 3) excerpts from current research into Alzheimer's.

In his second book, DeBaggio (2003) continues his narrative of living with Alzheimer's disease. When reflecting on present time, DeBaggio (2003) expresses a profound sense of loss. However, he seems to reflect less on present time and remembers vividly images and events from his past. Although DeBaggio (2003) deals with the difficult subject of losing his memory and thus his sense of self, his narrative is ripe with hopeful imagery from his past life, nature, and other people he has known. DeBaggio (2003) tells many stories of overcoming events that began as challenging. As Edey (2000) states in her article, these examples of the impossible becoming possible are extremely hopeful.

Cary Henderson (1998) has a matter-of-fact manner of describing his life with Alzheimer's and the frustration of his symptoms. He records his feelings and experiences on a tape recorder, as if keeping a diary for himself and giving advice to others with less advanced forms of Alzheimer's disease. He expresses hope that people with Alzheimer's will not be ashamed of their disability, will share experiences and help each other, and will maximize their abilities.

Diana Friel McGowin's (1993) story of living with Alzheimer's is one in which she returned from the brink of despair that she experienced when first receiving her diagnosis at the age of forty-five. This emotional account details McGowin's frustration with trying to continue her life as she saw it should be, and her realization that certain things would inevitably change. She finds joy and hope in many facets of her life, all the

while discovering new difficulties. She hopes that her book offers comfort to people with Alzheimer's and their families, and emphasizes the need of people with Alzheimer's disease for dignity.

Larry Rose (1996) has perhaps the most positive attitude of all the authors who wrote their first-hand accounts of living with Alzheimer's disease. Because he was already retired, Rose continued to go about his daily life in much the same manner as he had lived before the diagnosis. Though he has some difficulties, especially navigating his way to his cabin, he adapts to these challenges. For example, he used a cell phone in his car so that family could phone him when he was driving, and vice versa. Rose (1996) is a great example of someone who takes a diagnosis of Alzheimer's in stride, and I surmise he would fall in the 90% of people with dementia that Harwood and Sultzer found did not feel hopeless.

The seven autobiographies that I have chosen to include in this study of hope in narratives contain some similarities that are worth noting because they are not necessarily representative of a wider population of people with dementia. For example, there are only two narratives written by women, as opposed to five narratives written by men. Each of the six authors emerges from a certain socio-economic class, namely the upper-middle class. McGowin (1993) refers to her career as a legal assistant that once managed a law office, overseeing the office and acting as hostess at a dinner party honoring the governor. DeBaggio (2002, 2003) was a small-business owner, Rose (1996) was an electrical engineer, already retired at the age of fifty-four, Bryden (2005) was a senior-level government official in Australia, Henderson (1998) was a university professor, and

Davis (1989) was a pastor at the largest Protestant church in Miami. Because the authors included in this study are predominantly from an upper-middle class background, the findings may not be representative of the wider population of people with Alzheimer's disease or dementia.

The American health care system is one in which those with greater resources have more access to services. All six authors included in this study were diagnosed early enough in their disease to be able to author an autobiography (and in some cases, more than one). This speaks to the level of resources that the individual authors had at their disposal to pay for testing and to obtain such an early diagnosis.

Another point that restricts the wider applicability of the findings is the fact that all of the authors originate from industrialized nations. Apart from Australian Christine Bryden (2005), all of the authors are from the United States. Culturally, this may have some bearing on the levels of hope and hopelessness that are expressed in the narratives because America is often seen as the land of opportunity, where the 'American Dream' can be obtained by anyone who hopes for it and works hard enough. All of the authors are white, and so the findings and discussion of this paper cannot be applied to other cultural and ethnic groups. Snyder's (1999) collection of narratives by people with dementia is used as a supportive reference in this paper because it represents a wider spectrum of ages, ethnicities, and religions.

The above overview has highlighted hope literature, the social model of disability, and narratives of people with dementia. The social model of disability sees disablement as a social construction rather than an individual problem. It prioritizes the voices of

people with disabilities over the voices of professionals, and this is what this paper aims to do as well. Within this paper, voices of people with dementia are prioritized to begin to understand the hope and hopelessness that exist for someone who is living with dementia. The narratives included here represent a sampling of the voices of people with dementia. They contain evidence of personal hopes and despair, but when analyzed together, they contain evidence of greater hopes – collective hope. An analysis of these narratives demonstrates that people with dementia have shared hopes and grievances with the current state of social inclusion for people with dementia.

Barton (2001) argues that there is a need for a political analysis that focuses on the desire for transformative change and the central role of hope in the struggle for inclusion. Hope and hopelessness may co-exist (Farran, Herth, & Popovich, 1995), but hope is under-represented in the academic literature dealing with dementia. By exploring the hope expressed within narratives of people with dementia, I will endeavor to further challenge the stereotypes surrounding the 'personal tragedy' view of living with dementia. In Jevne's (2005) words, people with dementia continue to 'say yes to life.'

## *Methodology*

Seven autobiographies by six different authors were included in this narrative analysis that focuses specifically on evidence of hope and hopelessness. These seven autobiographies were chosen to represent the most accessible and prominent perspectives of people with dementia. In other words, they were the seven memoirs to which I could gain access over the course of a 9-month search through public libraries, university

libraries, and internet orders. In order to set parameters of the study, the number has been restricted to seven autobiographies due to time constraints.

From my initial reading of these seven autobiographies, I delineated initial categories of hope and hopelessness (despair) that were expressed therein, and were relevant to the social model philosophy. These categories of hope and hopelessness, and some short examples of each are listed below:

1- a) hope for a cure (including medical treatment). "*It was an agony of waiting, wondering and desperately hoping that whatever is wrong can be treated and life can go back to normal*" (Bryden, 2005, p. 95).

b) despair for a cure. "*Until there is a cure, there is forever emptiness and haunted eyes*" (DeBaggio, 2003, p. 218).

2- a) hope for social inclusion/involvement. "*My exchange with the world brings life into the dead places in me*" (DeBaggio, 2003, p. 190).

b) despair related to lack of social inclusion/involvement, including getting lost. "*After exiting the restroom, I attempted to retrace my steps back to the lab, but became hopelessly lost in a maze of corridors*" (McGowin, 1993, p. 43).

3- a) hope for voice (including being heard and taken seriously). "*I would like to be somebody who could help understanding from the patient's point of view – what it is like to be an Alzheimer's patient*" (Henderson, 1998, p. 4).

b) feelings of hopelessness related to voice, including not being taken seriously.

> *There is a stream of ideas coming through my brain, yet they don't remain there. They are fleeting glimpses of insight, there one moment, totally gone the next. Unless I speak them out, or write them down, immediately, they are lost forever.* (Bryden, 2005, p. 101)

4- a) hope for supports. "*The support I have received has been amazing and I hope it keeps up*" (DeBaggio, 2002, p. 81).

b) despair related to supports. "*I feel that I am walking a precipice alone*" (Rose, 1996, p. 35).

5- a) hope for personal development, control, and survival. "*I just hope my brain can keep up until I'm dead*" (Henderson, 1998, p. 72).

b) despair related to loss of personhood/self, or control of self.

> *But now everything that I had given myself for and studied for these past years was gone, lost in the dark recesses of my mind. As I thought of the sheer waste of this, I groaned out 'Why, God? Why?'* (Davis, 1989, p. 54)

During the second reading, incidents of hope/hopelessness were coded to identify the types of hope contained therein. These categories were neither exhaustive nor inflexible and the second reading of the narratives found hope and hopelessness that could not be slotted into one of these pre-existing categories. Two new catch-all categories were added to the analysis:

6- a) other evidence of hope.

> *My housekeeping was minimal. When more extensive cleaning or refurbishing was required, I would push the projects aside, hoping for a 'better day' when I would not feel so overwhelmed.* (McGowin, 1993, p. 82)

b) other evidence of hopelessness.

> *I do trust the Lord completely, not just because of blind faith but also because God has proven himself to provide for my every need in every situation. Yet, the devastation wrought by this disease brought me to despair*. (Davis, 1989, p. 90)

These new categories included spiritual, generalized hope, and other aspects that were not covered in the five original themes. By analyzing the narratives through these categories, it allowed for a tabulation of the amount of hope and hopelessness in the narratives, as well as a tabulation of the types of hope and hopelessness that were most prominent.

Conference presentations and papers written by people with dementia, as well as a book that combined seven narratives into one volume by a researcher (Snyder, 1999), were not included in the study but rather were used as further support for the findings. Chapters, Forewords, Introductions, Epilogues, and Afterwords that were written by someone other than the author with dementia were excluded from analysis (for example, Davis, 1989; Rose, 1996).

I did not necessarily identify times when these topics were discussed, but rather I identified times when they were referred to in a *hopeful* or *hopeless* context. Bryden (2005), for example, made many political statements that were not always framed within the language of hope, therefore were not included in the data. This is important to keep in mind because this research looked at hope and hopelessness of people with dementia and did not necessarily recognize these statements unless they were referred to in a hopeful or hopeless manner. The coding was re-checked by the researcher and adjustments were made if the original coding was incorrect.

### *Findings*

I found that the narratives contained multiple references to hope and hopelessness, or hopeful and hopeless situations. Each of the six authors expressed varying levels of hope and hopelessness in their autobiographies, and the manner in which these were expressed varied greatly as well.

Overall, the seven narratives expressed greater levels of hope than of hopelessness. In fact, the number of hopeful expressions was more than double that of hopeless expressions (272 as opposed to 123). These findings suggest that people with dementia have far more hope than despair in relation to living with dementia.

The types of hope contained in the narratives varied greatly between authors. Among the types of hope expressed within the seven narratives, hope for personal development, control, and survival figured most prominently, with 34 incidents in total. This was also the category with the greatest level of despair, suggesting that it is an area that is particularly important to the authors with dementia, and is an area over which there is much despair. This type of hope seemed to be particularly important for McGowin (1993), who expressed this type of hope 11 times in her autobiography. On the other hand, DeBaggio (2003) did not express this type of hope at all in his second book, and had the greatest level of despair over the loss of self and control over self out of all the authors with dementia.

Hope for a cure or treatments to ward off the disease also figured prominently in the narratives, with 27 incidents. DeBaggio (2002), Bryden (2005), and McGowin

(1993), all express this type of hope, 7, 8, and 9 times, respectively. It is also interesting to note that DeBaggio expressed hope for a cure seven times in his first book (2002), but only once in his second book (2003). Rose (1996) and Henderson (1998) did not express this type of hope at all.

Hope for voice, including expressing oneself, being listened to, and being taken seriously, was communicated in the seven narratives as well, with every author except Rose (1996) making reference to this theme. There were 27 incidents where this was expressed, with DeBaggio (2002) showing the greatest hope for voice. Similarly, some of the narratives conveyed despair at the idea of not being able to express their voice and not being listened to (Bryden, 2005; DeBaggio, 2002; McGowin, 1993). However, most authors discussed issues of voice in a more hopeful way. The content and purpose of this expression of self is important, and will be discussed at a later point in this paper.

Despair related to lack of supports was a theme that was expressed far less than I had expected, with only 3 references among the seven narratives. Hope for continued support or improved supports was a prominent theme, however, with Bryden (2005) and McGowin (1993) each emphasizing their hopes for supports 5 times in their respective narratives, and all of the other authors making some reference to having this type of hope.

Hope for social inclusion was an area in which there was some disagreement between authors with dementia. For example, there were 11 total incidents of hope related to social inclusion and social involvement. There were 5 incidents of hopelessness/despair for this theme. However, Bryden (2005) expressed the largest hope for social inclusion, and Davis (1989), DeBaggio (2002), and Rose (1996) did not express

this type of hope at all. Conversely, none of the authors except Henderson (1998) and McGowin (1993) expressed any despair related to their level of social inclusion and involvement.

There were other varieties of hope and hopelessness expressed in the seven narratives that were not included in my original themes. While reading the autobiographies, I was forced to create a sixth, 'Other' category for all the examples of hope and hopelessness that did not fit into the categories I had originally deemed to be relevant. This sixth category turned out to be the largest, with 154 expressions of hope, and 66 expressions of despair or hopelessness. Hopeful expressions that were included in this last category included things such as general, non-specific references to hope for the future, hopeful imagery examples involving nature or birth, and hopeful references to the spiritual or transcendental. Hopeless expressions in this category included references to death and darkness, feeling trapped, and having no options but a steady decline into what the authors saw as an inhuman state – "*The human scale is being bullied into extinction*" (DeBaggio, 2003, p. 38). It is important to note, however, that the researcher does not believe people with dementia are any less human than the rest of us, no matter what their mental state.

Included in this sixth 'Other' category were also expressions of the hope for death, or despair related to having no options other than death (DeBaggio**,** 2002; Henderson, 1998; Rose, 1996).

It was interesting to note some discrepancies between two memoirs written by the same author with dementia. DeBaggio's overall level of hope stayed fairly constant

between his two narratives. However, his level of hopelessness increased by approximately one third in his second book, mostly in the area of other varieties of hopelessness (2003). Also, the political categories of hope and hopelessness became less prominent with the writing of his second book, and the other varieties of hope and hopelessness became more prominent. For example, DeBaggio (2002) was the most vocal author about his hope for voice in his first book (10 incidents), but barely mentioned any hope for this in his second book (1 incident). Also, his hope for personal development, control, and survival was very prominent in his first book with 8 incidents, but stated no hope at all for this in his second book.

## *Discussion*

The narratives of people with dementia raise varying themes and complexities of hope and hopelessness that are important to different authors. Some issues resonated more strongly than others among the narrative accounts, and differing opinions have emerged. These themes and tensions will be addressed further a little later in this discussion.

When analyzing narrative accounts, methodological concerns figure prominently because of the pressure to conduct valid and reliable research. The following discussion of methodology and validity will precede a discussion based on the findings of the narrative analysis, including hope for a cure, death, social inclusion, time, voice, collective and political hope, and agency.

*Discussion of Methodology*

Originally in my proposal, I delineated five categories that could either be expressions of hope or hopelessness that I expected to find in the narratives. After reading through the narratives and coding for hope and hopelessness, I discovered that those categories were indeed not exhaustive of the hope and hopelessness voiced in the authors' narratives. There are some points that fit within them, but there are also generalized statements of hope and hopelessness that are not particular to certain desired objects/outcomes. These generalized statements are most common in Bryden's (2005) memoir, such as when she writes, "*I faced a defeat of spirit and of hope*" (p. 155), or "[*m*]*y neurologist has walked with me every step of the way…giving me hope*" (p. 13).

As another example of expressions that did not fit into one of the five categories, DeBaggio (2002, 2003) uses descriptions of nature quite frequently in his books. I have found some of these to be quite hopeful and others to be quite hopeless. For example, "…*there is not much left where dandelions once hummed of spring*" (2002, p. 137) is quite hopeless, but "[*t*]*his earth lived long before us and it will live long after us and it tells many stories*" is very hopeful (2003, p. 26). Bryden also refers to hope in nature when she writes "*…the bud represents the whole potential of life*" (2005, p. 83).

The position of metaphors in relation to hope and hopelessness is interesting to note. As the above examples demonstrate, symbols were often used to represent hope and hopelessness in the narratives. Perhaps this is further testament to human variance, demonstrated within the narratives by people with dementia studied here. Not all authors are as forthright with the specific words 'hope' and 'hopelessness' as Bryden (2005)

seems to be in her narrative. However, some authors (for example, DeBaggio, 2002, 2003) seem to be far more comfortable with representing hope and hopelessness in their narratives through metaphors. Larsen and Larsen's (2004) study of adolescents and self-metaphors uncovered hope as one of the central themes in the analysis. Hopeful metaphors included a sense of joy in the present, excitement and anticipation for the future, awareness of growth and change, a sense of unconstrained freedom, confidence in abilities, and the power of choice. For these reasons, Edey's (2000) argument for intentional listening was applied to my readings of the narratives, and I was open to metaphorical representations of hope and hopelessness as well.

Hope and spirituality was more prominent in the narratives than I had anticipated, and these expressions often did not fall into a pre-determined category. For example, Bryden referred to a speech in which she said, "[*m*]*y creation in the divine image is a soul capable of love, sacrifice and hope, not as a perfect human being, in mind or body*" (2005, p. 153). Davis wrote "*in the most helpless, hopeless, and extreme part of my life, Christ is here comforting and giving life meaning…*" (1989, p. 68). In their study of the meaning of hope to people who lived with chronic illness, Gaskins and Forte (1995) found that spirituality was the theme cluster identified most frequently.

The original categories did not include any of these themes. Therefore, the question arose as to how these themes should be organized. In the end, I created a sixth category – Other varieties of hope and hopelessness. This catch-all category ended up being quite large, and the suggestion arose to break it down so that the reader could see what it included. I have decided against this to a certain degree because the varieties of

hope and hopelessness that fell into this last category were less relevant to a discussion of hope within the context of the social model. In this situation, it is sufficient to be aware that there are other expressions of hope and hopelessness that were not included in the original categories. The authors with dementia expressed hope outside of the politicized categories created by the researcher. But to dissect this sixth category is beyond the scope of this paper because the five original categories provide an effective response to the research question. However, I have tried to include various examples of hope and hopelessness that were found in this last category throughout the paper so that the reader can gain a greater understanding of its vastness.

*Validity*

Edey (2000) draws attention to the subjectivity of interpreting hope in stories. She argues that an intentional listener can hear hope in any story. This has implications for validity in a research project that interprets hope and hopelessness in personal narratives. In an attempt to control definitions of the variables, one researcher coded all seven narratives to increase consistency. Then, the researcher re-checked the coding once all narratives were analyzed in order to further maintain consistency. All expressions that employed forms of the words ‘hope, ’ ‘hopelessness,’ and ‘despair’ were included in the analysis, as well as other expressions that followed the definitions of hope and hopelessness described earlier in this paper. Albeit, another researcher might find different levels of hope and hopelessness, or different expressions, this researcher is

confident that she did her best to remain true to the voices and the meanings of the authors with dementia.

In order to respect the true meanings that the authors hoped to convey, this narrative analysis took a flexible, open, and thematic approach to the uncovering of hopeful language. Though I recognize the critiques of validity and reliability that may emerge in face of this method, I feel that it is the most effective way for me to remain true to the storytellers' messages.

Keeping in mind the pressure to make this research emancipatory, narrative analysis was chosen as a means to represent the voices of people with dementia, recognizing hopes that reflect both the medical model and the social model. If the results present a challenge to dominant views concerning the hopelessness of living with dementia, this in itself will be emancipatory. Also, the fact that people with dementia are voicing their concerns and challenging stereotypes is emancipatory, and it deserves academic attention (Beard, 2005).

*Cure*

Hope for a cure/treatment and hopelessness at the lack of a cure figured prominently in the narratives of people with dementia. This has serious implications for a social model of disability that advocates the social-construction of disability and shuns tragic views of impairment. It is not my intent to provide a legitimation of the medical model here, only to respect what was expressed in the narratives.

In remaining true to the voices of people with dementia in these narratives, it is impossible to ignore expressions of hope for a cure. The following examples are a sampling of the hope for a cure that was found in the narratives:

> *Until there is a cure, there is forever emptiness and haunted eyes.* (DeBaggio, 2003, p. 218)

> *I am praying that I maintain a slower decline, and that researchers will soon develop a miracle aid for victims of this wretched ailment.* (McGowin, 1993, p. 119)

> *I plan to treasure each moment that remains with my family and my friends, hoping that I remain well enough long enough to benefit from any cure that might be discovered.* (Bryden, 2005, p. 12).

DeBaggio expressed hope for a cure seven times in his first book (2002), but only once in his second book (2003). This raises some intriguing questions, such as, does this mean his disease had progressed enough that he has lost hope for a cure? In his second book, DeBaggio (2003) had slightly more incidents of despair in relation to the discovery of a cure than hope in relation to the discovery of a cure (one expression of hope, three expressions of despair). Does this mean that he was finally coming to terms with the hopelessness of his disease? Perhaps it is true that DeBaggio (2003) was giving up hope for a cure, but this was not the only type of hope he had. His overall level of hope in the second book was still higher than his level of despair (57 as opposed to 43 incidents). This suggests that his perspective changed over time in relation to his disability, and that hope is fluid. DeBaggio's (2003) score for other varieties of hope doubled between his first book and his second. This suggests that his perception of hope became less political and more abstract, perhaps more spiritual and centered in the past. This supports the

notion of a social movement of people with dementia increasing in recent years because of the increase of people that are diagnosed early in the disease. This suggestion concurs with Gaskins and Forte's (1995) claim that hope takes on new meanings for older adults as they age and approach death. Rather than being defined in relation to success, achievement, and control (Gaskins & Forte, 1995; Larsen & Larsen, 2004), hope for older adults is defined as a 'brighter tomorrow' (Gaskins & Forte, 1995).

In Eliot and Olver's (2002) study of cancer patients' speech, hope as a noun was often used in relation to a cure. But the authors were careful to caution against equating hope for a cure with hope as a noun, because this serves to isolate the patient who has reached the limits of medical help. A similar caution will be voiced here: equating hope with hope for a cure is unjust to the social model of disability and those who are part of the disability rights movement. Though hope for a cure must be acknowledged, it is merely one type of the hope that was expressed in the narratives of people with dementia, and attention must also be paid to the other expressed themes.

*Death*

Within some of the narratives, the authors have expressed their hopes for death, or despair related to having no options other than death. Davis claims that there are "*times when death is actually better than life*" (1989, p. 122). Henderson (1998) and Rose (1996) make highly political references to hoping for assisted death, whereas Davis describes his aversion to technologically supporting life. Larry Rose discussed the issue with a friend:

> *Well, Ken, I have time to think now. Believe me, I think about dying a lot. There has to be a line drawn somewhere…when it is time to go, when life is not quality. I would rather die six months too early than six months too late. I hope, when my time comes, that I can find someone like Jack Kevorkian. If I can't, I'll do it myself. The "do-good" groups and the government have to get over their love affair with terminally ill people. Unless they are in my shoes and those millions of other like me, they have absolutely no idea what they are talking about. I want to live as much as the next man, Ken, but not lying in some nursing home, not knowing who the hell I am. I think Eddie Chiles said it best: "I want the government to do three things and only three things – protect our shores, deliver the mail on time, and leave me the hell alone."* (Rose, 1996, p. 76).

Rose (1996) believes that death is better than life when 'quality' of life decreases past a certain point. However, having not yet reached this point and experienced life, I would argue that Rose is thinking abstractly about living with a disability, and making assumptions about the quality of life that someone with a disability experiences. Similarly, Henderson expressed his feelings on assisted death in his memoir:

> *I really sincerely believe that if somebody wants to go ahead and die from Alzheimer's, if life's become that bad for them, I think anybody who can quietly assist them to die, I think, would be a boon.*
>
> *This Dr. Kevorkian, this doctor way up North who helped people kill themselves – I think he did the right thing. Apparently all of these people had wanted to die, and had a very good reason for it.*
>
> *When your mind is dead or dying and there's no recourse, and the best you can do is spend the rest of your life in pure stupidity and unknowing stupidity…I think that is one of the biggest travesties of what sometimes is called medicine that we have ever heard of. It seems fairly commonly we do read about people who die from Alzheimer's, but we can also speculate about people with Alzheimer's who – they're ready to die.* (Henderson, 1998, p. 71).

Finally, Davis describes his feelings on using technology to support life:

> *The non-Christian world cannot understand these feelings, since they have nothing beyond the grave. Thus they will fight at any cost to keep the physical shell of a body alive. That is why I insist on a doctor who understands our attitude toward life and death attending to me and my family. That is why long ago before anything ever happened, we all made out legal documents saying that should we be reduced to helpless vegetables with no hope of life that someone should pull the plug on the machines that were artificially keeping our bodies alive so that we may die naturally and be promoted to our eternal home in heaven.* (1989, p. 124)

Davis (1989) is talking about a different situation than were Rose and Henderson, however. Where the first two authors were expressing their desire for *actively* taking their own lives – or being assisted to do so – Davis was not advocating the active removal of life. Rather, he was arguing against supporting life beyond the body's ability to do so itself.

The differences of opinion expressed above are not unusual; these issues are contentious in any forum, and a random sample of the population would, in all probability, yield a similar division of opinion. However, it is important to note that some of the narratives have expressed a will to die because it is a contentious issue. It is also an issue that has been debated within the disability rights movement more recently with the death of Terry Schiavo in the United States (Johnson, 2005), the hit movie "Million Dollar Baby" (Carter-Long, 2005; Schwartz, Lutfiyya, & Hansen, 2005), and the Canadian murder of Tracy Latimer in the early 1990's (Enns, 1999). These instances, and the comments made within Rose and Henderson's narratives, exemplify the debate on which sort of life is worth living. It seems to be the authors' view that the disabled

life is not worth living because they would be unable to live the same quality of life within their societies.

*Social Inclusion*

Cary Henderson (1998) discusses the despair he feels in relation to being excluded from society, and wishing for a more inclusive society.

> *The feeling of being put on and the feeling nobody loves us, I think those are perfectly normal feelings. It doesn't mean that you always have to feel that way, but I think for a lot of us the feeling of being cheated, or the feeling of being belittled and somehow made jokes of, I think that's one thing that is among the worst things about Alzheimer's.* (Henderson, 1998, p. 37)

> *I'd like a larger world than I have right now.* (Henderson, 1998, p. 24)

Christine Bryden (2005) articulates her hopes that people with dementia will be treated with dignity and respect and will remain full participants in cultural life. Other authors with dementia have expressed similar views as well (Davis, 1989; DeBaggio, 2002; DeBaggio, 2003; Henderson, 1998; McGowin, 1993; Rose, 1996). However, Bryden's (2005) account of living with dementia takes her personal hopes for the future and positions them within a political arena through her advocacy work.

> *One day I hope that we will treat people with dementia with respect, recognize just how hard they are trying to cope with getting through each day, and provide them with appropriate emotional support, social networks and encouragement.* (Bryden, 2005, p. 11)

> *I look towards new horizons of hope, as we people with dementia seek liberation from internalizing the oppressor of dementia. To live with 'the fear of ceasing to be' takes enormous courage. The precious string of pearls, of memories, that is our life, is breaking, the pearls are being lost. But finding new pearls, those created in the struggle*

> *with dementia, we can put together a new necklace of life, of hope in the future.* (Bryden, 2005, p. 170).

Unlike Bryden (2005), DeBaggio's (2002, 2003) narratives express more individualized hopes, and despair related to his personal situation rather than the situation of people with dementia in general.

> *It was difficult for me to accept that I now had a fatal illness for which there was no cure, only the hope that my brain's eager course of self-destruction could be slowed for a while so I could dance with life a little longer.* (DeBaggio, 2002, p. 39)

This demonstrates that although some of the authors with dementia used their memoirs to make a political statement and try to improve social inclusion of people with dementia in general, others were more preoccupied with their personal situations.

*Time*

Time is an important factor to consider when discussing hope because it may influence someone's level of hope, as well as how hope manifests. Larsen and Larsen (2004) found that adolescents' hope was strongly tied to anticipating future possibilities, engaging in life, and confidence in their own abilities. Gaskins and Forte (1995) reinforce the idea of hope being defined in relation to success, achievement, and control in younger people, and describe hope being defined as a 'brighter tomorrow' for older adults. With Jevne and Miller's (1999) description of hope as a variable that can fluctuate for various reasons, the importance of time to the concept of hope is apparent.

Bryden (2005) speaks to issues of hope in relation to time. She discusses ways to encourage hope in people with dementia in the present and the future, and suggests

drawing on the past to inspire hope. Drawing on the past to inspire hope is something that DeBaggio (2002, 2003) did often in his memoirs. For example, he wrote:

> *After my Alzheimer's diagnosis, my cat Sabina established a new pattern that pleases me. Each night, she sits in the upstairs hall waiting for me to go into the bedroom. After I get under the sheets, she jumps on the bed in the darkness and lies down next to me. I think she is trying to tell me something. She remembers when she came back from death as a result of Joyce and I making her want to live. I often choke with emotion when I whisper in her deaf ears: 'Cat, I watched you come back from dying.' It is a good thing to remember when you are in the same circumstance.*
> (DeBaggio, 2002, p. 53)

Jevne and Miller (1999) claim that times of illness or unwanted change are particularly hard on one's hope. That is why it can be valuable to have past memories where things turned out better than expected on which one can draw to inspire hope in the present.

DeBaggio's two memoirs raise interesting points in relation to time (2002, 2003). Because levels of hope and hopelessness in relation to different things fluctuated between the first narrative and the second, one might question the extent to which hope in each narrative is influenced by the state of the disease at the time of writing. Did his hope for a cure go down in his second book because the disease had progressed too far for him to think it was feasible? Did his hope for voice decrease so dramatically because he was losing his ability to communicate? Perhaps his hope for personal control and survival decreased because he realized the fruitlessness of hoping for this with a degenerative disease. It is very interesting to note that his levels of hope in these political areas may have decreased, but that his overall level of hope did not decrease. It is beyond the scope

of this study to answer questions in relation to levels of hope at certain stages of the disease, but in DeBaggio's (2002, 2003) case, it appears that time did indeed influence his hopes.

*Voice*

Special care was taken to respect the voices of people with dementia and the power relations that exist in re-interpreting their meanings (Proctor, 2001). Following Ganzer's (1994) claim that autobiographies can be used to understand how an individual constructs meaning, morality, and their subjective experience, the methods employed by this research aimed to maximize these elements by being fluid in the interpretation of each author's narrative.

I believe that this is a very important consideration when using narrative analysis in research, but perhaps even more so in this particular situation because of the high level of hope for voice that was expressed by the authors with dementia.

Carole Mulligan (personal communication, April 5, 2005) comments on the lack of respect for the authority of people with dementia about their own experiences:

> When D.A.S.N.I. members speak about dementia, we want to be seen as authorities on coping with dementia itself, at least in a social/educational context. This idea, I realize, is a political one, but we have been intensely studying the subject of dementia for five to ten years. D.A.S.N.I. founding members came from a number of relevant professional fields and have applied their background training in their study of dementia. Yet it is rare for them to be considered authorities in any field. We are seen as material for ethnographic research only…I am no longer interested in D.A.S.N.I. members "telling their stories" so "professionals" can

> interpret what they mean. (Carole Mulligan, personal communication, April 5, 2005).

Hope for voice was very prominent in the narratives of people with dementia. Henderson describes his hope for voice as follows:

> *I guess probably the best thing that ever happened to me was while I was with Alzheimer's is that my speech has not been impeded – it's still pretty good. I may not know all the time what I'm talking about, but I, damn it, still I can talk.*
>
> *It's a sincere effort to get this off my chest. I never was quiet. When I hurt, I yell, which is what I've been doing for several years now, and it's food for thought, as least, an Alzheimer's picnic.* (1998, p. 3)

Henderson's (1998) willingness to yell may be useful to get people to listen to him as he struggles with disabling attitudes and institutions as his disease progresses. Perhaps he can be one of many voices of people with dementia that will rise in unison to protest these disabling conditions.

*Collective and political hope*

A key effect of expressed hope and hopelessness is the emergence of collective identity between storyteller and readers. This research will need to explore how a collective identity emerges from narratives, and similarly, how political hope emerges from personal hope. Following the emergence of political hope in the narratives, how does this collective hope contribute to a social movement of people with dementia? How does it relate to the larger disability rights movement?

Narrative analysis is an attempt to "understand the hearts and minds and emergent processes, not merely the bureaucratic ones," of social movements (Gamson, 1987, p. 9). While Fine (2002) recognizes the importance of individual narratives, he goes beyond an examination of individualized stories to describe narratives as important to social movements because they are shared discourses to which members of the movement can refer. As such, shared stories can broadly be referred to as group narratives or metanarratives, and "[n]ew members become socialized to the narratives of the group" (Fine, 2002, p. 237).

The narrative accounts discussed in this paper may act as tools to recruit other people with dementia into a group with common desires and collective hopes. The politics of hope discussed by Barton (2001) is a unifying force that voices the collective hopes of people with disabilities. Fine states that "[s]tories bind individuals to each other as they recognize that they have common experiences that shape their identity and their linked futures" (2002, p. 238). As we have seen in this study, people with dementia have things that they hope for in common, but this does not necessarily mean that they are organizing and acting upon their personal hopes and grievances.

As it turns out, the collective hopes of people with dementia are represented internationally by Dementia Advocacy and Support Network International (D.A.S.N.I.). D.A.S.N.I is an internet-based group created by people with dementia, for people with dementia. This group communicates mainly via message boards and chat rooms, but also has members that speak at international conferences to share what it is like to live with dementia.

Christine Bryden (2005) attempts to articulate a grand narrative for people with dementia, inspiring political hope in others with dementia through her advocacy work with Alzheimer's Disease International (A.D.I.) and D.A.S.N.I.

> *I think the key to helping us cope with the trauma of living with dementia is to give us hope. Let us know we are unique, with our own inner resources. We have our life story, which tells us how we coped in the past. And this affects how we can cope today. We can try to discover an identity as a survivor of dementia and its diagnosis. Most importantly, encourage us to be positive, to hope for a new life in the slow lane, as we reach for the stars together.* (Bryden, 2005, p. 134)

The notion of 'survivor' articulated by Bryden (2005) is an important one in a discussion around issues of empowerment for people with dementia because it reinforces how people with dementia continue to live despite the restrictions imposed upon them by society because of their diagnosis.

It is fortunate that people with dementia are beginning to voice their concerns and organize their collective voices because this collective organizing is providing the fodder for a rights-based movement by people with dementia.

*Agency*

It is important to note that this research implicitly and explicitly addresses the sense of agency held by people with dementia. Recognizing this agency is something that many people with dementia have already done, and is something that gives them hope. For those of us who do not have dementia disabilities, recognition of this sense of agency is vital to developing an inclusive society for people with dementia.

Narratives challenge stereotypes of dependency for people with dementia in many ways. They position the authors as active agents, not just passive victims of a disease. Speaking for themselves is a very empowering action for people with disabilities, specifically for people with dementia in this case.

Within the narratives, the authors included chapters, prologues, and epilogues that were written by other people. Discussing agency raises the question of why the authors chose to incorporate others' voices into their narratives. Whose narrative does it become? If someone other than the person with dementia writes it, is it his or her narrative? If the person with dementia chooses to include it in their memoir, does it then become part of their narrative? Does it represent the beliefs of the person with dementia, or of the family member? Does the inclusion represent acceptance of these views by the person with dementia? Because of these questions, these sub-narratives were not included in the analysis.

### *Implications for the Disability Rights Movement*

It is important to discuss how the hope of people with dementia relates to the larger disability rights movement. If these authors with dementia are beginning to voice their hopes and effect change on a global scale, it begs the question of how this relates to other people with disabilities' attempts to be more hopeful (see, for example, Barnes, 1995). There was no explicit mention of the social model of disability in the narratives, so the reader can assume that the authors with dementia do not identify with the larger disability rights movement. However, Bryden (2005) makes many political statements in

her narrative that follow the basic philosophies of the social model of disability and the disability rights movement.

The implications of this research for the social model of disability are worth noting. Many of the narratives express hope for a cure and hopelessness in regards to the dementia impairment. How can these perspectives be reconciled with the social model of disability that argues for social change over individual change?

The wider disability rights movement has not made a concerted effort to include people with dementia into the movement, and I have not come across any mention of people with dementias such as Alzheimer's disease. This may reflect a separation between older people's issues (of which dementia is often assumed to be), and disability rights issues.

Many of the authors are averse to identifying themselves as people with disabilities (DeBaggio, 2002; McGowin, 1993; Rose, 1996), and this is often evidenced in their reactions to being approved for disability benefits.

McGowin, for example, argues that she would never qualify for disability insurance, when her physician suggests it, because she is "not that… that disabled" (1993, p. 42). To McGowin, being labeled disabled is a tragic event, and she reflects upon being approved for benefits.

> *I was approved for disability benefits. The day the approval came in the mail, my world exploded. I spent the entire afternoon sobbing, and trying to sort out what I should do now. Jack came in to find me distraught in the kitchen, trying to throw things about to vaguely resemble a meal. I was still fighting the miserable, uncontrollable sobbing. Jack, with all of his volatile moods, had not been able to*

> *reduce me to tears for a long time. He was startled to see them flowing so readily.*
>
> *He sounded genuinely concerned as he asked me to tell him what had happened.*
>
> *Jerkily, I told him I had been approved for benefits. He put his hand on my shoulder.*
>
> *"Diane, that is good news," he said softly. "Why are you crying?"*
>
> *"Because I thought they would say no! Don't you see? This means it is really true, all of it! I want my records! I want to see… I want to see…"* (McGowin, 1993, p. 73-74).

Larry Rose (1996) also grieves when he was approved for disability benefits.

> *The letter from Social Security came today. I was afraid to open it; Stella looked at it first. I had been approved for the maximum benefits. It was the saddest day of my life. I am sure most people would have been thrilled, and maybe I was too, in a way, but it also meant that this thing in my head is real. Social Security doesn't just give disability benefits for the asking. They really do an investigation; they have good doctors at their disposal, who check every tiny symptom before making their decision. The whole process took just over 90 days. (I must add that I was treated with kindness and respect from everyone at the Social Security offices.)*
>
> *My feelings could best be termed "bittersweet" about the news that I had just received. I didn't go outside for days. It was cold and cloudy. The sun wasn't shining. There were no stars in the sky at night. It was a dreary world. (1996, p. 36)*

This has implications for the larger disability movement. If people with dementia internalize the negative stigma of having disability, it may weaken the stance of people with disabilities who argue against taking a tragic view of disability, and instead argue that it is society that disables them. However, a prominent scholar in the disability rights

movement pointed out that it may have the opposite effect, and make people in the disability rights movement more resolved to challenge such perspectives (Len Barton, personal communication, July 27, 2005).

Many of the authors also carry prejudices against people with disabilities and distance themselves from identifying as someone with a disability. In his memoir, Rose included a poem by an unknown author that "seemed to fit [his] feelings just then" and reinforced his aversion to identifying as someone with a disability (1996, p. 49).

> *Today, upon a bus, I saw*
> *a lovely maid with golden hair.*
> *I envied her – she seemed so gay.*
> *I wished I were as fair.*
>
> *When suddenly, she rose to leave,*
> *I saw her hobble down the aisle.*
> *She had one foot and used a crutch,*
> *but when she passed, a smile.*
>
> *Oh, God, forgive me when I whine.*
> *I have two feet – the world is mine!*
>
> *And then I stopped to buy some sweets.*
> *The lad who sold them had such charm.*
> *I talked with him – he said to me,*
> *"It's nice to talk with folks like you.*
> *You see," he said, "I'm blind."*
>
> *Oh, God, forgive me when I whine,*
> *I have two eyes – the world is mine!*
>
> *While walking down the street, I saw*
> *A child with eyes of blue.*
> *He stood and watched the others play;*
> *It seemed he knew not what to do.*
> *I stopped a moment, and then I said,*
> *"Why don't you join the others, dear?"*
> *He looked ahead without a word,*
> *and then I knew he could not hear.*

> *Oh, God, forgive me when I whine,*
> *I have two ears – the world is mine!*
>
> *With feet to take me where I go,*
> *with ears to hear what I would know,*
> *with eyes to see the sunset's glow,*
> *God, forgive me when I whine,*
> *I am blessed indeed! The world is mine!* (Rose, 1998, p. 49)

Conversely, Cary Henderson (1998) expresses hope that people with Alzheimer's will not be ashamed of their disability. Henderson (1998) believes that the humanity of people with Alzheimer's is often forgotten, and it is time to challenge that notion.

> *I would love to see some people with Alzheimer's not trying to stay in the shadows all the time but to say, damn it, we're people too. And we want to be talked to and respected as if we were honest to God real people.* (1998, p. 7)
>
> *We can, I hope, encourage people who have Alzheimer's to not be ashamed and not be any more, you might say mind-paralyzed, than they are…* (1998, p. 57)

Barton (2001) argues that the struggle for change often involves moments of demoralizing defeats and frustrating setbacks. Therefore, hope is vital to preserving the momentum in the movement for an inclusive society. The author stresses the reflexivity of hope, taking past circumstances and future desired outcomes into account. He recognizes the disempowering effects of hopelessness and argues that there is a need to encourage collective hope in organizations of disabled people. Barton's (2001) discussion of political hope as a tool in the disability rights movement is valuable, and this research attempts to provide a hopeful base for a political movement for the social inclusion of people with dementia.

## Directions for future research and activism

Hopefully this research has challenged ideas about dementia being a hopeless disease by showing that people with dementia have hope. There is room for further research into how levels of hope fluctuate during various stages of the illness, as well as wider investigations into the hopes and despairs of a larger sample of people with dementia – North American as well as people from other ethnic backgrounds. Averill, Catlin, and Chon (1990) found hope to be socially constructed, and it would be very interesting to discover if people with dementia from other ethnic backgrounds construct hope similarly to the authors studied here.

Perspectives of people with dementia should figure prominently in any further research. As claimed by Ganzer, how an individual constructs meaning, morality, and subjective experience are "not easily discernible by positivistic research, in which objective measures and empirical studies often conflict with field data" (1994, p. 616). There is a need for more qualitative research into the perspectives, issues, and insights that people with dementia have to offer. These insights, and the questions that people with dementia put forward, will provide direction for further topics of investigation.

It is important to note that any further research done in this area should be conducted according to the philosophy of the social model of disability, and focus on emancipatory outcomes for people with dementia. If these two criteria seem to conflict, as in the case of people with dementia expressing hope for a cure and/or hope for death, this presents even more reason for complexities to be teased out within further research.

Researchers aiming to address contentious issues could explore what implications for the social model of disability are presented by expressed hopes for a cure and/or death. Research that aims to address these complexities has the crucial, yet difficult task of respecting emancipatory principles of voice, and analyzing results according to the social model of disability.

This paper has presented a challenge to traditional positivistic research methods by prioritizing the voices of people with dementia. As stated by Carole Mulligan (personal communication, April 5, 2005), "I am no longer interested in D.A.S.N.I. members 'telling their stories' so 'professionals' can interpret what they mean." This statement provides a fundamental challenge to the way in which this project, as well as many others have traditionally been organized in terms of power relations between researchers and subjects. Research *by* people with dementia, *for* people with dementia, is a pressing area for future study.

There is also a need for further research into the possible partnership of the disability rights movement and people with dementia. How can people with dementia be included in the larger disability rights movement? How can the inclusion of people with dementia advance the interests of the disability rights movement? How can attention to narratives be a valuable tool for both groups to advance their agendas? How can hopeful policy and planning result from scholarly research into the narratives of people with dementia? It would be interesting to explore how people within the disability rights movement feel about people with dementia, their potential for inclusion within the larger

movement, and implications for the social model. Hopefully this exploratory study will serve as a tool for future research into the empowerment of people with dementia.

There is a great need for further research that focuses on the supports available to people with dementia to remain included in mainstream society. This research would focus on the forms, quality, and extent of services experienced by people with dementia. This research would be expressed both in qualitative terms that prioritizes voice, and quantitative terms that include information on financial support, number and locations of Alzheimer Associations, and profiles of the people served by these programs. By emphasizing the social supports available to people with dementia, it reinforces the importance of social conditions on empowering or disabling individuals, and thus on the politics of hope that arise as a product of social conditions (Zournazi, 2002).

### *Conclusions*

Undertaking this research has impacted my professional practice by challenging me to think critically about ways in which people with dementia are excluded from mainstream society. It reinforced my belief that there is hope in living with dementia, and it opened my eyes to the range of hopes that people with dementia expressed in their memoirs. For example, I was unprepared to recognize that people with dementia would express such a strong and consistent desire for a cure. However, I was also challenged to think in terms of a multiplicity of truths, specifically in terms of the possibility of hoping for social inclusion at the same time as hoping for a swift death.

This narrative research discovered that authors with dementia do indeed foster hopes for their futures. Though they express despair with certain aspects of their lives, hope is far more prominent in their narratives. As a professional who currently works with many people in later stages of dementia, I am reminded daily of the hope that continues to grow within individuals with dementia. I am challenged to support this hope through my own actions, and I work towards following through on the politics of hope represented in the narratives of people with dementia. My respect for the individual's narrative is expressed daily through my interactions with the people I serve. After undertaking this research project, I see it as my duty to minimize disabling conditions in existing ways of operating, and maximize social inclusion for individuals with dementia. This is a difficult task within an institution that finds such thinking very challenging to put into practice.

In future work, I would very much like to partner with people with dementia to explore areas of interest to them. This would challenge me to address issues raised by individuals with dementia, and come to grips with ideas of emancipatory approaches to research, and emancipatory outcomes. It would also challenge me to grapple with the power issues that present themselves between researcher/professional and person with dementia. There is a politics of hope beginning to be expressed by organizations of people with dementia, and my personal hope is to provide whatever support I can to this movement.

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