The Experiences of People Living with Dementia in Acute Care Environments

By

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Abstract

Increased life expectancy and the population of seniors are growing rapidly which comes with an expected rise in acute hospital care needed. Nearly one quarter of hospital in-patients have dementia and caring for this population will be a significant part in the provision of health care services. The current knowledge base is through the perspectives of health care professionals and shows that the hospital culture, and environment, produces negative effects for people with dementia who are hospitalized. The effects of the stigma of dementia have not been studied in this environment specifically.

The aim of this research was to explore the experiences of people with dementia in the acute care environment, paying particular attention to stigma and exploring if, and how stigma was a factor in people's experiences. This qualitative study employed hermeneutic phenomenology that focused on the lived experience from the perspectives of people with dementia. Semi-structured interviews, and a focus group discussion was conducted with participants that included two men with early dementia and their care partners, one woman with early dementia, and two care partners caring for their spouses who were residing in long-term care facilities. The central overarching theme revealed throughout the continuum of care was stigma related to both age and dementia. Additionally, the findings reveal stigma to be present in system issues and the interpretation of stigma is very individual. Finally, enhancing care, revealed the critical role that advocacy played and how the culture of hospital care was understood. The use of the four structures of phenomenology showcased how the body, the hospital, relationships, and sense of time, interacted in making meaning in the acute care experience of the participants.

The findings revealed unique knowledge provided from detailed experiences of the participants where illness, age and dementia, influenced perceptions of stigma, and how stigma further impacts the perception of care and ultimately, how it is experienced and understood, by people with dementia and their care partners. These insights may provide areas where stigma can be tackled through the perspectives of those being stigmatized and draw much needed attention to facilitating change in the approach to care within the acute care system for people with dementia.

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Chapter 1 – Introduction

1.1 Background and Context

The population of seniors is growing rapidly and along with longer life expectancy, chronic illnesses, including dementia, are projected to increase, resulting in a rise in acute hospital care needed (Kurrle, 2006). There is also potential for a rise in crisis situations as Canadian families are changing and there are less children and smaller families to provide informal supports (Statistics Canada, 2012). Up to one quarter of hospital in-patients have dementia, and caring for this population is becoming a very significant part in the provision of health care services (Abley, 2012). Clearly, knowledge of dementia and quality care practices is necessary for health service providers to meet the needs of people living with dementia.

Dementia is considered one of the most costly and significant causes of disability globally in people over age 65 (World Health Organization, 2012). One person in twenty over the age of sixty-five is affected by dementia and by ninety years of age the number climbs to one person in every three (Gow & Gilhooly, 2003). Dementia rates are also considerably higher for women who represent two thirds of those with dementia (Alzheimer's Association, 2012). In addition, the life expectancy for women in Canada is also a significant factor as women live close to five years longer than men, which increases their risk for dementia. This also contributes to more years of living with the disease and requiring care (Statistics Canada, 2013).

In Canada, the prevalence of dementia is expected to rise significantly as the demographics change and the number of older adults with dementia increases (Alzheimer Society of Canada, 2010). Over 3,200 people in Northwestern Ontario alone currently live with dementia and this number is expected to double within a generation (Alzheimer Society of Thunder Bay, 2013). As age is the primary predictor of dementia, the ageing of the baby boomer generation will contribute to exponential growth of both incidence, and prevalence, suggesting of course the necessity, and urgency of research in this area.

The numbers of people living with, and impacted by, dementia are clear, yet it is a limited representation reflecting only those that have received a diagnosis. Estimates suggest that 1/4 of people with dementia have not received any type of formal diagnosis (World Alzheimer Report, 2012). These rates and associated economic impacts cost Canada approximately $33 billion dollars per year, and are predicted to reach $293 billion dollars per year in direct and indirect costs by 2040 (Alzheimer Society Canada, 2012). Globally in 2011, the economic impact related to dementia was estimated at a cost of $604 billion dollars (Alzheimer Society of Canada, 2012).

The majority of people with dementia are living in the community being supported and cared for by family members or living alone, with some receiving additional professional supports (Cunningham & Archibald, 2006). The decline in the average number of children per family from 2.7 in 1961 to 1.9 in 2011 also poses significant challenges as there may be fewer children to provide supports for a parent living with dementia (Statistics Canada, 2012). There is also a current shift in care through government strategies and initiatives that focus on aging at home and moving away from placement and care provided from facilities (Alzheimer Society Canada, 2010). Due to a decline in fertility rates and increase in lone parent families in Canada (Statistics Canada), there is a lack of informal care available to support a person living with dementia increasing the vulnerability and risk of hospitalization for those who remain in their own homes.

1.2 Hospitalization and Dementia

The prevalence of dementia is increasing as the aging population rises and with this comes the associated risk of hospitalization. For a person with dementia, there are significant negative consequences as a result of being admitted to hospital or receiving care in an emergency department (Kelley et al., 2010; Moyle et al., 2008; Sparks, 2008; Mitchell et al., 2009; Sampson et al., 2009). Although older individuals often seek hospital care for health issues other than dementia, their presenting condition, whether chronic or acute, can be intensified by dementia (Sampsom et al., 2009; Mecocci et al., 2005). Confusion and behaviours associated with dementia can also increase and become difficult to manage during a hospital stay, contributing to lengthier stays and delayed recuperation (Goodall, 2006; Mukadam & Sampson, 2011; McCloskey, 2004). In addition, various hospital care practices can also play a role in negative health outcomes (Holroyd-Leduc et al., 2007; Sorrell, 2010; Weitzell eta al., 2011). There are multiple factors which contribute to exacerbation of dementia and ill health for an individual with dementia while in hospital, which can also result in higher associated demands on the health-care system.

1.3 Dementia in Aging

As people age, the brain also ages and changes occur which can result in difficulty with memory or slowed thinking. Dementia, however, has unique characteristics that define it apart from the natural aging process and it is a broad term for loss of memory and other mental abilities severe enough to interfere with daily life (World Alzheimer Report, 2012). Dementia denotes a group of disorders that causes physical changes and damages in the brain that are long-term and progressive in nature, irreversible, and terminal (Alzheimer Society of Canada, 2010).

Alzheimer's disease is the most common type of dementia and accounts for an estimated 60 to 80 percent of cases. With Alzheimer's disease, a person can live on average for a period of 8 years, yet can survive up to 20 years with symptoms that progress from mild memory loss to severely affecting a person's capability to communicate and relate to his or her own environment (Alzheimer's Association, 2012). While Alzheimer's disease varies by type, it is largely irreversible, and impacts a person by progressive loss of knowledge and skills (Sparks, 2008). Vascular dementia is the second most common cause of dementia and is as a result of vascular problems in the brain. Previously known as multi-infarct or post-stroke dementia, vascular dementia occurs after a stroke (Barker-Collo, Feigin & Senior, 2006). Dementia with Lewy-Bodies (DLB) is the third most common form of dementia, with some differences in symptoms including memory loss, sleep disturbances, visual hallucinations and issues with muscle rigidity and difficulty initiating movement, much like Parkinson's disease dementia (Alzheimer's Association, 2012). Although medical care for people with dementia has improved with medications that provide benefits to some and can delay progression, there is no cure for dementia and treatment focuses on a supportive framework (Alzheimer's Association, 2012). Research continues to seek improvements in preventing and delaying onset as well as dementia treatments; however there is growing emphasis on research in improving the quality of life for those living with dementia (Alzheimer's Association, 2012).

1.4 Stigma and Dementia

Stigma is described as undesired differentness that is deeply discrediting, or a symbol of shame (Goffman, 1963; Link & Phelan, 2001; Byrne, 2000). Individuals who possess a chronic illness such as dementia may be viewed as differing from others and this may result in stigmatization from those who do not have the illness (Joachim & Acorn, 2000). Dementia stigma is related to poor prognosis, and perceptions can include the view that individuals with dementia are responsible for their illness, they are dangerous, and can also cause social interference (Mukadam & Livingston, 2012). Dementia is attached to negative associations related to fear (Gilmour & Brannely, 2010; Langdon, 2007;Mukadam & Livingston 2012), and the stigma of dementia has caused individuals with dementia to feel less valued, isolated, non-existent, marginalized and suppressed (Katsuno, 2005; Liu et al., 2008; Langdon 2007; Gillmore & Brannely, 2009; Crocker & Major, 1989). As dementia is predominantly, although not always, an illness associated with older age, people with dementia are exposed to stigma related to both mental illness and to negative stereotypes related to age (Godfrey et al., 2005). The World Health Organization, recognizes that, “stigma against older people with dementia… is widespread and its consequences far reaching” (Graham et al., 2003).

1.5 Rationale for the Current Study

In spite of a growing body of research on dementia, little is known about how people living with dementia experience acute care hospital environments. The proposed research seeks to explore the experiences of people with dementia in an acute care environment, paying particular attention to stigma and exploring if, and how, stigma is a factor in people’s experiences. These important insights will be gathered through a qualitative exploratory study including interviews with people living with dementia and their care partners, with the goal of developing appropriate practices, policies, and education for staff working in the acute care environment to enhance the quality of care for people living with dementia. As there is an expected significant rise in the number of people with dementia requiring acute hospital care for conditions other than dementia, special care is necessary to respond to the unique needs of older people with cognitive impairment (Moyle, 2008). Greater understanding and awareness is necessary to reduce the stigma associated with dementia and reduce the negative impact it has on the health of those living with dementia and receiving care in an acute care environment.

Chapter 2 – Literature Review

2.1 Introduction

The existing knowledge base relating to stigma and people living with dementia in the acute care environment is presented in the literature review. Moyle, Olorenshaw, Wallace and Borbasi (2008), provide a review of the literature published between 1986 and 2006 focussing on principles of best practice in caring for people with dementia in acute care. Their research recognizes that acute care hospitals constitute a unique care environment in comparison to other environments and identify a number of interventions that may improve care for people with dementia, while reducing the burden of care. Their findings indicate the importance of early detection of dementia, the relevance in staff knowledge, attitudes, communication and multidisciplinary approach to care. In addition, family and care partner involvement was also essential. This review provided important research-based literature regarding management practices of people with dementia experiencing chronic confusion in the acute care setting and provided significant information about the health consequences discussed in my study. Their 2008 research was also drawn upon as it also examined the acute care environment through a qualitative perspective similar to this research. In this study, acute care staff perspectives were examined through semi-structured interviews and found themes demonstrating paradoxical and inconsistent approaches to care that occurred at the expense of patient's well being.

The abundance of the literature captured the perspectives of health care professionals and stigma was not addressed specifically in the acute care environment. There are studies and citations included that explore other environments such as long-term care as well as stigma and mental health as they are particularly relevant in this overview.

Current literature has examined caring for people with dementia primarily through the perspectives of health care professionals through medically dominated perspectives and clinical frameworks although acute hospitalization has received little attention (Park, Delaney, Maas & Reed, 2004). According to Park et al. (2004), care for people with dementia during hospitalization has received very little focus in comparison to the care in long-term settings and within the community. Further, research by Moyle, W., Olorenshaw, R., Wallis, M. & Borbasi, S. (2008), and Mukadam & Livingston (2012) suggest that there is also insufficient research that addresses reducing stigma related to dementia specifically. Stigma, and its potential presence in the acute care environment, is clearly absent from current literature.

2.2 The Effects of Hospitalization

Research has demonstrated that experiences in acute care environments, such as hospitalizations and care in emergency departments, have an enormous negative impact on the health of people with dementia (Kelley et at., 2010; Moyle et al., 2008; Sparks, 2008; Moyle et al., 2010) When an older person is receiving care in an emergency department or admitted to acute care, there can be a negative impact on their physical and mental health with increased risk of poor outcomes (Kelley et al., 2010; Moyle et al., 2008). Along with poorer health outcomes for those with dementia, there are heightened complication rates, delayed recuperation, greater rates of readmission, increased mortality, and escalating health care costs which are all consequences of hospitalization (Sparks, 2008). In addition, a person with dementia is impacted even further, in comparison to other groups, as care in the hospital setting is tailored toward acute problems, and people with dementia are often treated as low-priority cases (Moyle et al., 2010).

Hospitalization is most likely to occur when people experience acute illness or issues such as hip fracture, heart failure, respiratory or gastrointestinal problems. When older people with dementia access hospital emergency services or are hospitalized, dementia in these environments can contribute to a range of negative effects. Increased delirium, falls, onset of incontinence issues, pressure ulcers, untreated pain and increased mortality are all increased risks specifically for people with dementia (Sparks, 2008). Of immeasurable concern are the higher mortality rates associated with complications frequent in dementia patients including pneumonia, fever and nutritional deficits (Mitchell et al., 2009). A study by Sampson et al. (2009) found that older people with dementia admitted into acute care had an increased mortality rate of three times, and in those with advanced dementia, the mortality rate was five times higher. The authors argue that a patient's condition was clearly exacerbated by dementia, and that unresponsive and poor quality care that older people with dementia receive, are contributors to increasing mortality rates.

Receiving hospital care is found to increase confusion, agitation and behavioural issues contributing to longer hospital stays as their conditions are complicated in terms of receiving care, and poorer health outcomes are a result (Goodall, 2006; Mukadam & Sampson, 2011). Aggression, wandering and vocalization are common dementia-related behavioural challenges that can be difficult to manage in the hospital environment (McCloskey, 2004). Managing dementia care was found in a study by Moyle et al. (2008) to impact not only the health of the person with dementia but also extended to negatively impacting their family, or care partners, as well as the care provided to other patients.

Dementia is also a key risk factor for delirium; two thirds of the delirium in an acute care setting is experienced by people with dementia (Inouye, 2006). Dementia and delirium, either present at admission or manifested during the patient's hospital stay, was also shown to contribute to longer stays in hospital (Sarvay et al., 2004). Falls are also more prevalent occurring 1.6 to 3.6 times more often in hospital in-patients with dementia (Mecocci et al, 2005). An Italian study involving over eighty-one hospitals and thirteen thousand participants found that patients with dementia are five times more likely to develop urinary incontinence and six times more likely to develop fecal incontinence in comparison to other patients (Mecocci et al, 2005). This same study indicated that pressure ulcers also occur five times more often for hospitalized people with dementia. Nutritional concerns and weight loss are also problems central to dementia patients in acute care as there are concerns with the person's ability to recognize hunger, chew or swallow, as well as difficulty focussing on eating due to distractions from the surrounding environment (Weitzel, 2011).

In comparison to care for other hospital patients, care practices for people with dementia within the acute care environment contribute to adverse health effects for people with dementia. Studies suggest that staff employ certain procedures more often for people with dementia including the use of catheters, feeding tubes and physical restraints (Holroyd-Leduc et al., 2007; Sorrell, 2010; Weitzell et al., 2011). Patients with dementia are three times more likely than any other patients to be catheterized in the absence of clinical explanations for such procedures (Holroyd-Leduc et al., 2007). There is also greater risk for invasive feeding tube insertion during their hospitalization for an acute illness contrary to evidence demonstrating that feeding tubes do not benefit clinical outcomes and may negatively impact quality of life in addition to causing increased agitation and mortality (Sorrell, 2010; Weitzell et al., 2011). Research further suggests that feeding tube insertion for patients with dementia is reflects hospital practices rather than the needs, or desires, of people with dementia and their care partners (Sorrell, 2010).

Nurses have the added responsibility of managing serious medical conditions in addition to managing the very challenging, and complex, behavioural issues associated with dementia. Dementia related behaviours that are problematic in the provision of care include aggression, resisting help, hallucinations, restlessness and agitation, wandering, as well as reactive behaviours (Normann, Asplund & Norberg, 1999). These behaviours, as well as a decline in health, are precipitated by fatigue, routine disruption, the setting or person providing care, demands that surpass one's ability, chaotic stimuli, affective reactions, and physical issues including pain which all exist within the acute care environment (Moyle et al., 2010). Moyle et al. (2008) provides evidence of inconsistencies and paradoxical care in care practices for people with dementia in the acute care environment that may contribute to not meeting the needs of patients with dementia. McCloskey (2004) point out that unmet physical, emotional, or social needs can also exacerbate confusion. The needs of people with dementia are insufficiently addressed through current hospital care practices and particularly by health care staff where approaches and care practices emphasized safety often at the expense of the patient's health, welfare and dignity (Moyle et al, 2010).

Pain management is of primary concern within hospitals that treat acute illnesses and untreated pain is more prevalent in patients with dementia over other patients. For older adults in general, the prevalence of pain is as high as 84% and this is likely similar for people with dementia (Weitzel et al, 2011). Several studies reveal that people with dementia in acute care receive less pain medication in comparison to others that are cognitively intact (Smith, 2007). For example, research by Morrison & Sui (2000) concluded that people with dementia hospitalized as a result of experiencing a hip fracture received only one third of the opioid medication received by patients who were cognitively intact. The presence of pain for people with dementia that is un-diagnosed and left untreated also contributes to increased agitation and behavioural problems for this group (Husebo, Ballard & Aarsland, 2011). Research indicates that exacerbated conditions contribute to negative outcomes for people with dementia and predict greater demand on medical services, care, and contribute to increasing the length of hospital stays, costs and resources associated.

2.3 Culture of Care and Care Practices

The provision of care for people with dementia embodies challenges which can result from a lack of knowledge and understanding of the unique needs that exist within the acute hospital setting (Cunningham & Archibald, 2006). Lack of understanding, combined with ageism and mental health stigma, contribute to inequalities that are experienced by people with dementia and are embedded in the care that they receive, particularly within the hospital environment.

Nursing staff are the primary hospital caregivers for patients and they have minimal understanding of what dementia is and how to manage dementia-related challenging behaviours (Moyle et al, 2010). It was also revealed that their lack of dementia knowledge combined with negative attitudes toward aging and dementia care contribute to negative health outcomes for individuals with dementia (McCloskey, 2004; Pritchard & Dewing; 2001; Cunningham & Archibald, 2006). Staff education was cited as lacking importance in a study by Moyle et al. (2010) where there was no emphasis placed on learning appropriate assessments for people with dementia, but focus was concentrated on relocating the dementia patient elsewhere. Gilmour and Brannely (2010) further argue that nursing education is insufficient in addressing stigmatic beliefs as their texts and teachings are grounded in the biomedical & historical accounts of dementia which is fundamental in shaping and perpetuating an age old culture of care that continues to negatively impact people with dementia.

Caring for people with dementia is described by nurses as ‘difficult, unrelenting, and frustrating’, and participants in a study by Moyle et al (2010) stated that there were ‘more valuable things they could be doing’ which resulted in presenting undesirable attitudes toward their patients with dementia. Pritchard and Dewing (2001) suggest that the negative attitudes that nurses maintain about older people with dementia are significant impediments to providing optimal care for them as well. One example was the use of restraints where staff was aware that the restraint measures they used contributed to an exacerbation of confusion and aggression; however they continued to use the same restraint techniques and further placed blame on the person for his or her behaviours (Moyle, et al., 2010). Although nurses were aware of the negative impact that restraints had specifically on people with dementia, they justified their use for staff and patient safety reasons which was endorsed by hospital policy (Moyle et al, 2010). Acute care nurses also report feeling fearful toward patients with dementia, being neglectful or having to use force in comparison to other patients. Further to those responses reported by staff, a study by Eriksson & Saveman (2002) described abusing their patients with dementia in some cases as a way of managing difficult behaviours. Nurses also describe difficult or disruptive behaviours of their patients with dementia such as aggression, resisting help, and “reactive behaviours” as impeding their time management and routines (Borbasi, 2006). Reactive or responsive behaviours are challenging behaviours such as aggression, wandering or agitation that is not unpredictable but in response to external triggers from something negative, frustration or confusion about their environment (Alzheimer Society of Ontario, 2011). In Fessey’s (2007) study exploring a theoretical approach to person centred care, nurses consistently commented that lack of staff and time constraints contributed to influencing their approach to care often impeding their ability to provide any care at all. Moyle et.al. (2010) also found that nursing staff claimed that hospital management did not recognize or support them in any way in dealing with aggressive behaviours from dementia patients citing budget constraints for nurse shortages and time management. Within the culture of care, the priority and focus of staff remains in care delivery that revolves around safety where person centred care and dignity are often compromised (Moyle, 2010). Although care partners and family members can often provide support to people with dementia in the hospital environment and studies have indicated benefits to their participation in care, this is not a hospital priority or consideration in the care for a person with dementia (Moyle et al., 2008).

Communication of people with dementia can also be another challenge to the abilities of hospital staff in providing appropriate care. Dementia can impact a person's ability to express him or herself and make decisions regarding care potentially resulting in unmet needs, reactive behaviours, and negative health impacts in the acute care environment (Cunningham & Archibald, 2006). An acute illness, or the acute care setting, can contribute to exacerbating communication difficulties for a person with dementia further affecting their health (Moyle et al., 2010). Communication difficulties, confusion, or memory impairment can also make it problematic for nurses to identify pain, manage pain, and conduct accurate pain assessments. Nurses describe lacking knowledge in this area and declare recognizing and assessing pain as too time consuming when they are already short staffed and over worked leaving patients with dementia with enduring untreated pain (Herr et al., 2006a,b).

Although nurses provide the majority of care for in-hospital patients, physicians are integral in the decisions and care that people receive. The World Health Organization reports that studies have found that physicians can be dismissive about individuals’ dementia symptoms which may also result in their unhelpful response (London, Alzheimer’s Society, 2008). Identical to statements made by nurses in previous studies, physicians also perceive that little can be done for patients with dementia, and describe having more acute patients to care for (Moyle, 2010). Avoidance was consistently noted for physicians regarding their treatment of people with dementia, and utilization of power status to coerce them into taking medication both provide substantiation of stigma within this group (Benbow & Jolley, 2012). In a British study by Iliffe (1994), physicians have also been reported to hold “nihilistic” attitudes toward patients with dementia stemming from their absence of value for people with dementia (Katsuno, 2005). The World Health Organization (2012) suggests that this unsupportive attitude from physicians undoubtedly contributes to people with dementia having negative perceptions of care providers and the care that they receive.

2.4 The Hospital Environment

When people living with dementia are hospitalized, they are in a strange environment where they are cared for by people who are unfamiliar to them, and unfamiliar to their preferred routines, and care. People with dementia may have difficulty orienting to a new environment, consequently making them at much higher risk for delirium, dehydration, inadequate nutrition, untreated pain and unmet spiritual needs (Borbasi, Jones, Lockwood & Emden, 2006). A strange environment can further impede a person’s ability to understand explanations, follow directions, voice their symptoms, request assistance, and can impair relationships with health care providers (Moyle, 2008). The acute care environment incorporates a culture of care that revolves around active, invasive monitoring and creates attitudes and behaviours amongst staff where the needs of people with dementia, whether or not they were acutely ill, are difficult to assess and are viewed as a lower priority (Moyle, 2006). Literature confirms that hospitals are not beneficial places specifically for people with dementia as the unfamiliar environment, with unfamiliar people providing their most personal care, can cause an exacerbation of their confusion (Borbasi et al.2006). Other negative care practices, such as restraints for example, are often employed in this group as a result of an environment that is not adaptable for people with dementia (Moyle, 2010). For many hospitalized patients, their access to acute care is through the emergency department. The emergency department is described by Kelley et al. (2010) as a fast-paced environment that is filled with commotion that impacts the attention and quality of care that patients receive and which can be overwhelmingly confusing for a person with dementia. Studies have highlighted simple environmental interventions, such as lighting and using memory cues, that could be implemented to assist people with dementia and although there is interest in changes through trial dementia units, these strategies are found to be low- priority throughout hospitals (Moyle et al., 2006). In Borbasi's study (2006), staff describe that although they put effort in providing the best care possible, they are largely limited by their environment, sociocultural constraints and economic limitations.

People with cognitive impairments are not considered in the design and development of hospital environments which has a variety of implications. Ward layouts, often being generally more linear than circular, are unsafe and increased the risk of disorientation for confused patients (Borbasi et al., 2006). Moyle et al. (2008) further suggest that this intensifies the burden of care and impacts safety of in-patients with dementia. Institutional parameters guide and impose constraints on the care provided to people with dementia that is not person-centred (Borbasi et al., 2006).

In the absence of specialized dementia care units, patients with dementia are also often placed across a range of wards that lack in specialized training and care for patients with dementia. Some hospitals have implemented “specialling” as a form of care management that provides one on one care, and is a way to help manage care for people with dementia. Although the concept of specialling is positive, there are still concerns where it is implemented, as it is often only junior staff members assigned to observe (Moyle, 2010). The patients with dementia are not given experienced staff, as specialling is viewed as being the job of a “babysitter”, and the care provided is by newly trained nurses who lack knowledge, skills, and experience in managing dementia. In addition, specialling is found to further aggravate the person with dementia as his or her privacy can be compromised (Moyle, 2010). Without designated dementia units, or specialized training and care for patients with dementia, the priorities in care for people with dementia revolve around getting the patient out of the hospital as soon as possible rather focussing on enhancing care practices (Borbasi et al, 2006).

Both care practices and the myriad of exacerbated conditions, complications, and negative outcomes for people with dementia contribute to increasing length of hospital stays with implications in increased consumption of medical costs, services and resources. Studies in a review by Mukadam & Sampson (2011) consistently indicate that the duration of hospital stays for people with dementia in comparison to other hospitalized patients are significantly longer ranging from six to thirty days. Longer hospital stays along with hospital over-capacity issues and significant shortages of long-term care beds, creates challenges that can affect the care of a person with dementia in the acute care environment. People with dementia are also being placed in acute care hospital beds inappropriately while waiting for long-term care placement (Kelley et al. 2010).

The negative health impacts that people with dementia experience are influenced by key areas of hospital care that surrounds the environment, the system, those who provide care, and care management. Policy, practices, and relationships in the acute care environment are dominated by the medical model that is rigid and ignores the unique issues that a person with dementia has. The literature acknowledges that people with dementia receive different care treatment within the acute care environment. A lack of knowledge and understanding, negative attitudes, language, and care practices by health care staff, combined with an unsupportive environment are all sanctioned through hospital policies and result in negative health outcomes for people with dementia. Research demonstrates that within this environment, there is evidence of stigma through stereotyping, prejudice and discrimination, where people with dementia are viewed undesirably based on dominant, yet distorted, historical & medical conceptualizations.

2.5 The Illness Experience

Illness, pain and discomfort can be experienced very differently by different people. Although symptoms are related directly to the body and can be very private, suffering from illness is an experience that is also profoundly social (Nettleton & Gustafsson, 2002. P.177). How people identify, interpret, and manage their own illness varies according to multiple factors, including context (for example, a hospital environment). When a person becomes ill, certain behaviours are engaged in to relieve sickness and the processes of illness behaviour are socio-cultural, psychological, physiological and structural (Young, 2004).

The sick role concept was examined through sociological perspectives and described the social construction and processes that contribute to illness behaviour. Historically, through Parson's (1975) work, illness was viewed as deviance from social norms and that it was a patient's responsibility to seek medical attention to move out of their deviant sick state. In addition to obtaining the necessary physiological interventions, healing sickness depends greatly upon the participants of the illness event interacting and communicating effectively (Young, 2004).

The nature of the relationship between health care provider and patient is complex, and involves differential power between the participants in the relationship. Social relationships are inherently embedded with power (Goodyear-Smith & Buetow, 2001) and in the realm of health care, the power of the physician encompasses their medical knowledge, resources, and the ability to provide services, care and healing (Toffler, 1990, Goodyear-Smith et al. 2001). Physicians largely view sickness as a process that is biological, thus the social aspect of the illness experience is often ignored (Twaddle, 1969**).** The emphasis remains in the practitioner's power to diagnose and provide treatment. Specifically, in acute hospital settings, the studies of both Rier (2000) and Zussman (1992) found patient involvement excluded in the decision-making process and emphasis on the dominant role of the physician. Goodyear-Smith et al. (2001) points out that it is necessary for doctors to hold power as they require specific knowledge to advocate on their patients' behalf; however patients also need power to have their health care needs met, which is shown as often limited in the health care environment (Rier, 2000. Zussman,1992. Goold & Lipkin, 1999, Young, 2004).

For vulnerable patients, there is a heightened reliance on the practitioner's knowledge and competence which is critical in designating power in the relationship and further disempowering those that are vulnerable (Goold & Lipkin, 1999). For people living with dementia who are ill in an acute care environment, the additional power imbalance embedded in care can contribute to an exacerbation of ill health. Although patients' rights have progressed, power in the care relationship is inherently imbalanced and inequitable (Young, 2004), and the role of power in patient-health care provider interactions must also be considered in the hospital experience.

2.6 Stigma

Historically, stigma became known initially in Greece as a branding or tattoo that signified religious devotion and later stigma became known in relation to negative bodily signs, criminals, or about negative moral status of an individual (Link & Phelan, 2001). The work of Erving Goffman (1963) contributed to understanding the complex social processes of stigma and how undesired differentness created extensive negative implications for those that are stigmatized. Goffman brought forward the processes by which identities became "spoiled" which was relevant to many societal challenges such as women's rights, gay and lesbian rights, disease, race, and the rights of the mentally ill. Goffman defines stigma as an "attribute that is deeply discrediting" and diminishes the individual "from a whole and usual person to a tainted discounted one" (Goffman, 1963, pg. 3). Byrne (2000) further describes stigma as a symbol of shame or dishonour, which positions an individual at a distance from others. In addition, Goffman suggests that referring to stigma as an attribute should be complemented by language that also embraces stigma as relationships (Goffman, 1963). Kitwood (1997) further supports the aforementioned notion of stigmatic relationships by suggesting that social and interpersonal factors can influence health either negatively, or by having a positive impact and improving a patient's condition. According to Goffman (1963), the stigmatized person is not recognized for his or her actual identity but for the virtual self within an interaction or relationship. He further suggests that there will be avoidance of what is deemed discrediting, yet this awareness and careful effort put toward “disattention” by others produces tension and unease within the relationship (Goffman, 1963).

Although there are differing theoretical definitions of stigma offered in the literature, the term generally denotes adverse experiences based on exaggerated perceived differences for those that are stigmatized. Link & Phelan (2001) suggest that there is a significant amount of research on the nature, sources and consequences of stigma and there is an abundance of evidence of the negative impact on those that are stigmatized. Although there is multidisciplinary interest in stigma research social psychologists have contributed much of the research on stigma (Link & Phelan, 2001). The concept of stigma has been applied to a wide variety of circumstances and the social cognitive approach was employed to link categories that are constructed to stereotyped beliefs and the relationship with attributes, stereotypes and discrimination (Link & Phelan, 2001). Stereotypes, prejudice, and discrimination are three characteristics of what is known as stigma (Benbow & Jolley, 2012). Stereotypes describe the common judgements, while prejudice is the emotional response and discrimination is the resulting behavior against a particular group (Benbow & Jolley, 2012). The social message conveyed by stigma involves labels and stereotypes and which are often automatic occurring at a level of pre-consciousness as it happens almost instantaneously (Link & Phelan, 2001). Stigma is broken down into five interrelated and converging components by Link & Phelan (2001): 1) There is an oversimplified attribute or category that is salient to society reflecting dominant power structures and which is grouped and labeled; 2) Labeled characteristics are linked with negative stereotypes encouraging society to view those individuals as fundamentally different; 3) Stigmatized individuals are differentiated by the ‘us’ and ‘them’ label; 4) The effects are discrimination incorporating status loss both personally and at a structural level as an immediate consequence of a stigmatizing label; 5) The stigma process depends upon the social, economic and political powers that are able to impose discriminative action on the individuals or group (Link & Phelan, 2001, p. 367).

Important to note are the effects that stigma has on a labeled person. There may not be obvious discrimination toward the person; however pre-conceived expectations of treatment or rejection from a particular label becomes part of the person's worldview per se. Link and Phelan (2001) write of the internal negative consequences as losing confidence, expecting rejection, and reduced self-esteem, which can all affect life quality. Internalization of stigmatic ideas results when people perceive themselves as stigmatized (Graham et al., 2003). Denial and socially isolating one's self can impede a person who is stigmatized from not seeking, or being offered, support that is needed (Nolan, 2006).

2.7 Stigma and Dementia

The World Health Organization describes dementia as an overwhelming disease that produces disability and dependence, and where lack of knowledge and awareness of dementia contributes to stigmatization (World Health Organization, 2012). Stigma related to mental health has been suggested as maintaining a discriminatory discourse as it has lacked language, such as 'racism' or 'sexism' for example, which are recognized descriptions of prejudiced beliefs that have been instrumental in political campaigns put forward to diminish the presence of stigma (Byrne, 2000). The development of stigma in dementia is contributed to by four main factors: people with dementia are perceived as dangerous, they are responsible for their illness, the illness has a poor prognosis and dementia is perceived to cause social interference (Mukadam & Livingston, 2012). A UK study by Langdon (2007) exploring the social effects of dementia found themes that revolved around perceptions of stigmatization. Participants of the study, having been diagnosed with dementia, felt there were negative associations attached to the word “dementia” and felt that language such as “crackers” or “screw loose” were what others commonly associated with the dementia term. The Latin meaning for dementia is “without mind” and is used in the western world as a derogatory depiction as reference is made to the “demented” producing social fear (Gilmour & Brannely, 2010). Mukadam and Livingston (2012) also find that dementia is commonly associated with fear and misunderstanding as it is often judged in the same manner as mental illness yet the incurable and progressive nature of dementia attracts stigma that is suggested as even greater (Mukadam & Livingston, 2012). A study done in London, UK including more than 2000 participants, also found fear highly associated with dementia where 18% feared death the most, followed by 27% that feared cancer the most and greater than both death and cancer, 33% claiming that dementia was what they feared most (Alzheimer’s Research UK, 2011).

Self-perception and self- esteem were also found significantly affected by stigma. A qualitative study by Langdon (2007) evaluating the social effects of a diagnosis of dementia found participants describing themselves as feeling less valued, experienced deteriorated social status, and also felt that they were taken “less seriously”. In addition, the use of the terms ‘dementia’ or ‘Alzheimer’s disease’ were described as unfavourable labels and participants were reluctant to use the terminology preferring ‘memory loss’ or ‘forgetfulness’. In a US study exploring negative public attitudes and their impact on people with dementia, Katsuno (2005) found participants reporting that they felt devalued, treated in a way where they felt non-existent, felt isolated and lost friends. Liu, Hinton, Tran, Hinton, and Barker (2008) found “shame” and “loss of face” described as a response to the person with dementia as well as his or her family members in social experiences which is similar to related literature regarding mental illness. This study also found that stigma was a common theme evident in 91% of the interviews and suggested that there were two sources of stigma; one being toward mental health as well as stigma related to general aging. Stigma was found related to discrimination against older people with cognitive impairment in health care services and was a classification that was doubly disabling in the health care environment (Mendonca et al., 2003; Nolan et. al., 2006).

Historical representations of people with dementia reflect that they are marginalized and suppressed (Gillmore & Brannely, 2009), and this dominant view burdens healthcare staff's ability to move beyond to challenging stigma in current practices. There are historically entrenched perceptions and treatments of people with dementia as they were admitted to asylums for control and public safety, rather than being cared for and treated as valuable human beings (Gilmour & Brannely, 2010). Tom Kitwood's notion of personhood in the 1990s prompted a change in how dementia is approached although personhood still receives insufficient respect as decisions related to a person with dementia are often made for them, and without them (Kitwood, 1997). Personhood, described by Kitwood (1997) is a status of recognition and respect, within the context of social relationships, that is placed upon an individual by others. Additional research indicates, however, that people with dementia are still considered within a social category in which others hold negative attitudes, stereotypes and beliefs and as a result are devalued (Crocker & Major, 1989).

Within the contemporary health care context, and particularly within the hospital environment, biomedical models, historical concepts of the disease, and medically driven perspectives continue to dominate and impede the values of respecting the rights of a person with dementia (Moyle, 2010). The medical model, and treatment of people with dementia, has led many in acute care to see the person with dementia within the "sickness framework" and see dementia as a condition of hopelessness conveying negative feelings that affects a person's well-being (Goater & Woods, 2006). In the study by Borbasi et al (2006) participants, who were health care providers, believed that most staff were "reasonably tolerant and knowledgeable about dementia", and yet they admitted that stereotyping was entrenched. Research by Clarke et al. (1993) found that many health care providers regarded people with dementia as "effectively dead". Stigma appears to underpin barriers that exist to effective treatment for people with dementia throughout the system, from those involved in care, the culture of care management, and environmental barriers. The current knowledge base, values, and learned patterns and responses from healthcare professionals have evolved through distorted views and perpetuated stigmatization that is embedded in practices, policies and throughout our health care system. Borbasi et al (2006) point out that the current dependence on the biomedical model indicates that education for health care providers is not progressing to respond to the needs of a growing population of seniors continuing to reinforce negative images of seniors in the health care system and for those with dementia, those images are even greater. Stigmatized individuals are also vulnerable to structure, including policies and practices that further discriminate and disadvantage (Link & Phelan, 2001).

2.8 Gaps in the Literature

Despite the importance of stigma and its impact on those living with dementia, there is a lack of research investigating the impact of this phenomenon in health care settings. The literature in this review provides insight into the experiences of people with dementia in the acute care environment from the perspectives of health care providers, although there is little that describes stigma specifically, and little describing the experiences of people living with dementia from their perspectives. Difficulty operationalizing stigma to study may contribute to the lack of research in this area as well as that it is defined and characterized in many different ways. There is also a gap in the literature that the voices of people with dementia have not been given opportunity to provide their input. Gilmour and Brannely (2010) suggests that the focus on caregivers along with the suggested loss of insight that dementia represents, and the ethical aspects of involving people with dementia in research have contributed to keeping the interest off the person with dementia. Kitwood (1997) adds that power and control issues, particularly involving health care providers, also contributed to excluding and devaluing the person with dementia. Research in this area requires further exploration, particularly as the population of older adults is increasing, and dementia is the most disabling, yet common condition affecting older adults (Liu et al. 2008).

Further research should also focus on the perspectives of people with dementia to bring greater knowledge and understanding and reshape the expert driven, medical models of care. It is necessary to challenge stigmatic thinking, current practices, and norms in care to strive toward improving the experiences of people with dementia in ways that are meaningful to people with dementia, effective, and contributes to appropriate dementia care practice and policy. The focus of research highlights the economic impact and health care system; however the impact on the health and quality of life of people with dementia has received considerable less attention. Research that gives people with dementia and their care partners a voice in improving the quality of their lives and care within the hospital experience is necessary to generate a more supportive environment and healthier outcomes.

2.9 Study Purpose

The aim of this research was to explore the experiences of people with dementia in an acute care environment, specifically seeking to understand if and how stigma played a role in shaping these experiences. Additionally, I sought to explore stigma within the current model of care, and examine ways to address stigma within the provision of care, to generate a more supportive environment and healthier outcomes for people living with dementia. Specifically, the research questions included:

- What experiences do people living with dementia have in acute care and what factors contribute to shaping those experiences?
- How do people living with dementia describe the care they receive and their interactions with health care providers?
- Do people living with dementia describe being perceived or treated differently and experiencing stigma and if so, in what ways?

This research intends to contribute to a greater understanding of the experiences of people with dementia in an acute care environment to address challenges of how people with dementia are viewed and treated within the hospital environment. This research will highlight areas for further education and provide practical information related to policy change and development that informs, guides, and supports, people with dementia in navigating through their hospital experience in a way that is empowering and optimizes their health and recovery.

Chapter 3 - Research Methodology

3.1 Research Approach

The research design was qualitative in nature resulting in rich data that provided an in-depth picture, which was particularly useful for exploring how and why events transpired (Creswell, 2013). This method incorporated inductive processes in understanding a phenomenon and specifically, hermeneutic phenomenology focusing on the subjective experiences of individuals and groups (Van Manen, 1997). Hermeneutic phenomenology reveales understanding of the lived experience of the phenomenon and closely examines the lived space (spatiality), the lived body (corporality), the lived time (temporality), and how others interact and contribute to influencing and shaping individual experiences (relationality) (Van Manen, 1997). These four essential structures of the lived experience directed exploration of the experiences of people with dementia in an acute care environment. Creswell (2013) supports a phenomenological approach as most appropriate in seeking to understand the common experiences of a phenomenon from the viewpoint of several individuals in order to promote practices and policies relative to the phenomenon. Van Manen (1990) describes phenomenological text as that which encourages us to see what tends to hide itself and brings depth and insight to the meaning of lived experiences, which assisted in constructing and revealing layers of meaning particularly valuable in exploring stigma and its effects.

3.2 Participant Recruitment

Permission to recruit and proceed with this research was granted by the Lakehead University Research Ethics Board prior to engaging in the recruitment of participants. This study was advertised through an information letter provided to staff and clients through local organizations offering services to people with dementia. In collaboration with these organizations, people were recruited through support groups and existing research collaborations in Ontario. Although there was no specific inclusion criteria employed, individuals living with dementia who were known to be active and able to participate through demonstrated involvement in previous research in addition to being able to provide their own consent were recruited. The participants living with dementia were recruited through various organizations, as well as under the guidance of my thesis supervisor Dr. Elaine Wiersma who has an extensive research background working with people with dementia, and who was familiar with the participants. The participants who were recruited were able to understand the research and consequences of their participation, and had the ability to make reasoned choices with an understanding of possible alternatives, or options, which embodies consent according to Lai & Karlawish (2007).

Specifically, through purposeful sampling, the participants for this study included people living with dementia and their care partners who received acute care hospital services within the last two to three years in the province of Ontario (Creswell, 2007). This length of time was necessary for purposive sampling in order to expand inclusion, as well as being recent enough that participants' recall of experiences would still be accurate and in detail. The participants in this study were either admitted as an in-patient or spent a minimum of one day or night in the emergency department of an acute care hospital. Primary care partners, or those who provide instrumental care and assistance, were also recruited through the same process and were closely involved, and present, in the hospital experience of the person living with dementia.

An information letter was provided to each participant explaining the research and written consent was obtained for the researcher to interview the participants. One individual who was interviewed over the telephone was provided with the research information through email and consent was provided verbally and audio-recorded. All participants provided consent for an interview lasting approximately one to two hours as well as participation in a focus group of the same approximate duration. Permission was also obtained for audio-recording during the interviews. Potential participants who had any additional questions were encouraged to contact the researcher directly. Once the participants were fully informed of the research and consent was obtained, the participants were interviewed.

3.3 Participants

The participants for this study included two men with early dementia and their care partners, one woman with early dementia, and two female care partners who were caring for spouses with dementia who were residing in long-term care facilities. Each participant is described using pseudonyms as follows:

- Samantha was diagnosed with dementia in 2000 at the age of 53. At this time she was still employed in the workforce and was a single parent of two adult children. Obtaining a diagnosis was challenging, taking over a year and a half and a total of 127 appointments. The process of receiving a diagnosis created an immense financial burden, as she was no longer working during this time and her daughter was still in school. In the years that followed, Samantha committed her time to advocating for others with dementia and is often engaged in public speaking for the cause. The health care experiences that Samantha talks about in this study included two separate occasions where she accessed care through an emergency department.

- Jack is a retired public servant and lives with his wife Jordyn. Together they have five children and seven grandchildren. Jack, who is now in his early eighties, was diagnosed with dementia approximately eight years ago. In addition to dementia, Jack has an extensive medical history and has experienced serious health problems requiring multiple hospital stays involving a variety of acute care services. Jack's wife has been by his side supporting him through his medical problems and has been integral to assisting him to manage his dementia. Both Jack and Jordyn have contributed their perspectives in this research.

- Bert and Tabatha have been married for 54 years. Bert became a mechanic when he was 22 years old and at age 27, he purchased and ran his own service station. Bert and Tabatha have 5 children as well as 5 grandchildren. Bert was diagnosed with Alzheimer's disease while in his early 70s, approximately 12 years ago from the time of the study, and has continued to stay active with his life-long passion of mechanics and family. Both Bert and Tabatha have also become very involved in advocating for others living with dementia. The hospital experiences they discuss include two separate occasions when Bert received in-patient care at a hospital.

- Sherri is the caregiver for her husband Dean who experienced memory loss and decreased mobility as a result of a stroke in 2007. In 2009 at the age of 88, Dean's increased confusion prompted Sherri to bring him to the emergency where she was stunned to learn that he had dementia. Dean was 88 at the time. For the next few years it became increasingly difficult for Sherri to care for her husband as he developed reoccurring bladder infections that significantly intensified his confusion. Dean spent several months as an in-patient receiving treatment for his infections and waiting for placement in long-term care. Sherri talked about their experiences during this time.

- Kelly has provided care for her husband Neil throughout his dementia journey both at home and while he was a resident in a long-term care facility. Kelly and Neil retired together in their late 50s and enjoyed a few years of very active retirement living until Neil began to experience symptoms of dementia that started to impact their lives. At the age of 61, Neil was diagnosed with atypical Alzheimer's disease with aphasia. As his disease progressed, he refused to accept respite workers as he became very fearful and at times aggressive, often leaving his home alone without assistance or supervision. Eventually, his inability to communicate and resulting behaviours became very difficult for Kelly to manage. He had become a danger to himself and his wife which led to the involvement of crisis response and emergency services and resulted in his hospitalization. Kelly told her story about obtaining care for her husband through emergency care and various other hospital wards and services.

3.4 Data collection

This research occurred in two phases. Semi-structured interviews with individual participants, or the person living with dementia together with their care partner participating were done in the initial phase. The interviews led by initial guiding questions and core concepts were used to broadly explore the participants' experiences in a way that encouraged, where possible, full expression of their viewpoints and experiences. The interview guide was developed to explore and address the research questions (see Appendix B). The use of semi-structured interviews provided participants the opportunity to control the telling of their own experiences (Corbin & Morse, 2003). The questions were loosely structured around several focal questions designed to cover main aspects of the research examining experiences related to health, dementia, the environment, care received, interactions with staff, and autonomy. Five interviews were conducted and arranged as follows:

- Two face-to-face interviews took place both with the person with dementia participating with their care partner.
- Two face-to-face interviews were conducted with individuals who had cared for an individual with dementia while they were in hospital.
- One person living with dementia participated in an individual telephone interview

The interviews were conducted at a time and place chosen by the participants to facilitate comfort through an environment where they felt safe and free to engage in discussion. Follow-up questions that stemmed from the interview questions were used where needed to encourage expansion of ideas deemed most relevant to the research. Additionally, probes were used to inspire continuation or elaboration of thought, or experience, and for redirecting the dialogue when necessary.

All participants were interviewed at a location of their choosing to assist in creating a comfortable environment to help facilitate an informative and accurate interview. One individual participated through a telephone conversation with interview questions being provided prior to the actual interview. All of the interviews were initiated with friendly conversation to ease the interaction. Building rapport and trust with the participants was also facilitated through this welcoming and pleasant approach to the interview. As I was already familiar to some of the participants, this also contributed to the trust generated which was important, as there was potential to discuss sensitive personal topics. The initial interview questions asked the participants to talk about their dementia journey. This offered an opportunity to understand participants' broad cognition, communication, and general mood. Following the initial interview questions, questions related to the research purpose were explored and at appropriate times, I also chose to self-disclose where I felt it could support their discussion and experiences.

As an ethical responsibility of the researcher to minimize risks involved in research participation, it is essential to be attentive to non-verbal cues to identify when the participant has signs of fatigue or anxiety (Moore & Hollet, 2003). One participant was visibly tired and was closing his eyes and resting his head down with diminished participation by the end of the interview. His care partner and I concluded the interview quickly with respect for how the person with dementia was feeling.

The interviews and focus group discussion was digitally recorded with the participants' permission and were then transcribed verbatim, by either myself or a third party transcription service. Field notes were also recorded after each interview to document observations relevant to the research purpose and questions. The participants were assured that confidentiality would be maintained through the use of pseudonyms within the transcripts as well as the final research report. In addition, all identifying information including location, names of health care centres etc. were removed from the transcripts or any research documentation. All participants were informed that as the primary researcher, I was responsible to treat all information confidentially throughout the research process. The participants were also advised that all information related to the research would be stored securely at Lakehead University for a period of five years.

The second phase that followed was a focus group discussion with those who participated in the initial interviews except for two care partners, and one person with dementia, who were unable to attend. The focus group guide was created based on the initial findings that emerged from the interviews and was developed to provide opportunity for participants to comment on preliminary findings, and share additional thoughts on how their stories and experiences could shape interventions that enhance the quality of care for people living with dementia.

3.5 Data Analysis

Analysis of the interviews was consistent with phenomenological reflection as described by Van Manen (1990). Significant statements or themes that illustrated the experience in context influenced by the phenomenon were highlighted followed by a descriptive culmination of the underlying structure, or essence, of the phenomenon (Creswell, 2013).

The interviews were transcribed and read over multiple times by the researcher. In addition to reading the transcription, the interview audiotapes were also listened to by the researcher numerous times to ensure accurate contextual understanding of the data as well as full data immersion. The researcher also engaged in note taking, or memoing, throughout the interviews and during data analysis to assist in expanding ideas and themes generated. The transcribed interviews were imported into a qualitative analysis program NVivo 8 (QSR International, 2006) where coding of text was completed using free node and tree node coding to further classify data into categories that had identified similarities. In the initial phase of coding, the data was coded and categorized in a way that described what occurred in the hospital environment. These codes were further opened up and deconstructed reflecting deeper layers of analysis of how these experiences were lived. These categories were further organized into a reduced number of broad overarching themes and interpretation into the larger meanings followed. The researcher engaged in reviewing and renaming the codes which also assisted in the researcher keeping tight with the data to fully reflect the participants (Charmaz, 2006, P.51). A constant comparative method was utilized as thoughts, ideas, and actions, emerged from the data and continuous assessments and associations were also made to assist in creating the most applicable category (Creswell, 2007). An additional methodological strategy I employed to further illuminate thematic categories was the creation of a graphic image of the information using coded sticky notes to visualize categories of text for comparison and analysis. This was similar to a Hurricane diagram which assists in visualizing patterns to create and organize codes into categories (Kirby & McKenna, 1989).

The NVivo 8 qualitative analysis program assisted in data analysis, storage, and data management. Analysis of interviews and the focus group occurred separately since the focus group was intended partially as a member check in order to ensure that the researcher interpretations of the data were synonymous to the constructed realities of the participants (Guba and Lincoln, 1989). The suggestions obtained in the focus group discussions aimed at enhancing quality of care in acute care environment were also presented in the findings.

3.6 Trustworthiness of the Data

Although the literature shows several terms and approaches related to assessing criteria for accuracy or validity in qualitative research, Guba & Lincoln (1989) bring forward 'trustworthiness' in qualitative research as being similar to rigor in quantitative research. In order to address trustworthiness of the findings, it is important to consider that the findings answer the research question. Guba & Lincoln (1985) suggests for the researcher to seek how to convince their readers to take notice of the research findings and they propose credibility, transferability and confirmability as necessary in evaluating the trustworthiness and accuracy of how the researcher has represented a participant's subjective experience.

Credibility in qualitative research deals with ensuring that the findings are congruent with reality (Lincoln & Guba, 1985). Credibility was addressed through choosing a qualitative research design, which maximized the potential for participants to thoroughly answer the research questions (Marshall & Rossman, 1995). The use of semi-structured interviews encouraged the participants to engage in reflective thought and discussion throughout the interviews. I also acknowledge that there are multiple realities to individual experiences and each required exploration and accurate reporting. Although it was the goal of the researcher to focus on the accuracy of responses, it is important to consider that participants may have responded in such a way as to protect themselves or to elicit sympathy and understanding from the researcher. To address credibility, the researcher reflects on the information provided and ensures that what participants provide is also reported as what they meant.

Transferability is the degree to which the findings of one study can be applied to other situations (Shenton, 2004). Although transferability is not robust in this research as the findings cannot be generalized beyond the framework and participants involved, it is possible that through rich description and context in the findings there would be some degree of transferability where wider inferences can be drawn. Lincoln and Guba (1985) suggest that if there is enough similarity in contexts that it is possible to apply research findings in qualitative studies to other like situations. I have attempted here to provide in-depth descriptions of the participants' experiences as shared with me through the interviews and focus group.

Confirmability is comparable to objectivity where steps are taken to ensure that the findings result from participant experiences, rather than the researcher's preferences (Shenton, 2004). Confirmability is also another measure in which trustworthiness of the findings and I ensured this through methodically recording, checking, and re-checking the data. Lincoln and

Guba (1985) suggest that using this type of systematic manner in the research process referred to as a “confirmability audit” allows for the justification of how conclusions have been reached from the data.

3.7 Interviewing

As some of the interviews took place with both the person with dementia and the care partner together, special consideration was taken to ensure a balance of voices. In order to privilege the voice of the person with dementia, the researcher clearly directed questions specifically to each person individually and allowed each person ample opportunity to respond. Rephrasing or repeating a question was employed when necessary to assist the person with dementia in their comprehension of the question being asked. During the interview it was important for the researcher to offer the participants the opportunity to tell what they felt was important, and for the researcher to understand that it may not necessarily be answering the questions asked.

Interviewing older people, people living with dementia & care partners also required special consideration. Robertson & Hale (2011) claim that what an individual chooses to share is greatly dependent upon who is listening and the relationship between interviewer and interviewee. As the interview consists of two or more individuals that interact, interpersonal phenomena plays a significant role in influencing the interview process where the content of the narrative as well as the manner in which it is communicated (Buckner, 2005).

It is suggested by Manderson et al. (2006) that characteristics of the interviewer, such as age and gender for example, can pose an influence on the interactions and sharing that takes place. It can be presumed that the age difference, or social location of the researcher and what is being researched, can influence how the data is investigated as well as the findings that are interpreted. It was important for the researcher to contribute to an interview relationship that showed respect for the participants and communicated in a way that supported full and in depth sharing of stories and experiences through the use of good listening skills and non-verbal communication aimed at encouraging a feeling of comfort in the interaction.

Being experienced is highlighted by Moore & Hollet (2003) as being highly beneficial to the interview process. As I had previous opportunity to listen and participate in qualitative interviews and research with an experienced qualitative researcher in dementia studies, I was able to expand my skills in communication approaches for interviewing individuals with dementia. Although I had previous participation in interviews with people living with dementia and their care partners which were beneficial to my interview skills, I was still known by the participants as a new researcher. Being perceived as an inexperienced student researcher may have contributed to minimizing any perception of power imbalance within the dynamics of a dialogic interview. This would also have contributed to participants feeling able to fully participate and not feel manipulated or coerced in any way. Although five of the participants were familiar to the researcher, it was only through previous research encounters where familiarity would not have obscured the objectivity of the researcher, or communication between the researcher and participants being interviewed. Also important to note is that exploring how experiences may, or may not, relate to stigma, requires sensitivity to unconscious and unseen phenomena throughout the interviews being considered for deliberation and interpretation.

3.8 Interviewing People Living with Dementia

In conducting the interviews, the recommendations from the Murray Alzheimer Research and Education Program (https://uwaterloo.ca/murray-alzheimer-research-and-education-program/news/when-interviewing-people-dementia) for interviewing a person with dementia were followed as there are recognized potential challenges in interviewing a person with dementia. The recommendations that were followed included: being flexible regarding when the scheduling of the interview based on how the person may be feeling; providing interview questions in advance and again providing them in writing for reference during the interview; ensuring questions were simple and one at a time while being attentive to when a question required repeating; demonstrating patience and ensuring sufficient time was given for the person to formulate a response and answer interview questions; not finishing sentences for a person; speaking slowly and clearly; being alert to the person becoming tired or confused during the interview; and above all, knowing that although they may have difficulty articulating at times, that they are still intelligent and thoughtful and should be treated with respect. Although I was aware of these strategies and attempted to follow them during the interview, it was particularly difficult, and at times uncomfortable, to endure the long pauses waiting for a participant’s reply. When care partners and people with dementia participated together, the care partners were often able to prompt their partners’ memory with cues and reassurance. There were also questions, however, that care partner was quick to answer and where I would turn to the person with dementia to ask his or her opinion to ensure the person with dementia had the opportunity to answer. When interviewing the person with dementia over the phone, it was more challenging for the researcher to ascertain whether or not the person was being distracted or unable to remember without the help of visual cues. In this case, the participant was very aware of her difficulty in recalling certain information or details and asked for assistance from the researcher. Although dementia can affect communication abilities for a person with dementia, they are still able to express their preferences and feelings (Bourgeois, 2002). It is important as a researcher to be an attentive listener through making eye contact, not being contradictory to their statements, refraining from extensive questioning, and being respectful throughout the conversation (Bourgeois, 2002). The structure of the questions was also general and straightforward inviting the participant to tell their story and it was only seldom that a question required reframing to assist the participant in understanding. I also refrained from interrupting the participant by noting any follow-up questions and returning to them later.

3.9 Personal Reflections

My research decision and approach was rooted in my own experiences where my critique of the inadequacies of the care provided to older people in the hospital environment emerged. I was privy to many personal and private details through the stories of health care experiences that were shared with me. The development of my own understanding of stigma was based on my experiences in the hospital environment and transporting patients via ambulance from my previous employment. I witnessed many situations where seniors, and particularly those with cognitive decline and behaviours, fell through the cracks of the health care system. I saw this group of people being treated differently in hospital care with little voice or power to make change. Although my past experiences and beliefs clearly led me to this research, my personal awareness also made me cognizant to suspend my beliefs where possible and focus on obtaining an understanding of the phenomenon from the participants' perspectives.

I am well aware that my own preconceived opinions regarding health care for older people shaped the direction of my research and although I acknowledge this influence in my choice of research topics, I also know that those were my experiences and not those of the participants in this study. I am however, cognizant that it may have been easier for me to see evidence consistent with my own preconceived expectations. Although my expectations may have shaped my research, I constantly reflected on my opinions and questioned my interpretation of the data to ensure the accuracy of my representation and judgments of the participant's words. I am hopeful that any preconceived notions have not caused me to overlook any important data or messages from the participants and that I was sensitive to what I did not know rather than focusing on what I thought I knew. That being said, it was also important that I knew enough about the dementia and the acute care environment for meaningful conversation to take place.

Through this research experience I have been exposed to the intricacies of how individuals experience, understand, and explain events in their lives. I have gained an appreciation for this through taking a step back and focusing on how the participants re-live and explain their stories. The experiences, which were shared with me, emphasized the need for flexibility and reflectiveness throughout the interviews and research process, and I have learned that qualitative research does not necessarily go according to plan.

Chapter 4 - Findings

The themes that emerged in this study were present throughout the continuum of care and were highlighted by the participants as four distinct phases that they progressed through their acute care experience. The first phase involved an initial intake or admission process where individual information was gathered and recorded within the hospital system. Two types of admissions that were discussed were either an emergent situation with admission through the emergency department, or an elective procedure where the person was scheduled through the admitting department. The second phase integrated prioritization of an individual according to the urgency of their illness or injury incorporating nurse or physician assessments, diagnostics, and laboratory services. Phase three revolved around the treatment that participants received which included consultation with specialists, observation, and ongoing medical care. The final phase described by participants involved the discharge process. This included discussion related to their condition at discharge, information that was provided for follow-up, or future medical care, and referrals to other services.

Stigma related to both age and dementia was described by all participants as the central overarching theme in the care provided within the numerous interactions and experiences explored in this study. Disentangling the stigma of age and dementia was unquestionably the key challenge in relation to the research questions in this study. There were also 4 prominent themes that emerged from the data and each is demonstrated through the use of participant quotes to support conceptualization of the development of each theme. Although there may be some overlap between the categories and themes, numerous iterations of analysis and hurricane diagramming were applied several times to ensure coherence of the findings. The main theme, *disentangling the stigma of age and dementia*, encompassed numerous themes which included *being discounted*, *being ignored, being uninformed,* and *disclosing dementia—the double edged sword*.

In addition to the main theme disentangling the stigma of age and dementia, other themes emerged including: *system issues*, which focused on hospital structure, services, and education; *interpreting and internalizing stigma*, which included rationalization, and reduced expectations; the last theme *enhancing care* incorporated advocacy and compassionate culture of care.

It was evident in this study that stigma played a key role in the hospital experiences for people living with dementia as it was embedded throughout the complexities of care, pace, and the environment. The health care experiences discussed by the participants were complex and dynamic processes, and although uniquely experienced by each individual, revealed that stigma was clearly entrenched in attitudes, practices, and hospital systems.

4.1 System Issues

An evident lack of services, standardized care, and systemic stressors were described as present in the hospital environment. Within this theme, hospital structures and services, insufficient staff and patient placement options, as well as a lack of knowledge and inappropriate care were discussed by most participants. Structural status loss occurred as a result of stigmatization related to age and dementia in line with Link and Phelan's (2001) theory of stigma. The system was often referred to as being the overall structure responsible for inadequate care for a person with dementia while in hospital. The sub-themes were highlighted as too many people – too few staff, no place to go which related to lack of beds as well as inappropriate placement; hospital structures and services; health care provider's lack of knowledge; and inappropriate care. Most participants described the present acute care system as not designed to meet the needs of individuals who have dementia and stigma was alluded to the overall experience within the hospital environment as they described their experiences with the higher powers of decision making that affected their care.

4.1.1 Too Many People – Too Few Staff

Participants recognized that insufficient staff was a systemic problem with increasing patient numbers exhausting resources, and they felt that specialized dementia care was therefore too much to expect. Lack of staff, along with inadequate institutional policies and practices, were also obvious contributors to negative care for people with dementia. The hospital was described as having insufficient resources and particularly for some of the unique needs of people with dementia such as wandering, aphasia and agitation.

Insufficient nursing staff to meet patient care needs was reflected on by participants. Care partner Tabatha described how her husband was unable to get staff to assist him in getting out of bed and attempted to do it on his own instead. *“He managed to get out of bed and faint while at the hospital shortly after his surgery and I think the smallest nurse there was the one that was trying to hold him while they got some help.”* The lack of staff to respond to the needs of their patients could have potentially resulted in increased injury due to a fall. Sherri (care partner) talked about lack of staff resources to effectively respond to the unique needs of a person with dementia.

There isn’t enough staff to sit with the person and maintain a conversation or try and make conversation, which heaven knows is difficult enough. But even to keep an eye on, and some of them are wanderers.

Sherri (care partner) points out that there were limited resources in general and certainly not enough staff to address the additional needs of someone with dementia in the hospital. *"That's acute needs, that's really high needs, and a high needs area because, they need more staff, they need more beds, they need more of everything, they need more knowledge*."

Bert, a person living with dementia, recognized that the lack of front line staff is part of the larger systemic problem with the growing number of patients balanced against the increasing costs of healthcare. *"They keep on cutting nurses down and keep putting more patients in."* He further observed that the hospital is too busy and that there were too many demands placed on the nursing staff at times, which had an impact on how the nurses related to their patients.

> *The first set of nurses were happier a lot more than the second ones but maybe the second ones were busier you know with more than they could cope with because we'd walk down the full length of the hallway and every room is filled with people who have had hips or knees done.*

Bert highlighted the challenging jobs of nurses to care for people with complex needs and many patients: *"I think it would have been a really hard job to have that many people with that many severe surgeries and of course after the anaesthetic wears off then you're dealing with the pain too."*

Sherri (care partner) also pointed out that although some staff were very good at their jobs, her husband often did not receive care when needed because there were not enough staff to respond to a patient's basic needs.

> *We had our favourites of course because they were very thorough, they looked after him very well, I mean I can't complain about the care that he got, it was just sometimes you couldn't find somebody, you know to address an issue, I mean if he needed toileting or something like that sometimes it was difficult to find somebody to help with that.*

Again Sherri (care partner) echoed appreciation for how staff responded to the challenges in the emergency department; however, she also highlighted that it was often impossible to find care when needed.

Considering the amount of work those people have they do an amazing job, they really do, I mean they have people coming and going all hours of the night and day and they just run off their feet and uhm getting a hold of a doctor was an exercise.

The lack of staff in the emergency department was cited by Kelly (care partner) as a primary contributor to a person with dementia being restrained. Indeed, circumstances were described where people with dementia were restrained, often to decrease wandering and keep people "out of the way".

They could never have kept him from getting up and leaving or going over there and seeing who that person is or what's that reaching into a cupboard and taking a file or whatever so I ended up going home for breakfast lunch and dinner and pretty much spending the rest of the time there. He's restrained now in the psychiatric hospital and the only reason I'm comfortable with it there is because there is enough eyes watching that he is not restrained to keep him out of everybody's way, he is restrained gently to keep him from hurting himself.

Kelly described how the restraints caused fear and anger. *"hands and feet, he had the whole, both times. But he was angry and scared. I think it was fear more than anger."*

4.1.2 No Place to Go

Some care partners described situations where the person with dementia they were caring for was placed on wards or given beds that were not appropriate for someone with dementia. Kelly (care partner) shared her story of having no appropriate place, or care, for her husband who had dementia, with aphasia, and wandering behaviours. After the long-term care home sent Neil to the hospital as a result of his responsive behaviours, he spent a week of waiting in the emergency department. After emergency, he was placed in the adult mental health unit, which Kelly perceived as not appropriate for a person with dementia.

[The doctor] came down from adult mental health and said we are stacking them up like cord wood up there. There's no room. For six days he was waiting and sleeping in the hallway, because no one knew again what they were gonna do and so he was sleeping in emerg, restrained, sort of near the security guards. And nobody wants somebody with responsive behaviours.

When a bed was finally available, it was on a medical floor, and this unit was not equipped to care for a person with dementia. Kelly appeared frustrated when discussing this situation, particularly since there no place seemed appropriate for her husband Neil.

It was really, ok, here we are again. Isn't this interesting, now what are we gonna do and now the same idea only worse this time because nobody wants him. The long-term care home has tossed him out. You're never gonna get back on a CCAC list ever in a million years so where are we supposed to go?

Kelly talked about the challenges that she experienced in finding an appropriate placement for her husband who exhibited responsive behaviours. He was not able to stay in the long-term care home, the mental health unit was not the best fit for him, and he ended up in the emergency department a number of times. After each time accessing care, there were still no different options available for Neil.

I just had the feeling that nobody knew what to do with him. I got two messages: the first one was-- this happens all the time. The second one was-- but we don't know what we are going *to do with you. So clearly if it happens all the time, no one is learning anything from the experience. I just sort of felt, ok, people don't know what to do with a dementia patient who has behaviours. It seemed like as I say here we are back again only it's worse. If they didn't think they knew what to do with him the last time, they sure as hell don't know now because he's more combative than ever.*

She expressed her frustration with the emergency department as a result of a lengthy wait for admission where she felt they clearly lacked appropriate accommodation, care, and services, able to respond to the needs of a person with dementia.

He was in emerg for 3 or 4 days on a form 1 and the adult mental health unit was full as always and finally, and he slept in the hallways which just makes me nuts you know, in emerg, the fact that they don't have beds for the dementia patients, they don't have a spot. They are just kind of out there. And he was restrained.

Her husband's placement in the mental health unit was also not a fitting place for a person with dementia, which staff on the floor also recognized.

He was in a mental health unit. There were people there that were deeply, deeply mentally ill. And to their credit, the staff always got it that this was a man with dementia and that he had to be treated differently.

Bed shortages were also discussed as it related to Samantha's experience (person living with dementia), where even though her condition warranted staying in the hospital due anaesthetic effects exacerbated by her dementia, she was told to leave as there were no beds available. *"They wanted me out of there because the bed was for somebody else. Oh that was the other thing to that night. There was no bed available when I got in there which because of hospital shortage problems".*

Additionally, problems were identified in how staff dealt with bed shortages in front of patients. Care partner Jordyn described when they brought her husband up to the floor the staff engaged in a conversation in front of the patient that was distressing.

When they had a bed for him and the nurse from emerg brought him up and the one at the desk said well, who is that? – Well she says this is – and she says well I called for that patient 20 minutes ago and she says well I'm sorry I was busy with other patients. Well she said the unit says we're not supposed to, I guess it was her coffee break or something, and she made such a kerfuffle, and he`s lying there and he`s getting really upset. I mean there are certain things that they don`t need to be discussed in front of patients.

Sherri (care partner) felt that her husband was being sent home too early which was also attributed to bed shortages.

When it got to the point when they were talking about sending him home, I said I can't take him home and they said you're going to have to take him home and I said well you're going to have 2 patients instead of 1, because they don't realize its 24/7. I mean I understand that there's not a whole lot of beds out there, but...There's one poor soul that's been in there for a year and a half, in the hospital, he has dementia, he shouldn't be there he should be in a psychiatric hospital, really.

She went on to tell her experience caring for her husband at home when he should have been in hospital and how bed shortages had such an impact on their quality of life.

It was just too much for me because I mean ... like you're doing 24/7, and I was burning out. I cried on Kerry's [a support worker] shoulder more than you can shake a stick at because I was just beyond and beyond, it was just so much, and he'd get up in the middle of the night to go for a pee or whatever and I was sleeping like one eye open and one ear open because you know I *didn't want him to fall, and so I'd zoom around to his side of the bed and you know assist him to go and then I couldn't get back to sleep and you know it was really hard, really hard.*

The bed crisis was also reflected on by Kelly (care partner), *"The business about not having enough beds is crucial, it's absolutely crucial."*

4.1.3 The Structure of Hospital Services

Hospital set-up was also cited as a concern as structurally and operationally they are confusing to navigate as described by Tabatha (care partner). *"I think the way its set up is the way the architect wanted it but I find it confusing you know it seems like everything's in a circle and you go there and you're in the wrong place."* A confusing hospital design is not a practical environment for a person with dementia.

Samantha (a person living with dementia) described another significant barrier where it is well known that there are few services for people with dementia. As a result, there was little attempt by staff to seek out appropriate assistance where possible limiting access to care. *"You know that the excuse is, that well there is nothing out there for them, so they have taken it upon themselves to a make a decision."* She further goes on to point out how important changing this common way of thinking is *" So it's really important, the timing is really critical now to get people on board and get their thinking changed".*

Systemic barriers were described by Kelly (care partner) as she talked about the frustration she experienced in having to negotiate these obstacles in her husband's care.

I'm a pretty calm person who was completely, like my hair was on fire a lot of the time and I didn't like that. I don't like myself when that happens because most of the time I'm able to *stand back and grapple with things but both of those times I felt as lost as I have ever felt in my whole life.*

Samantha was so frustrated by the system and care she received that she stated it would be better to leave the hospital and pose significant risk to her health rather than stay. *"I just want to get out of here, I just want out of here, like I have had it. Like if I'm going to go I'm going to go at home, I want out of here*".

Sherri (care partner) talked about the emergency department being a very negative experience due to the lack of privacy and dignity in the frenzied environment. *"Well yeah the horror story yeah well uhm at one point they had him in the hall which wasn't the best."*

The business of the emergency treatment area specifically, was a very distressing environment for a person with dementia, and Kelly (care partner) reflected on how having a private room produced a more calming atmosphere for both the person with dementia as well as the care partner. A private room however was not provided to people with dementia as a common practice as patients were placed where room was available based on the presenting physiological concern, and without consideration of dementia.

I think just the chaotic atmosphere is really upsetting to a dementia patient uhm I don't know how you get around that though really, I think having him in that one room was good because that really calmed him down.

Another issue raised by Kelly (care partner) was how sharing a room can add additional disruption and confusion. Hospital practices show that they do not accommodate based on the needs of a person with dementia. *"I think one thing, put them in a private room, or a semi private at least, not in a room with 4 other people or 3 other people because that's chaotic for a dementia person."*

In Sherri and Dean's experience, a person with dementia having to share a room was frightening and very upsetting.

One morning I went in and he was sitting by the nurses station and he was all kind of restrained and because they had placed him in a ward with 4 other people, and, uhm, the men in the other beds had been shouting at each other and he got agitated, and so he got made to stand in the corner effectively so I thought well ya know maybe a little sensitivity about the fact that they, can't, the dementia people are very sensitive to loud, to loud noises. Really there's bells and there's calls and there's never a moment of peace there ya know.

4.1.4 Lack of Knowledge

Participants in the study consistently indicated that staff knew little about Alzheimer's and related dementias. Dementia education was highlighted as invaluable in combating stereotyping, prejudice and discrimination in dementia stigma. Avoidance was demonstrated as dementia appears unknown and feared by staff.

Jordyn (care partner) described a lack of knowledge contributing to a lack a care or regard for dementia.

You get the feeling from I'd say 75% of the medical profession, nurses, doctors, people in the x-ray all those things that it doesn't mean anything to them. So they've got Alzheimer's so like big deal, what am I supposed to do with that?

Sherri (care partner) stated that in her experience, health care professionals did not demonstrate the specific skills or knowledge required to understand the particular needs of a person with dementia. *"I don't think they are very knowledgeable, I think that's sort of a foreign field for most of the nurses there, and I think maybe the doctors, I don't know."*

In this example, Kelly (care partner) discussed the difficulty staff had understanding her husband's dementia and aphasia. The staff demonstrated a lack of knowledge about the different types of dementia as well as limited knowledge about those who may be affected by the disease. Here, the lack of dementia knowledge, along with expectations of only older adults having dementia, resulted in staff's inability to understand to her husband Neil's unique needs as a person with Alzheimer's and aphasia.

I think that because he looked young. He wasn't a doddering old man. He was tall and carried himself well and had a young face and then he couldn't talk to you. They were immediately trying to puzzle that out.

This comment by Kelly also lends credence to how profoundly rooted cultural expectations are for older people. She stated that her husband was grouped under the guise of mental health problems and was admitted to a mental health ward in the hospital where even the other patients in that unit held deeply engrained expectations that a person with dementia should look old. As Neil was diagnosed with early onset dementia and looked young at the time, other patients sensed a difference. *"And a number of times the people that were in the other room who could be deeply troubled, they got that Neil was different from the mental health patients."*

Specifically, in the emergency department, Kelly (care partner) recognized that staff were not trained to communicate with a person with dementia. *"Another reason why the dementia patients shouldn't be sent there unless there are some people who have training in communicating with people with severe dementia"*

Jordyn (care partner) also reflected on the fact that there is limited time spent in training new nurses to work with people with dementia indicating that stigma exists within the education system in the development of educational platforms and curriculums.

So my thinking is that they need more education and nurses training in medical school. You know they do rotations with every department, so they need to do rotations with people with Alzheimer's. Whether they are going to do anything with those people and especially if they are working in emergency they pretty much have to do the whole spectrum.

Opportunities for health care workers to learn about dementia were highlighted as non-existent by Samantha (person living with dementia) who has family working in an acute care hospital. According to Samantha, her family member was not provided, or offered, the opportunity for education on dementia. *"She did it all on her own".*

Kelly (care partner) also reflected on insufficient education being so widespread that it reaches beyond those in healthcare services. *"I think more education is needed all the way around, not just with the medical profession. It's needed in a lot of areas."* Staff may have a cursory understanding of dementia but according to the participants, clearly did not have an understanding of the different types and various symptoms of dementia.

4.1.5 Inappropriate Care

Lengthy wait times and overcrowding in the hospital emergency department was a common complaint and participants felt this impacted the quality of care provided. There was recognition that there were few services for people with dementia and participants exhibited an acceptance for poor quality of care and placed blame on the organization rather than those specifically responsible for direct care. In addition, participants identified that staff were not knowledgeable in dementia education as they also practiced clinical skills that did not demonstrate, or reflect, an understanding of the needs of individuals with dementia.

The initial point of intake was highlighted by some participants as fragmented and unnecessarily lengthy. Samantha (a person living with dementia) described her intake experience that involved repeated questioning and being forced to wait at several different stages in accessing care. This was very difficult for a person with dementia to understand.

Where you just go in and you're asked these questions umm, about…or do a more thorough question and answer on why you are at the hospital. And that's why I couldn't figure out, like that there was such a large space of time that I actually had a lot of questions asked of me.

Jordyn (care partner) pointed out concerns for the amount of time people had to wait and how for a person with Alzheimer's, the waiting room environment can be even more problematic. The increased sensitivity to the environment and altered perceptions that people with dementia may experience can be detrimental in their ability to persevere and wait for the treatment they need.

I think people with Alzheimer's, they don't like a lot of crowds or noise, and so if you're sitting in this waiting room that is full of people that are coughing and sneezing and groaning, whatever the case may be, it's not the best place for them to be.

Samantha (a person living with dementia) described how her emotions and frustration had become very overwhelming and how experiencing lengthy waits contributed to escalating these emotions. *"I'm agitated and I'm getting annoyed at that time because I've been in there all that time".*

The emergency departments discussed here were experienced as chaotic and extremely overwhelming for a person with dementia to navigate. The emergency department in particular was highlighted by participants as the wrong place for a person with dementia to access their care needs. Neglecting the needs of a person with dementia added unnecessary stress to an already frightening and confusing hospital visit as described by Sherri (care partner):

There were social workers that presented themselves a little further into the process but it seems to me that the social worker should be with the group of people who greet you at the door as soon as you arrive because everybody's nuts, ready to fly off the handle. Just, I don't know, is emerg the best place for entry point, I know that's where everybody goes but there needs to be a little quieter transition. Ya, but a quieter entry point, or in best-case scenario, don't send them there at all.

Sherri went on to emphasize that the emergency department was unsuitable for a person with dementia and contributed to inappropriate care, particularly those that may become agitated and upset as a result of increased confusion and unmet needs.

The thing that's bad is at bottom there's no, the dementia patients should not be there in the first place. There has to be another place where somebody with combative behaviours goes to be kind of tenderly looked at to find out where they are going to go long term but it shouldn't be emerg. It's just absolutely the wrong place.

Routine was also something that was revealed as important for a person with dementia to have consistency in practices and care schedules, which was unmanageable in the emergency department as described by Sherri (care partner), *"Take into consideration that the dementia patient doesn't like loud noises or sudden changes in routine"*. Once an individual was admitted, routine was described by Sherri as more achievable on the in-patient wards. *"They're pretty good about routines at the hospital"*. The wards may have more regimented patient care routines, which were not experienced in the emergency department highlighting how beneficial it is to admit a person with dementia as quickly as possible.

For a person with dementia, having inconsistent health care providers can also be threatening to their feeling of safety which was another concern stressed by the some participants. Kelly talked about how her husband was so fearful about new people being involved in his care even prior to going into the hospital. *"Who were these people and he had to re-meet them every time, every week, they were always new and they were always scary."* The lack of consistency of physicians and nursing staff contributed to inappropriate care for an individual with dementia. There were locums and different doctors for different areas of the hospital wards, often resulting in inconsistency of information being provided to both the patient and care partner as described by Jordyn (care partner). *"He had the ICU doctors up there. They have different doctors. They are the ones in ICU that look after you. No consistency"*

Kelly (care partner) also cited the lack of consistency in hospital care. *"One hospital stay he had a nurse practitioner and he was so good, but he didn't come back the next day, somebody else did".* Sherri (care partner) commented that having the same physician for her husband was essential. This consistency contributed to creating a trusting relationship where communication improved resulting in more comprehensive, individually focussed care.

> *The doctor that we had that came the most was Dr. Allman's assistant, Dr. Branch and he was wonderful, he came in pretty regularly and so I could talk to him and say, uhm what do we need to do here.*

Inconsistency in care and time constraints were viewed by some participants as a challenge in keeping rotating staff informed about the individual care needs of a person with dementia. Here, this is discussed by Jordyn (care partner), *"They really don't have time to read something like that so in theory it's a wonderful idea but on the ground I just…so many people were looking after him in the course of just an hour that they just wouldn't have time to familiarize themselves especially in emerg"*

4.2 Disentangling Age and Dementia: Framing the Hospital Experience through Stigma

People living with dementia described multi-faceted inequities influenced by negative attitudes toward age, the disease, and the stigma associated with condition, which was highlighted through communication in their interactions with health care staff. The participants in this study described experiencing different treatment associated with dementia as well as related to age. They described a double jeopardy of age and dementia that was communicated through adverse experiences based on their perceived difference in line with Link and Phelan's (2001) theory of stigma. As the majority of people with dementia are older, it was difficult to separate out aspects of being treated differently to clarify whether age or dementia individually was a key factor. Treatment based on looking older in this theme is what Link & Phelan's (2001) theory of stigma would attribute to being an oversimplified category perceived by others which imposed power within interactions. Aging, however, was more readily visible than dementia symptoms, which went unnoticed initially. The participants perceived their communication and interactions with health care staff as infused with negative perceptions of aging. Participants described age as playing a key role in the care they received as they described being perceived as dependant with increased vulnerability and were often discounted. Interestingly, stigma was implicitly described in the participants' experiences through being treated differently, yet when asked about stigma directly, many participants described not experiencing stigma. It is possible to conceive that the subtlety of stigma contributes to the ambivalent perceptions of their experiences. It is also plausible that although some participants did not directly describe stigma, it existed as operating beyond their awareness or control.

Both age and dementia stigma were evidenced in being discounted, being ignored, being uninformed, and disclosing a diagnosis of dementia which demonstrate components of Link and Phelan's (2001) theory such as being discredited, avoided, and based on participant's age, viewed as fundamentally different. Each of these themes is described next.

4.2.1 Being Discounted

Being discounted described being treated differently, which demonstrates a negative consequence of undesired differentness in Goffman's (1963) theory. This was reported by participants in their stories that often reflected on their wishes and decisions being overlooked by hospital staff. It was also highlighted that the direction of communication was primarily to a care partner disregarding any input from the person with dementia. This conveyed assumptions of their inability to communicate, understand, and discuss their own bodies, symptoms and health.

Samantha, who is a person living with dementia, referred to both age and dementia where reluctance to engage with this population was evident.

I'm just going to reiterate that one of the things that I think is the biggest problem is that so many people in the medical field just simply do not want to deal with seniors, and seniors that have memory loss or have dementia, and so there is and avoidance there and that was noticed very quickly.

Participants described how younger people with a single illness were prioritized over themselves, and while participants did not name this, this practice was certainly reflective of discrimination. When Samantha's son brought her to the hospital with symptoms of extreme dehydration and difficulty ambulating, she described how he had difficulty understanding the priority treatment young people were receiving over her when she was visibly unwell. Samantha felt that her needs were disregarded and as an older person, her needs were given reduced status and prioritized lower than others seeking care.

He (family member) can't figure out why these other people, these younger people have a bed in the corridor. They are sitting up, like not really even using the bed as a bed, and they were young. So that kind of annoyed him. I think its age related.

Samantha further described the compounding effect of age and dementia and how she felt both contributed to a negative decline in how staff treated her.

I think it had to be the age first and then, and of course that was one of the first things was, because they ask you what health conditions you have, and I just think it went downhill once they were told I had dementia.

Samantha also recounted her experience in providing her information to intake staff and how she felt she was disregarded.

And I thought you know what, sloughing me off feeling like…..I don't even know how to describe what it was like. She wasn't out and out rude but it was like...um...well she certainly wasn't overly friendly but then I didn't expect that either. I would rather expect her to be doing her job than to be making... you know… conversation. But it was just that air as if...um... she wasn't really. I can't find the right words... really involved in what she was doing, she seem to be…….you know when you're really into a job you can tell by a person's body language and she *was not projecting with her body language that she was into what she was doing. It was just as if. Well we'll just get this one outa here and get onto the next one.*

Dementia is often attributed to being old and frail and this perception means that many providers have the mistaken assumption that dementia is merely "getting old", rather than a serious condition which can lead to inappropriate treatment in the hospital environment. Normalizing dementia as part of aging was viewed as common and expected. Sherri (care partner) spoke about a physician who identified that her husband may have dementia, and what little regard the doctor had for dementia as he normalized it as a natural part of aging.

Yeah so that was a real shock. I think had I been that doctor, I might have taken me aside and said here's what I think is wrong, have you had him tested? Or anything like that I mean it was just flat out 'oh, it's just the dementia'.

Sherri (care partner) also described seeing how health care staff had discounted her husband. In her experience, the staff tended to focus their communication with the care partner rather than the person living with dementia. Although they demonstrated a symbolic gesture of speaking to the person with dementia, they expected the care partner to answer for him, conveying their assumption of his inability to answer questions therefore disregarding any input he had.

They try and get to the root of what's going on and I try to keep my mouth shut when they are quizzing him because I want him to answer and not me and then they'd look at me like uhh….

In the encounters described, clearly some health care providers assumed that people with dementia were not capable of discussing their own health, and directed questions to care partners.

The experiences that the participants discussed demonstrated that staff did not seem to have patience interacting with a person with dementia. People with dementia were not given the time by health care providers to adequately express themselves and comprehend the conversation. Here, Kelly (care partner) also went further to suggest that staff had assumptions about what a person with dementia should be like, typically further along in their journey.

So you know when people have Alzheimer's you know don't test them if they can't give you a straight answer, wait a while and then try again ask the question in an easier language or a softer voice like don't get angry and get pushy I don't think they did with him I think partly because he has so few symptoms showing.

Jordyn (care partner) described that hearing what a person is saying is also more than just listening, and described that staff were not attentive to the context, or the impact, that dementia has on comprehension of information and expression. This lack of listening and attempting to understand a person resulted in a disregard for what the person with dementia was trying to tell them. *"Listen to what the patient says and to pay attention to what they are telling you as bizarre as it may sound to you or as little as you think it is*".

Samantha (a person with dementia) talked about how necessary it was for staff to ask, or gently probe further, to ascertain what the person with dementia may be trying to tell them.

I mean somebody that listens to the patient and when the patient says, I don't feel good, I feel nauseous or whatever the complaint is, that she asks questions, and will maybe ease the patient's anxiety. They have to show some compassion.

Participants discussed the lack of attention, disregard, and discounting treatment that people living with dementia and their care partners received.

Power differentials can affect the dynamics that exist between those receiving care and those who provide it. This power imbalance was perceived by one participant as related to her generation. Jordyn (care partner) described being from a cohort when a physician was revered and not questioned, suggesting this additional barrier for communicating about one's health care.

You know one of the things that, and especially in my generation, we were raised to be so respectful, and that doctors know all, so it is difficult for my generation and older than me to, it's very difficult to question a doctor because they had that kind of a god complex to us when we were… And I see a lot of that when my friends that are older than me, they think it's, they are afraid to say to the doctor… But this is what is happening. They take everything the doctor says verbatim. They don't question them. I think that's why they can get away with what they have been getting away with for so long. That's one of the reasons.

Jordyn (care partner) also described her frustration in how some physicians approached their patients with a condescending manner. *You know we are not here in the forties anymore where the doctor was up here on a pedestal and believing like he was god walking through the door. They are human beings and they should be able to talk to you like you're human too.*

Kelly (care partner) described the practices of an older physician minimizing her husband's dementia symptoms.

He was in his early 70's himself… all business and not a lot of bedside manner and a little short with me about the fact that he could be forgetting things. Like everybody could be forgetting things sometimes.

Not taking a diagnosis of dementia seriously minimizes the challenges that people with dementia and their families face. Conversely, the physician's reluctance to discuss dementia may also be due to the misperceptions of dementia.

Common practices within the hospital were described by participants when accessing care with a care partner. The health service providers often directed questions to the care partner making the assumption that the person with dementia is unable to participate in the interaction. Although there were benefits to having a care partner present, health care providers were inclined to communicate with the care partner directly rather than viewing the care partner in a supportive role. Samantha (a person living with dementia) talked about when she sought care in the emergency department and her son accompanied her for support. She described that with her son present, the health care staff immediately directed questions to her son while she was disregarded.

Yes, they continued to ask him questions and he will not answer unless I don't….and that's the way it's always been and that's why I say my kids are really good, They will never… they will give me the extra time I need to answer before they answer for me…but no they didn't pick up on that so.

Participants did recognize that people with dementia should be treated differently to appropriately address the individual with the disease, which was described here by Jordyn (care partner).

In some ways you do have to treat them differently, with more care is how you have to treat them differently and pay more attention to what you are seeing in front of you.

4.2.2 Being Ignored

The theme above of *being discounted* refers to communication among staff and people with dementia. This section, *being ignored,* refers specifically to exclusion of people with dementia in decision-making about personal health and demonstrates being discredited which is a component of stigma in Goffman's (1963) theory. Participants described feeling like they had little choice, or control, over the decisions related to their care and they felt that there was a compounding effect of age and dementia that channelled decision making away from those that should be making decisions about their own health. Being ignored also related to being treated differently which again, demonstrated treatment based on stigma related to undesired differentness as in Goffman's (1963) theory. Some of the participants described this as commonplace in the hospital. Samantha (a person living with dementia) described that the health care provider ignored her need for information to make an informed decision, and presumed that she would not be part of the decision making process. "*That is what stands out and annoys me the most is when people don't, they just assume that I don't want that information.*"

Samantha stated that the health care provider took little, if any, time to work together to determine an effective treatment, and effectively did not take time to hear her perspectives.

> *[My son] then asked would the narcotics cause a problem with mom's dementia and she said yes and he said very much? Or... She says well it varies. And then she says I'll just give her something else, and I said, but the other hasn't worked, but she gave it to me anyway. So because we questioned and mentioned dementia, they wouldn't give me the narcotic and yet I had already said to them, that instead of saying this is the risk, or these are the side effects… and having me say… so I was a little annoyed at that because I knew what they were giving me wasn't going to do any good.*

Having experienced the effects of narcotics, Samantha (person living with dementia) was aware of their effects for a person with dementia "*They certainly have an effect on a person with dementia more than a person that doesn't have it"*. She described when she inquired about her concerns to the nurse about the pain medication and its effects, the nurse ignored her and provided pain medication that Samantha knew was not going to work. Samantha felt that while the staff disregarded her wish to be included in her decisions, people with dementia should be consulted on everything that concerns them, particularly their own health decisions.

Samantha also described a situation when she was attempting to inform the staff of her symptoms when she was experiencing pain and dehydration. She was not listened to, and as a result, was given medication that was ineffective for her and was forced to endure an extensive waiting period for relief.

It felt like forever when you are in that much pain. And they knew, like that was one of the things I said at the time when we first went in was. I said, um, that I was in a lot of pain, and that I knew that I had been dehydrated. So two key things that I told them when I first went to the window. And I still, it was quite some time because I thought, like, how long is it before I can get anything for the pain. They seemed to ignore the comment about the dehydration. In my mind they seemed to ignore that and concentrated more on the pain, And I, ya the pain was crucial but to me the dehydration was more important. I was surprised at that…. they didn't…it's as if that information went in and out of their head. I did vocalize that I never experienced anything like it in my life. And I was having trouble with. I kept having muscle spasms and the pain was really, really bad, and I was sitting there and sitting there and so the time factor I can't tell you. So I waited, and waited and waited after that assessment, and waited and waited and waited and at midnight I get to see a doctor…At Midnight!

When Samantha was asked if she felt she was listened to by the health care staff throughout her hospital care she responded with very strong conviction: *"That, you hit the nail right on the head. Absolutely not. Absolutely not."*

As the symptoms of early dementia can go unnoticed by staff, yet have an impact on seeking and receiving care, the needs of a person with dementia can easily be ignored in a busy environment if symptoms are not visible, as was demonstrated by Jack's experience.

We were at the tail end of a big line, I can remember that and I started to feel a little unsteady so they had, and there's kind of like a shelf on it and I was leaning on that and I was walking and I figured if I could get down to the end there maybe they will pay attention to me you know.

Jack (a person living with dementia) commented on the lack of staff responsiveness given to a patient in the hospital. *"When you go in there, you're unwell when you are going to the hospital for gosh sakes. You don't want to be lying around and nobody's coming near you, you want the attention."* In addition, he discussed that his basic needs were ignored. *"When you are in hospital admitted and you ask for something for pain or something to drink, something to eat even, and they say I'll be right back and they never come back.*

4.2.3 Being Uninformed

Some participants cited the provision of information as a major issue and barrier to care**.** In their experiences, they were uninformed as a result of insufficient information provided, or as indicated earlier, assumptions of information not being wanted, or the delivery of information was inappropriate for the intended audience. The main concern highlighted was the absence of essential information provided to patients and their care partners. Some participants recounted experiences when they were not told what procedures were being done. In addition to feeling uninformed, when information was provided, there was little thought given to its delivery to ensure that those receiving it would comprehend. When participants discussed times when they felt they were informed, it was also narrated as a unique occasion. Being informed was cited as what mattered most about the care provided in the hospital and being uninformed was attributed to health care providers assuming that people with dementia could not make informed decisions about their care as they directed their communication to care partners.

Samantha (a person living with dementia) recounts not being informed that her blood was being taken or told what the testing was for. She further recalled that she did not question the staff; however, there was no explanation offered as staff did not give her information about what they were doing or why. "*What they were testing with the blood tests I have no idea. I presumed it was a test to see if I was dehydrated.*"

Samantha also stated that the anaesthetic effects were not explained to her, yet it was critical for her and her family to be prepared for. She also did not have flexibility in the time she needed to recover from the anaesthetic, putting her at greater risk of post-surgical injury or complication. Here, she talked about a past experience with anaesthetics during dental work.

I don't think that's always clarified either with me. I didn't know there could be changes with that. I'd had that to have two teeth removed and I wasn't told of what could happen so when I came out of that I didn't really come out of it like I should have. So you're not, you weren't explained, you weren't explained to. That was the first time and we didn't know about that until that happened. And we weren't told and he had a heck of a time with me afterwards and they want me out of there and he can't get me moving. I don't remember any of this, this is only what [my son] told me. I have no memory of it, only by what he's told me but he said he couldn't get me moving like even to get up on my feet.

Jack (a person living with dementia) described feeling that it was necessary to get angry with the nurses for not providing him with the information he needed. The nurse in this case did not describe what she was going to do which resulted in his fear, anger, and resistance to necessary treatment.

They were going to do something to me and I asked them whether it was another needle or something and they said well you know. And I said well I don't want it get out of here so I refused it, I can't remember what it was but I was p'd off really, that really got me, just come up an put your arm up and swab it and I'm going to jab a needle in you without any explanation, ya…. I got….they explained everything after that I mean cripes if I was going to move my foot on the stretcher they were going to explain it to me.

Jordyn (care partner) earlier stressed how being informed was important and valuable, and yet, she felt uninformed about the care being given to her husband. She also described when information was given; it was delivered in a way that was not clear or easily understood. *"I think being told in understandable terms and you really need to be able to say I'm hurting and have somebody to listen and know what's going on."*

Sherri (care partner) also touched on the importance of being fully informed about the care being given. She described how providing an understandable explanation, along with her support responded to the increased fear that her husband may experience.

Well they would say and I knew what was going on so I didn't need explaining but they would say were just going to do this but they were patient with him and they explained why they were doing what they were doing you know, I'm just going to give you a little pin prick and he hates needles so I'd grab his hand and I'd say it's okay honey, just look at me look at me, don't look at them you know.

Feeling safe was described as an important consequence of being informed in a comforting way, which according Sherri (care partner), can reduce feelings of fear and agitation for a person with dementia.

I'm sure that people who are more advanced get very frightened in a hospital situation, and not to have that comforting, you know, this is what we're going to do, and like explaining it to a child, like if you have to make them feel safe and if they don't feel safe, then they are nervous, agitated.

Kelly (care partner) talked about how her husband has become emotionally upset and vocal when a procedure was not explained to him *"He's said a few choice words to some of the nurses and doctors, they didn't take the time to say we're going to start an IV because… just here you go. And I think just the average person needs to know."*

Jordyn (care partner) discussed her surprise when the physician took the time to show her what her husband's procedure was all about, also demonstrating that being informed is uncommon as suggested by other participants.

He brought me right over by his side and [the doctor] was trying to get this iv going in his neck and they couldn't and then they tried on this side and they couldn't get it in and then they brought in the small x-ray thing to find out and this doctor says to me, "Now this is one of the strangest things I have ever seen." He said, "You see there, it's supposed to go straight down and you see he has two and that is very, very unusual". But he was explaining the whole thing as they were going and I thought wow.

4.2.4 Disclosing Dementia – The Double Edged Sword

Participants described being reluctant to disclose a diagnosis of dementia because of past negative experiences, particularly when staff minimized the diagnosis of dementia. This may demonstrate how participants may have viewed themselves as different, or having a spoiled identity, which is one aspect of Goffman's (1963) theory of stigma. The diagnosis of Alzheimer's disease did not come up as recorded in medical information that was accessed in an emergency situation according to Kelly (care partner), as she has had to provide that information for every hospital visit. *"No I would have to tell them so that they would treat him, I was hoping, treat him accordingly you know if he's upset or whatever you have to take these things into consideration."*

Jordyn (care partner) felt that it was essential to disclose her husband's dementia, as it was not recognized as necessary health information that was included in hospital charts. Minimizing or ignoring the disclosure of his or her diagnosis was interpreted by participants as a significant lack of awareness of dementia and a lack of interest in fully understanding and caring for them as a whole person.

> *I know I had to mention it to several nurses and doctors when they would ask him certain questions or their approach to shoving the needle in their arm without any "this is what I'm going to do" and I would say, he has Alzheimer's and it was like I said he had a cold last year. You know it didn't mean anything. Like I don't know, maybe they didn't know what Alzheimer's was.*

Samantha (a person living with dementia) described how she perceived the staff's reaction toward being an older person and her disclosure of dementia. She described feeling like she was treated and perceived differently because she looked older and had dementia.

I was very annoyed with the fact that I went in there and I think as soon as they heard dementia, and the fact that I was older, and looked weak because I was leaning on [my son] for support, grey haired, and I do look my age now even though my brain tells me I'm not… so I appeared very much older and frail when I walked in there, and as soon as they heard dementia...I just…that was my feeling, they just wanted me away, so you know, just away from them.

Samantha described that she felt dismissed when she disclosed her dementia to the health care staff.

Ya I really felt that once she heard the word dementia, I just felt that it changed. I don't totally say that it was totally dementia but I certainly believe 100% it was age related. But when she heard dementia I think that just added to it.

Dementia was not something that was noted in an individual's information at the initial point of hospital contact and it was up to individuals to disclose their diagnosis. When asked if it was necessary to tell the health care staff about the diagnosis of Alzheimer's at each visit, Jordyn (care partner) stated, *"It wasn't something that they could look up in their system."*

Jordyn recounted her experience immediately making the triage clerk/nurse aware of the diagnosis of Alzheimer's disease, and felt that it was not perceived as an important piece of information by staff. *"It was ok we will make a note of it, or not."*

Bert (person living with dementia) described that discussion of his treatment and care did not include discussion related to his dementia. *"No it wasn't referred to when they were looking after me."* When probed further whether dementia was known to the nurses, Bert felt that they must have had the information but chose not to bring up the subject of dementia with him *"It must have been known, but no, we didn't talk about it."* While a diagnosis of dementia can potentially be perceived to discredit individuals because of negative perceptions, not taking cognitive challenges into account was an additional way in which participants with dementia were dismissed and not taken seriously. Concealing the fact that he was diagnosed with Alzheimer's may also be a way of controlling what was felt to be discrediting information about himself.

4.3 Interpreting and Internalizing Stigma

Prior negative experiences, both age related and related to dementia specifically, contributed to anticipation of being treated differently. This theme demonstrates what Levy & Banaji (2002) identify as reinforcement of negative stereotypes in stigma. It was also evident that some participants interpreted stigma differently. Sherri described identifying no stigma at all in her husband's care, yet outlines several experiences where there were components of stigma present. Some participants appeared to use strategies such as rationalizing the care they received or taking on reduced expectations for care.

4.3.1 Internalizing Stigma

During their interactions with staff, participants described feeling that they were being treated differently such as being excluded and isolated. These experiences have reinforced expectations of different treatment for the participants. The feeling Samantha (a person living with dementia) described may suggest that there is an internalization of aspects of stigma that people with dementia may take on, where they feel that they are viewed differently, and subsequently perceive being treated differently. Dementia self-awareness appeared to influence interpretation of interactions with hospital staff where there was an expectation of stigmatic treatment from those that may be providing care. Samantha suggested that her past experiences have shaped her expectations about how people with dementia are treated.

That was the second time. I went in there seeing it right away because I have experienced it before, so it was oh here we go again. Like I don't know a person with dementia that hasn't experienced it. Like from the early days of trying to get their diagnosis, so they are fully aware of how you are treated and perceived before you ever get to the point where you have to go in for an emergency situation. We have already experienced it many, many, times with health professionals. So when we have to go in for an emergency, then I think it's magnified of course because of what we are there for.

There was also an expectation of inadequate hospital treatment expressed by this care partner. When asked if it was felt that people with dementia are treated differently in the hospital, Samantha strongly suggested that the difference in care was imbalanced and consistently weighs negatively for a person with dementia: *" I think so, absolutely. I have absolutely no doubt in my mind. I've seen it too much."*

Based on previous negative experiences and the resulting expectations of being treated differently, Samantha felt it was necessary to prepare with her family member prior to accessing care to ensure that the correct information regarding her current health issue was relayed at the initial point of contact to the health care team. She has experienced not being heard and clearly this had shaped her expectations and actions toward future hospital care.

So finally I get called in, and Travis went in with me, and Travis was even asking me questions on the way to the hospital to make sure in his mind was clear so that he could… cause we knew he would have to back me up in what I had to say. We knew that going in. So he wanted *to make sure he knew going in exactly what I had experienced so I answered the questions but he could back me up.*

She also recognized that it was difficult to recall when physical symptoms started, making it difficult for her to provide an accurate timeline of the progression of her illness to inform staff upon her admission. She was aware that she sometimes had limitations in her ability to recall and communicate her concerns, and had experienced that others ignored her communication needs. As such, she ensured that her son was able to speak on her behalf. This strategy however, also had the potential to reinforce discrimination by having staff speak to her son and not to her, potentially perpetuating the practice of avoiding or ignoring the person with dementia.

Samantha reflected on treatment in terms of medication and how she has seen many people with dementia being treated differently by being overmedicated.

And we know, we know still because I've gone in to visit my friends who have had dementia and they are still overmedicated when you have dementia. Once I got dementia myself and then all of a sudden your new best friends are your peers right. And because I have been around as long as I have and done so well…knock on wood…I've visited a lot of my friends in the hospital as they have been further along in their journey and in long term care and I've seen for myself when I go to visit, and I know they are over medicated.

These expectations were clearly anchored in memories of impasses experienced and had created a heightened sensitivity and awareness of being treated differently. There may be an internalization of negative stereotypes, which may partly explain how others' actions are perceived and how expectations are created influencing how a person with dementia seeks and receives medical assistance. This further serves to reinforce the negative stereotypes that are age related as well as those related to dementia specifically.

Stigma is a concept that can be unclear and remains difficult to define. Perceptions of stigma are also individual and the processes through which it is conveyed are elusive and it is challenging to detect its presence. For Sherri (care partner), stigma, or the word stigma, was not perceived as being directly associated with her experiences related to her husband's dementia, *"I didn't find any stigma at all, no, no not at all, they dealt with him as a person rather than as a, they dealt with the person rather than with the disease yeah."*

How individuals make meaning of their experiences is often based on the feedback they receive in the interaction. Samantha (a person with dementia) described her perspective on relationships dealing with professionals, even beyond the health care environment, framed by past experiences in her relationships.

I guess it goes back to the things that I say to anybody, Any professional that deals with a person with dementia is... We are not being heard... And it's no different in that kind of setting except that it's more critical in that setting…So you not only gotta listen…you gotta hear what's being said…and Acknowledge, acknowledge what's being said….Validate.

4.3.2 Reduced Expectations

Kelly (care partner) also talked about diminished hopes in relation to solutions in the treatment of people with dementia in the health care environment. *"Communication from people who knew what some answers were and that's the weak point because there were no answers. They just didn't have a solution."* She also reflected on her expectation that staff would perceive her husband's behaviour as difficult to manage and time consuming.

I think they were pretty cognitive of what was going on with him because they were fairly patient with him you know they didn't say you know get a grip or whatever you know they didn't *do that uh which you might have expected but no they were good with him they were very patient.*

While staff in the emergency department were not sufficiently educated to deal with patients with dementia, Sherri (care partner) felt that more education for staff would be futile since staff are too busy to take the time to appropriately deal with a person with dementia. As Sherri points out, *"No they may not have all the training that they need specifically with dementia patients and that would be good but as busy as they are, who's got time'.*

4.3.3 Rationalizing Treatment

Participants made attempts to explain or justify the care they received in their experiences. They accounted for, and even defended to a degree, their treatment by providing possible explanations. In this incident Sherri (care partner) excuses the removal, restraint, and isolation of her husband by explaining that it was for his own safety.

They said that uhm the 3 other men were shouting at each other and Dean got agitated and started to shout also so they removed him, I guess it was for his own protection too you know I'm assuming.

Kelly (care partner) also reflected on the use of restraints, reasoning their use as a result of predominant institutional policies and avoided blaming the front care providers. *"It may or may not be typical, but I often felt that their needs came first. And again, not with the front line staff but further back you got in the hierarchy the more it was about systems."*

Although stigma was only rarely and indirectly mentioned, the findings indicated here demonstrate that aspects of stigma, particularly being treated differently when one has a diagnosis of dementia, are perceived and understood in unique ways and influences how people make meaning in their interactions and relationships.

4.4 Enhancing Care

Enhancing care involved family, care partners and other health care providers advocating on behalf of a person with dementia while they were in hospital. At times, some participants found it necessary to advocate and speak up to get needs met. The sub-theme, compassionate culture of care demonstrated how health care providers were consistently perceived as attempting to deliver care and compassion for their patients.

4.4.1 Family Advocates "It's a Team Effort"

Dementia knowledge along with familiarity of an individual was identified as essential to effectively advocate for better care. Most participants described that this enabled them to be more supportive and assisted them in understanding the needs and challenges that exist for their family member. Participants with dementia described the integral role that their care partner played in their health care experience, often citing that it was not only beneficial, but crucial, to a person with dementia to have an advocate. The vigilance discussed by the care partners appeared multi-faceted where the care partners contributed mainly to a supporting role but were also highly protective when they felt necessary.

Samantha (a person living with dementia) talked about how she recognized clearly that ill health can have a substantial impact on the cognition of a person with dementia and how an advocate to assist in decisions related to care are important, and often necessary.

As it turned out, I had had another minor stroke, so hence why that really compounded the dementia part of it. And I wanted Travis just to call an ambulance to take me to the hospital because he was so sick himself, knowing full well when I said that, that he wouldn't allow that. So he said, well there is no way you are going on your own because at that point in time my clarity was not good. As soon as you are in trouble that it the first thing that goes is your thinking and being able to function well when something else was going on.

Having an illness may impede an individual's ability to explain their symptoms and provide onset and timeline of symptom progression impacting diagnosis and treatment as described by Samantha (person living with dementia).

Samantha goes on to describe how her daughter was a strong advocate for her. She made decisions that Samantha felt unable to make herself when she was unwell and her cognition was affected.

So Cindy got out here and I was kind of out of it mentally, not really functioning well at all and I had been sick to my stomach, and the ambulance came, and she went with me to the hospital. Now the difference between Cindy and Travis is that Cindy won't take a back seat when she gets in there. She's a stronger voice for me in those situations and that's why Travis had called her, but she normally does that, and she took me to my initial appointments getting a diagnosis because she will speak up more than Travis will. She is just stronger that way in those kinds of situations. Cindy is the one that's better for that medical stuff and taking me, and this was even before she had her education she was that way. So anyway, she went in there and, now they listened to her more and she got more help,….she just has that approach and she does it nicely but she is very firm in what she says and so they pay heed more to her because she is a stronger character, stronger force, but not in a bad way. Just you know, more forceful so they *listen to her in a way more, but they were wanting to do certain things at that time and she was saying no, but again it was the dementia and it really affected me then because I was out of it more.*

Bert (a person living with dementia) described that when he was experiencing pain, his wife could summon a nurse for assistance. When his wife was not there, he would press his help button; however, he had to wait much longer for someone to help. *"Yeah well I had to wait a bit longer for the nurse to get off her ass at the desk and come and find out why I'm buzzing. I must have buzzed 2 or 3 or 4 times and still didn't get her."*

Nutrition and mealtimes were also discussed by Sherri (care partner) in this study. She discussed that care partners were essential to assist with mealtimes, since people with dementia were not provided with the additional assistance they need in food selection and intake. *"He's a really poor eater, so I tried to order things he would possibly eat and I tried to be there at meal times to encourage him to eat."*

According to Sherri (care partner), the hospital did not have any meals that were accommodating for her husband, which was a concern that he might not get the appropriate nutrition if she was not advocating for his needs.

Like if you ask somebody if they want 2 things like at the long-term care home they show plates and they say would you like this or this, and he can choose, and he doesn't have a problem with that, but if you have a screen and you say would you like pork chops, or fruit plate…etc. That's very difficult for a person with dementia. "And that's an issue I think because especially for somebody like Dean who's not a good eater anyway, I mean he'd be just as happy to chug back an ensure as do anything, if I'd let him, you know or if the staff and I would let him.

I mean I didn’t have an issue with it because I dealt with it, but if a person were by himself or the family wasn’t involved I could see it being a bit of a problem.

The participants in this study primarily expressed fear if they had not been present to advocate for their loved one. Jordyn (care partner) described an expectation that the person with dementia would be provided less, or inappropriate care, without someone advocating on their behalf. *“If that person is by themselves with no family, or no advocate there to speak for them, what happens to them?”*

Kelly (care partner) voiced strong concerns over possible neglect in her husband’s treatment if she were absent.

Now of course, I don’t know what would have happened if he had been alone. I don’t even want to think about that if he hadn’t had an advocate. I can’t even begin to imagine what he would have done if I hadn’t been at his side at all times.

Care partners also discussed how it was important to know more about dementia in order to advocate effectively for a person with dementia. Sherri (care partner) described the personal impact of dementia and highlighted that able to understand a person with dementia and provide appropriate care, it was essential for her to educate herself about her husband’s disease when he was diagnosed. *“So what I did at that point was a lot of reading, I don’t think I contacted the Alzheimer’s Society at that point; I just did a lot of reading about dementia and Alzheimer’s at that point”*. Samantha’s daughter also felt it was necessary for her to learn about her mom’s dementia to advocate in a more knowledgeable way when needed. According to Samantha (person living with dementia), *“...[s]he educated herself right away as soon as I was diagnosed, went to the learning sessions at the Alzheimer’s society and did a lot of research on her own.”*

There was always a possibility that a person with dementia may experience a medical emergency in the absence of a care partner and end up accessing care alone. The participants in this study all discussed how dementia may impact a person's ability to communicate or express themselves, and expressed concern for those accessing care alone. Sherri (care partner) talked about expanding the circles of support for a person with dementia through a designated staff member in the absence of the care partner. *"Is there someone on the staff whose job it is to be that advocate however temporarily. Ya, what do the folks do who don't have somebody at their side?"*

4.4.2 Speaking Up

This theme demonstrates that at times advocacy involved having to stand up, or be assertive to ensure that needs were being met. These participants brought to light that the presence of an advocate was not always respected by health care providers. Jordyn (care partner) knew that her husband was often not clear in his answers, or often did not remember, making it difficult for him to answer questions appropriately. She described feeling rejected when trying to provide vital information.

Jack is being very vague to all the questions that he's asking. He does this when he goes to the hospital. I don't know if he just doesn't remember or just doesn't feel like answering or what it is, I don't know, he says ask my wife. Well they don't want me telling them anything. They want everything to come from him. Now if you had somebody with Alzheimer's maybe the pain feels greater to them than it would to somebody else, or maybe they don't remember how bad it was, so I thought I was helping them out by going in there and saying exactly this is what's happening, you know and he's got this, this, and they don't want to listen. I just find that a lot of *the medical profession, whether it's lack of knowledge or lack of care, they are very passive about when you tell them, like if I was a nurse or a doctor I would be so happy if somebody said to me, ok this is what my husband has, this is the medications they are on, you know just to tell them what's happening so they have something to go from but they don't want to listen to that, they really don't care.*

In this situation, Jordyn (care partner) was asked to leave for a procedure and refused to do so. *"They told me to leave the room and I said no I'm not leaving."* When further questioned as to whether or not the staff was aware of the fact that her husband had Alzheimer's, Jordyn confirmed that they were aware; however, it was disregarded, and her attempts to stay with him were ignored.

Jordyn understood why a care partner may be asked to leave, although she was not offered a choice.

I think a lot of times too they don't want you to stay because some of the stuff is really traumatic that they do to a patient and if you don't have the stomach for it and you pass out on the floor, they don't have time to deal with that so I can understand.

Sherri (care partner) pointed out that staff need to recognize, and accept, that people who were most familiar to the person with dementia can play a key role in supporting their well-being while in hospital as they are more knowledgeable, and familiar, to the individual receiving care.

You know so a little sensitivity when dealing with the families wouldn't go missed too, because you know when a person has dementia they do need their support of people that they know well.

Being sensitive to the care partner was also suggested as necessary in assisting to put the person with dementia at ease, but according to Sherri (care partner), also makes the job easier for staff to provide care for a person with dementia.

I think that's something that the care giver aspect of it with the hospital uhm like I said before the sensitivity of the dementia patient's care giver is important and uhm you know some of the nurses were better than others at that and you know seeing to it the care giver is alright because you know when the care giver goes and upsets the dementia patient that's not helping their job you know.

Kelly (care partner) talked about how dementia affected her husband Neil in such a way that he was afraid of, and challenged, others who were responsible for providing his care. Staff responded to this behaviour by putting her husband in an isolation room in the emergency department. Her husband's behaviour, and lack of appropriate response, served to endorse what can be interpreted as courtesy stigma. In this case, the care partner had also been isolated and stigmatized as a result of her association with her husband. *"I had to become his personal support worker because he wouldn't let anyone touch him. It was really tricky."*

Samantha (a person with dementia) talked about the power of self-determination and the value of taking initiative in seeking information in addition to how being proactive was necessary in accessing care.

For people coming along new, I think that's something that could be so beneficial, and had I not had strong determination myself and decided I was going to do certain things myself, even though everybody told me it wouldn't be beneficial, had I listened to them I don't think I would be where I am today.

Samantha further discussed how she learned to advocate for herself by experiencing significant delays in getting an initial diagnosis.

I had 127 appointments, either doctor's appointments specialists appointments, blood testing, anywhere they sent me in relationship to appointments, 127 appointments before I got my diagnosis and a year and a half and I thought that was atrocious.

Samantha stated that prior to her diagnosis, due to her young age, she was funnelled into the mental health system. She knew the services were not appropriate for her, and was forced to fight to access more appropriate services. Here she talked about the frustration she experienced in trying to acquire the right assistance.

So, finally I just got really, again, really angry and said to my doctor look it I know I don't belong there. They are having me do all these things that I already know and do myself, like I don't have a mental health issue. And I'm not going back, and had I not had a doctor that was willing to get on the phone at the time, I, I, would have lost my payments, but I, at that point in time I was so frustrated that I didn't care if they cut me off...even though I didn't have any money.

Other health care providers have also advocated on the behalf of a person with dementia. In this case, the physician was also faced with obstacles in providing care and achieving the right placement. This physician took on advocating for her patient when beds and resources were unavailable for those with responsive behaviours.

It was Dr. Elmer, She was as pissed off as anybody about how it was all going and someone transferred out and she was coming in everyday to be his psychiatrist and she came in one day and she said someone has transferred out of the older adult rehab and I'm gonna try to get him a bed and I said what? I thought it was closed, like I was thunderstruck. Who knew?

And 24 hours later she said, he's going over tomorrow. He will be transferred to a medical bed tonight to sleep and then he will be escorted over there tomorrow and he's been there ever since. So I guess it was her magic to some degree, but he has a bed there.

Samantha (person living with dementia) again reflected on her daughter's personal knowledge of dementia, which helped her to advocate for others in her role at the hospital. She described that her daughter's advocacy for another person with dementia was difficult and she was fearful of employment repercussions.

She also refused to do an x-ray on a patient that had dementia that the nurses had sent down to her while she was working in the hospital and the person was so agitated because, again, nobody accompanied her. And Cindy refused and she came home and said, you know I might lose my job. That's what she told me because she refused to do this x-ray. Now it didn't turn out that she did but she was worried.

4.4.3 A Compassionate Culture of Care

In contrast to the interpersonal encounters that participants in the study described, they also emphasized the compassion that staff displayed toward their patients. Staff often exhibited obvious angst when the care system itself constricted their ability to provide appropriate care. Kelly (care partner) referred to empathetic listening by staff however also recognized that administrative barriers, out of staff's control, prevented them from responding to the needs of a person with dementia.

You know people complain about the health care system being cold and all that sort of thing but whenever there was someone sitting across a desk from me, I always felt that I was being heard and listened to, and that day they were empathetic to my problem although they *couldn't always solve it, but they understood that I had a problem that eventually was going to have to be solved.*

Kelly also talked about watching, and admiring, the staff working under such enormous pressures, and how staff were able to express care and compassion to their patients.

I would sit sometimes holding Neil's hand and we'd be watching, and I'd be watching the nursing staff and thinking how do you do this hour after hour and they smile at people, you know, kind of efficient and yet caring, I was in awe I really was. They are special people.

Participants felt that staff were constrained in providing the quality of care needed at times, but this was compensated by the compassion that staff demonstrated. Sherri (care partner) described an acceptance to the minimum standard of care where her husband's basic needs were provided for, because despite the limitations in care, staff had a caring attitude. She expressed no expectation for treatment specific to his needs.

I think just the caring attitude that they show there, they really bend over backwards there to make sure he's comfortable and that he's cared for, you know toileted properly, cleaned up properly and uh fed you know, the care aspect was really, really, good.

When asked how her husband was treated, Kelly felt that although there were systemic issues, those who provided front-line hands-on care demonstrated true kind-heartedness, and genuine compassion.

Just kind. That was kind of the overarching feeling that I got. Officially a little farther up the line were a problem but for the people on the front lines, he was just a patient and he had to be dealt with and he had to be treated a little more delicately because he couldn`t understand anything they were saying but I never got the feeling that he was in anybody`s way or that it was a drag to have to deal with him. I never ever got that.

Conversely, in this statement discussing care, Jack (person with dementia) referred to the bigger picture of hospital care for people with dementia where there is no compassion for people in how they are treated, or how their health is managed within the system. *"Nobody seems to really care anymore. That's the feeling I get, there's no compassion.*"

While participants did not describe experiencing stigma, their descriptions of their experiences demonstrated that stigma did occur through stereotyping, demonstrated by being perceived differently, and discrimination, demonstrated by being treated differently. Stigma appeared to exist in all aspects of care, and participants described coping by accommodation and feelings of acceptance in relation to their care expectations. Most participants felt that there was a reluctance to care for people with dementia. By their accounts, there was an evident disconnect between the front line care providers who attempted to provide the best care possible with little knowledge of dementia, and the larger system of policy development, service provision, and professional culture that contributed to creating a discriminatory environment that ignored the needs of people living with dementia.

Chapter 5 - Discussion

Hospitals need to adapt to serving the aging population and in particular, identifying through research, the unique care needs of people with dementia within the acute care environment to optimize resources, the environment, and cultivate effective clinical practice that supports and contributes to reducing inequalities and improving health outcomes. The research demonstrates that prejudice, discrimination and negative consequence exist for members of this stigmatized group, and research that focuses on how dementia stigma is experienced within the acute care environment is clearly necessary. Research based evidence examining acute care practices and policies is an opportunity to identify and understand the best practices that currently exist and work toward improving and creating further solutions that foster positive views of people with dementia. This review highlights areas of need and changes necessary to reduce risks for people with dementia by examining the technological and task-oriented culture of care that devalues people with dementia. This knowledge can contribute to building environments that reduces stress, are more dementia friendly, and that enhances partnerships with carers, people with dementia, as well as the health care team. Building these relationships encourages the creation of effective and appropriate strategies in caring for people with dementia that reduces the inequalities in care and negative impacts of hospitalization as a result of stigmatization. It is important to bring stigma to the forefront of dementia research as it highlights that changes are also needed in awareness, education, training and policy development that encompasses a paradigmatic shift in care for people with dementia that moves from the medical model to a care relationship that is person-centred.

5.1 Age and Dementia Stigma

The task of this study was to explore the acute care experiences of people living with dementia with a central challenge to reveal if, and how, stigma played a role in shaping their experiences. The findings offer insight into how stigma impacted perceptions of how care was offered, provided, received, and ultimately experienced and understood by people living with dementia and their care partners. This was encompassed by four main themes that reflected the dynamic process of making sense of dementia within the acute care experience. The themes identified are represented in Figure 1 and distinguish the main themes as follows: disentangling the stigma of age and dementia, system issues, interpreting stigma and enhancing care.

The findings from this study revealed stigma is present and relevant throughout the hospital care system with a lack of policies, practices, and care specific to dementia, which many felt were guided by dominant beliefs that nothing can be done for people with dementia. These experiences demonstrate environment and health care relationships, which can discriminate and ignore the needs of this population. Although it would be unreasonable to take the findings from this research and infer that stigma was an explicit and direct cause of negative health effects for people with dementia (although this has been found in previous studies--see Kelley et al., 2010, Moyle et al., 2008, Sparks, 2008, Mitchell et al., 2009, Sampson et al., 2009, Goodall, 2006, Mukadam & Sampson, 2011), it is abundantly clear that stigma exists in the healthcare environment and that has a negative impact on care practices. This is not surprising, given that stigma is commonly reported by people with dementia generally (Alzheimer's Research, 2011). As a consequence of being ill, people are not able to engage in normal day-to-day activity, and people are at risk of further stigmatization as a result of their additional health problems (Pierret, 2003). Participants in this study described experiencing an environment and care practices infused with stereotypes, prejudice, and discrimination in care that is tailored toward acute health problems that affords low-priority to people living with dementia (Moyle et al. 2010). In this chapter I describe the significant themes generated in this research in relation to existing literature.

5.1.1 Stigma

Living with a stigmatizing illness and the harm it causes is quite pronounced in the literature, and while there are some differing theoretical definitions offered, it encompasses adverse experiences based on exaggerated perceived differences for those who are stigmatized. The findings from this study are similar to current research where the impact of stigma is identified in social relationships (Meyer, 2013). The participants in this study described their heath care relationships in a way that they perceived being treated differently which served to transform the caring relationship for people living with dementia.

The participants in the present study described negative experiences that were descriptive of stigma in ways that were unique and complex. In my study, participants described their experiences where association was not specific to stigma, but to its components including stereotyping, avoidance, being discounted or ignored and were demonstrated in the themes disentangling age and dementia, interpreting stigma, system issues and enhancing care. This is similar to Nolan et al. (2006) who also found that stigma was not identified as an all-encompassing entity. In essence, participants described the actions related to stigma, but stopped short of labeling these actions as stigma. Gove (2012) revealed the experience of stigma is dynamic and consisting of interrelated elements. Goffman's (1963) work also supports the complex social processes of stigma that are deeply discrediting. Participants described both age and dementia as disabling characteristics. Some illnesses are embedded with shame and stigma (Pierrett, 2003), adding to a stigmatic construction of the illness experience.

Following Link and Phelan's (2001) theory on stigma, stigma is broken down into five interrelated and converging components. According to Link and Phelan (2001), the first component is an oversimplified attribute or category that is salient to society reflecting dominant power structures and which is grouped and labeled. The attributes or categories of age, illness, and dementia are three characteristics of the individuals in this study, which are either oversimplified, overgeneralized, or distorted and can create power imbalance and negative undertones. The second component includes labeled characteristics are linked with negative stereotypes. For example, in my study, stereotypes of the participants included the labels of 'dementia' and 'old' which conveyed being incapable, frail, and needy, and encouraged others to view them as fundamentally different. This stereotyping paves the way for what Link and Phelan describe as the 'us' and 'them' label. This is clearly defined in the hospital environment by relationships, and structures, that were defined by those who were in need of care and those who had the power to provide it. The fourth component is discrimination resulting in an almost instantaneous status loss, both personally and at structural levels, which was sensed by the participants in their relational experiences as well as the experiences of place. They described instant associations particularly in relation to their appearances and being perceived as 'old'. The final processes of stigma depend upon the social, economic, and political powers that impose discriminative action on the individuals, or groups. This was demonstrated in the systems theme findings that outlined perceptions of insufficient services and standardized care in the hospital environment. Link and Phelan (2001) suggest that although the components of stigma are related, it is not necessary that they be experienced together to be influential. As it can be various degrees to which these components are experienced, even a small degree of stigma can significantly impact a person's experiences, depending upon circumstances, environment, context and what may be salient to the individual.

5.1.2 Age and Dementia – "I just think it went down hill once they were told I had dementia"[Samantha]]

Prominent in the participants' experiences were feelings of being treated differently where the manifestation of stigma related both to age and dementia was perceived as discrimination by the participants. Being viewed as older and having dementia were both attributes described as discrediting, which resulted in treatment that they recognized as different.

Similar to the previous findings of Levy and Banaji (2002), participants related to the ageism they felt as not only explicitly exhibited but that there was also an automatic association with dependency and weakness. These associations appear common, and are strong carriers of ageist stereotypes and discrimination (Levy & Banaji, 2002). Interestingly, most participants perceived the association with dependency and weakness related to their age, and not in relation to the illness that caused them to seek care. Physical and cognitive age related stereotypes that position individuals as incapable and weak are what Palmore (2001) and Butler (1969) suggest as paving the way to stigmatization, exclusion, and ageism. This was quite evident in this study as participants described feeling disregarded and treated differently based upon their age. This is also consistent with Gove (2012) who added that general practitioners emphasized how the aging population and potential for dementia poses a significant financial burden and can provide the basis for resentment toward those utilizing health care services. Discovering ageism in the hospital environment was not a surprising finding, as ageism, although at times facilitated by place, can emerge from larger global views regarding aging (Dobbs et al. 2008). Additionally, the illness experience exposes additional insight into how contemporary society views ageing (Sanders et al. 2002).

This theme further demonstrates Goffman's theory of undesired differentness, where age and dementia contribute to the complex ways in which negative implications are experienced by those that are stigmatized. The participants in this study described their experiences in a way that they process and view themselves as having 'spoiled' identities also analogous to Goffman's work (1963). Discrimination also emerged in the findings by prioritization of care for younger people with a single illness over caring for those who were older that may potentially have numerous health issues.

Stereotypical beliefs and discrimination were related to both age and dementia in the findings of this study, although these were often difficult to separate. As age was more visible and readily identified, it was believed a primary influence on care. Dementia was seen as related to normal aging by those providing care yet, when mentioned, still carried an additional set of stereotypes to the already negative stereotyping of older people. Nolan et al. (2006) pointed out in their findings that age and dementia were commonly associated, even inevitable and expected, which influenced professional attitudes toward aging. Their participants also described negative attitudes and apathy toward older individuals. Bulet et al. (2015) also found that health care providers held views of older people that affected the treatment and care they provided. The participants in my study described how health care staff, particularly physicians, normalized dementia as expected with age, or ignored it altogether in their care. I argue that stigma of dementia may likely contribute to health care providers normalizing dementia as well as their disregard for its presence. Gove (2012) found that physicians described emotions related to dementia that involved an array of feelings of hopelessness, helplessness, sympathy and frustration. Other studies have also suggested negative attitudes of general practitioners where they maintain beliefs connected to the insufferable existence and terminal nature of dementia, loss of awareness and the self, and physicians feel they have little to offer individuals with dementia (Gove, 2012). These beliefs likely fuel the common disregard physicians showed toward people with dementia as described by the participants in this study where they had minimal, or no, response to individuals' dementia.

5.1.3 Being Ignored, Disregarded and Ill Informed – "*That is what stands out and annoys me the most is when people don't, they just assume that I don't want that information."[Samantha]*

Being ignored and disregarded were commonly reported by participants, and which resulted in wishes and decisions being overlooked by hospital staff. Participants felt that the compounding effect of age and dementia channelled decision making away from those that should be making decisions about their own health. The findings in this study were consistent with the conclusions in the study by Legace et al. (2012) where older residents of long-term care homes also described feeling that they were simply ignored within the decision making process, which impacted their autonomy and feelings of patronization. Parallel to the findings in this study, Nolan et al. (2006) also found that participants were concerned about the potential for being dismissed, which they considered connected to attitudes.

The participants cited the provision of information as a major issue and barrier to care**.** In their experiences, they were uninformed as a result of insufficient information provided, assumptions of information not being wanted, or delivery of information that was inappropriate for the intended audience. The main concern highlighted was the complete absence of essential information provided to patients and their care partners. When participants discussed times when they felt there were informed, they also described it as a unique occasion. Being informed was cited as what mattered most about the care provided in the hospital however being ignored was a common experience.

Legace et al. (2012) points out that previous research has shown that communication can convey stereotypes that are age-related and can result in reducing an older individual's self-esteem as well as increasing their social disengagement. In their study which examined the function, and influence, of communication in the context of a caregiving relationship in long term care facilities, they found that broader social representations of aging are often conveyed and can have very negative effects that threaten an older person's health and welfare. The participants in my study also described staff's language and communication as powerful and disabling similar to what has been found previously by Legace et al (2012). Participants also described that the direction of communication was an issue as it was primarily to care partners, disregarding any input from the person with dementia. In Turner's study (2004), physicians were found to share attitudes where they did not value or encourage communication with individuals with dementia or their care partners (Turner et al. 2004).

Giles and Oguary (2007) framed the manifestation for implicit ageism where communication was based upon the perceived characteristics of the individuals' social identity or group. Coupland et al. (1988) described stigmatizing communication with older people that included baby talk and patronizing speech; however, this was not disclosed by the participants in my study in relation to the communication with their health-care provider in the hospital.

Social distancing is most identified as discrimination in stigma research (Link et al., 2004) and was evident in the experiences of the participants as they described staff avoidance in the emergency department. As identified in the experiences of one care partner, social distancing also differed depending on the perceived competence of the person affected with dementia (Werner, 2006). Avoidance, along with prejudice and stereotyping, is one of the three components of discrimination (Bourke, Ferring & Weber, 2012).

5.1.4 Loss of status and power – "I*t's very difficult to question a doctor because they had that kind of a god complex to us" [Jordyn]*

Link and Phelan (2001) offer the 'us' vs. 'them' conceptualization as a significant part of stigma, which may exist here. Hospital staff provide care, as people with dementia and care partners receive it. Hospital staff are typically in a position of power, as people with dementia are in vulnerable states when they enter acute care, and care partners are vulnerable as well. Once there is a perceived separation, according the Link and Phelan (2001), it becomes easier to devalue and to discriminate against that particular group. Exclusion was also described as part of Link & Phelan's (2001) status loss and discrimination, which was described by the participants in this study where they were felt excluded from receiving appropriate care. They described feeling marginalized by lacking control in their health care, although their reference was mainly related to the visibility of their age and condition.

In their encounters, participants described an acute awareness of the power difference between those receiving and providing care, revealing the perception of status loss, which coincides with power imbalance and resulting discrimination. Hospital staff, particularly physicians and nurses, are in positions of power and patients are particularly vulnerable when unwell. Link and Phelan (2001) state that power is the driving force in imposing stigmatization and that as power is necessary to stigmatize, it is also necessary to defend against it. In Gove's study, physicians also reflected on the loss of power that a person with dementia might experience in dealing with health care professionals. General practitioners ascribed a "non-person" status to those with dementia with the belief in treatment only in a physical sense implying the depersonalization in care (Gove, 2012). Physicians can therefore be instrumental in conveying and reinforcing stigmatization through the power they hold in the patient- physician relationship, which was also described in the current findings.

5.1.5 Disclosing Dementia – "it was just flat out 'oh, it's just the dementia" [Sherri]

Stigma related to disclosing dementia was also identified as participants described a reluctance to disclose, as well as dismissing, or diminishing, of their disclosure by health care providers. A diagnosis of Alzheimer's disease was not recognized as necessary medical information included in patient charts and when individuals did disclose, some participants described being avoided by staff. The reluctance to disclose was based on doubts of the value of the diagnosis providing opportunity for additional supports to address the disease, and that they would feel further stigmatized by disregard and avoidance by staff, many of whom lack dementia knowledge and who are unaware of dementia support services. The avoidance of dementia produced an apprehension or strain within the relationship, similar to Goffman's theory of being discredited.

Reluctance to disclose dementia may also be considered as a strategy for coping. Bert (a person living with dementia) concealed the fact that he was diagnosed with Alzheimer's disease, which may have been his way of controlling what was potentially discrediting information about himself. Paradoxically, this strategy was engaged in to avoid or reduce negative consequences of disclosure and associated stigma, but can be quite counterproductive, inducing increased stress for the individual (Miller & Major, 2000). Concealment of dementia, or hiding one's stigma, results in the cognitive burden of an unrelenting preoccupation with deception. Smart and Wegner (2000) describe both conscious and unconscious cognitive processes in maintaining secrecy related to stigma a "private hell" (p.229). Although disclosure theoretically should open the doors for appropriate medical care, staff responses to disclosing a dementia diagnosis were dismissive. One care partner described that the response she received from disclosing dementia was similar to informing someone of the common cold.

The label of 'dementia', may be a means of identification, however the relationship or connection created can hold strong negative accentuation. Physicians felt that there were negative connotations conveyed with both the term dementia as well as the term Alzheimer's disease (Gove, 2012), which may have influence on whether or not an individual chooses to disclose their diagnosis. The use of the label "dementia" as a general and comprehensive term was described as being applied by general practitioners based on societal understanding and beliefs of the consequences of the disease (Gove, 2012). Although only one participant referred to labeling, it was abundantly clear that participants recalled their experiences in a way that they felt they were categorized, stigmatized, and treated differently based on their dementia. Stigma attached to the diagnosis, and associated labels, was often cited as a reason for not disclosing a diagnosis of dementia (Bamford et al., 2004).

5.2 System Issues – "They just didn't have a solution." [Kelly]

An evident lack of services, standardized care, and systemic stressors were described as present in the hospital environment. Although stigma was not described directly by all participants, it was suggested in the elements of the overall hospital experience. Gove (2012) found that the majority of the general practitioners in their study felt that health care services were discriminating against individuals with dementia. They cited barriers to care, inappropriate or inadequate treatment as well as diagnostic issues, often based upon negative attitudes toward dementia. The social norms of the hospital also contributed to shaping how people with dementia were treated within that environment. As the acute care environment has established practices for those who are acutely ill, encountering an individual with dementia was outside of the norms established to categorize an individual's needs. This was reflected in participants' comments where they described that nobody knew what could be done for a person with dementia. Recognition of this consistent lack of specific treatment plans is consistent with how Goffman (1963, p.11) described categorizing as a process engaged in by particular groups where in this case, health care providers grouped people with dementia together and provided the same standard lack of treatment.

One participant with dementia described insufficient staff as a systemic problem with increasing patient numbers exhausting resources, and further felt that specialized dementia care was therefore too much to expect. Lack of staff, along with inadequate institutional policies and practices were obvious contributors to those with behavioural challenges. Aggression, agitation, and wandering behaviours common to dementia were difficult for hospital staff to cope with, particularly in the emergency department. One care partner described restraints as the only answer hospital staff appeared to have with responsive behaviours. Like the study by Moyle et al. (2008) she also described how hospital management of these types of behaviours had a negative impact not only on the health of the person with dementia but also on the family members present as she felt it necessary to stay and maintain watch over her husband. The hospital engaged in care practices emphasizing the safety of others over the health of the individual, also similar to Moyle's (2008) research.

As Richards (2000) noted, nurses are faced with competing priorities in acute care including central directives that may knowingly or unknowingly undermine the nurses' capacity to provide holistic care that is person-centered and supports the person with dementia. Webster (2011) further cited that a nurse's experience, knowledge and willingness, affects the prioritization of task completion over other activities. Additional barriers to care provision have also been identified as professional silos in professional work (Webster, 2011). I argue that the influence of the stigma of age and dementia in health care providers would also affect what tasks are deemed more important, hence this population being prioritized below other responsibilities or care.

The lack of quality of care was cited as a result of lengthy wait times, overcrowding, services that were challenging to navigate, as well as an absence of services for people with dementia. Intake that involved repeated questioning, lengthy delays, and the environment all posed significant difficulties for the participants and were described as overwhelming. Bed shortages also impacted individuals with dementia, as there was placement on wards that were inappropriate and not geared in any way to assist a person with dementia. Private rooms were described as beneficial but were not the norm of hospital practices for a person with dementia. Those who are stigmatized are at risk of structural discrimination, which was described in these findings, where the structure surrounding the individual exposes them to a variety of unfortunate circumstances (Link & Phelan, 2001). Even though the individuals in this study did not identify bed shortages and lengthy delays as stigma, it is structural discrimination that is underpinned by larger factors and evidenced in services that disadvantage stigmatized groups (Link et al., 2004;

Corrigan et al., 2005b). Additionally, care partners have also described high levels of structural discrimination toward both care partners and older individuals with Alzheimer's disease, and report that as an individual's cognition declined, structural discrimination increased (Werner & Heinik, 2007).

The emergency department in particular was consistently experienced by participants as the wrong place for people with dementia to access their care needs. It was experienced as chaotic, adding unnecessary stress, as well as increasing fear and confusion, and was also identified as even more inappropriate for individuals with responsive behaviours. In their study examining palliative care for people with dementia, Davies et al. (2014) found that the health care professionals also described care as frenzied, disorganized, lacking structure, and provided limited resources in comparison to care for other populations.

Lack of routine and inconsistent health care providers also caused feelings of fear and threatened feelings of safety. The lack of consistency of physicians and nursing staff resulted in inconsistencies with information being shared and contributed to inappropriate care for an individual with dementia. Participants describe some acceptance for poor quality of care going as far as to say that it was for their own safety and blaming the system rather than those directly responsible. The hospital care system as a whole made one participant so frustrated that she perceived leaving and risking her own health by not receiving necessary treatment as a better option.

5.2.1 Knowledge - "So they've got Alzheimer's so like big deal, what am I supposed to do with that"[Jordyn]

Participants consistently noted that they didn't feel that health care staff demonstrated the knowledge and skills necessary to understand and provide appropriate care in response to the needs of a person with dementia, which was described as contributing to insufficient care, or concern, for dementia. Although participants indicated that staff had a general understanding of dementia, they did not demonstrate knowledge in the various types, degrees of the disease, or symptoms associated. This was highlighted specifically by Kelly, whose husband was young and diagnosed with Alzheimer's disease with aphasia, which left staff puzzled about his condition and diagnosis. Lack of knowledge played a role in the difficulty staff had in determining care for this individual.

Essential training for health care professionals was referred to as acquiring the skills and increasing confidence in a health care provider's ability to deliver appropriate care to a person living with dementia. Similarly Davis et al. (2014) found in their study that education and training was necessary to improve insufficient awareness regarding dementia and dementia services. Moyle et al. (2010) also found lack of dementia knowledge was a main concern similar to these findings as participants identified this as a main theme of care.

The participants in this study reflected on their experiences where they were confident that both physicians and nurses were lacking knowledge and ability to effectively manage care for a person with dementia. This is consistent even from the perspective of a group of physicians in the study by Turner et al. (2004) where two-thirds of the 127 general practitioners interviewed felt inadequate in their abilities to manage dementia related behaviour and additional matters. Veteran physicians, as well as physicians with limited knowledge of dementia, and particularly those who were male, demonstrated pessimistic attitudes about dementia care (Turner et al 2004). These findings are consistent with the participants in my study where they perceived their physicians' knowledge of dementia as limited and they expressed attitudes, which conveyed their lack of value held for engaging with people with dementia as well as their care partners. Although dementia education was emphasized as invaluable in combating dementia stigma, education was seen as fruitless, particularly in the emergency department, as there was limited time to apply that knowledge and appropriately care for a person with dementia.

Dementia, like other diseases, is culturally and socially constructed. How it is embedded and constructed within the context of the hospital environment has shown that stigma encompasses the illness with the perspective of hopelessness or tendency to disregard its presence. It of course follows that there is also a tendency for staff to incorporate this in the treatment of people with dementia, as well as negatively affect the development and provision of care.

5.2.2 Enhancing Care- "I don't know what would have happened if he had been alone. I don't even want to think about that if he hadn't had an advocate" [Kelly]

Participants described the crucial role that their care partners played in their health care experience. Care partners provided familiarity, support, knowledge, comfort, and protection for the person with dementia. It was highlighted that care partners tend to seek out dementia education in order to better understand and advocate when needed. Advocates were valuable in assisting with decision-making as it was recognized that illness has the ability to negatively affect the cognition of an individual with dementia. Staff, however, did not recognize, or value, when advocates could be of assistance, as they did not encourage participation of advocates in the care of a person with dementia. Webster (2011) also found that the biomedical model of the hospital that focuses solely on ‘systems’ and ‘illness’ is challenged when it comes to including supporters in the care of another person. Sherri stated that being sensitive to care partners was also necessary as they can assist in putting the person with dementia at ease, which she found made the job easier for staff to provide care for a person with dementia. These experiences suggest that isolation may occur as a result of courtesy stigma, which is due to association with the person with dementia and is quite likely what was felt by care providers and close family members in this study (Goffman, 1963).

Finally, the resiliency and strong sense of advocacy care partners applied toward enhancing care was experienced as powerful in response to their treatment. Allport (1954) proposed that coping and resiliency are common minority group responses to stigma where the group members strongly support each other through solidarity and cohesion. As care partners held expectations for inadequate care, they expressed fear if they were unable to be present and advocate for their loved one as they knew how necessary it was in obtaining appropriate care.

In contrast to the previous encounters, the hard work, empathy and compassion of the front line staff was also emphasized and admired by the participants. It seemed understood that systemic barriers were the cause of inadequate care and staff did the best they could within those restrictions. There was an awareness implied that some dementia behaviours would be perceived as difficult and time consuming and that staff attempted to accommodate when able. Although compassionate care was experienced at times by the participants, discrimination was clearly present, yet not perceived in their care. Participants concentrated more on the belief that there is no compassion embedded in overarching hospital systems. Gove (2012) also had similar findings where most people accessing services were not aware of the discrimination.

5.2.3 Internalizing Stigma

Experiencing stigma can also lead to internalization of stigma (Ritsher et al., 2003). Internalization of negative stereotypes and self-stigmatization were found in this study to affect participants' expectations for care. When negative stereotypes are endorsed and applied back to the individual it causes reduction in a sense of self-worth, secrecy, and social withdrawal (Livingston & Boyd, 2010), losing confidence, expecting rejection, and reduced self-esteem can all be of consequence effecting life quality (Link and Phelan, 2001). The "traits due to victimizations", (p. 142), Allport (1954) proposed that the association between adverse favour from others and damage to the minority individual is self apparent: "One's reputation, whether false or true, cannot be hammered, hammered, hammered, into one's head without doing something to one's character" (p. 142).

Similarly, the individuals in this study discussed expecting certain treatment from staff, and their responses to this treatment was rationalization and reduced expectations in regards to the hospital care they received. Dementia self-awareness, and incorporating previous treatment experiences, contributed to shaping expectations for care particularly for one person with dementia where she described an overall expectation of stigma and associated reduced quality of care for herself and others living with dementia. The internalization of negative stereotypes also contributes to lax strategies, such as rationalization and reduced expectations as mentioned, that ironically facilitate and support these same stereotypes (Levy & Banaji, 2002).

Most participants did not refer directly to stigma as part of their experiences, although stigma may still be feared. Thornicraft et al., (2007) suggested that even where prejudicial treatment may not have occurred, it may be feared, or anticipated which is also harmful to those who are stigmatized. Autobiographies analyzed by Page and Keady (2010) identified that instrumental to the dementia experience are processes of awareness and subsequent positions of anticipation. This is also similar to Nolan et al.'s (2006) study where the presence of dementia subjugated individual's perceptions and experiences with regard to the services they were provided.

Dementia self-awareness and internalization of stigma appeared to affect the interpretation of care provided, and how expectations of care were created, influencing how a person with dementia seeks and receives medical assistance. Interestingly, the internalization of age stereotypes are thought to blame for strategies such as being willing to wait for care, putting others needs first, and being the least demanding for instance (Levy & Banaji, 2002). These have also been strategies identified by the participants, where they let others go first and identify their problems as less important which also demonstrates reinforcement in negative stereotypes (Levy and Banaji, 2002). Ritsher and Phelan (2004) argued that internalization of stigma is the most psychologically damaging characteristic of stigma affecting self-esteem, well-being and state of mind, which may partially explain how participant's interpreted their experiences.

5.2.4 Interpreting and Coping - "I didn't find any stigma at all, no, no not at all" **[Sherri]**

The participants appeared to interpret stigma in a variety of ways demonstrated in their responses to being stigmatized. Interpretations ranged from stigma being described as irrelevant and absent from care, to describing discrimination in their experiences. Most participants did not talk about stigma directly, but provided examples of their experiences where they perceived different treatment. Although participants did not describe their experiences in a way that was captured as ‘stigmatization’ per se, they provided responses that indicated how they make their own meaning to their interactions and the presence of stigma.

Detected across all themes were the coping mechanisms that participants used, whether knowingly or subconsciously, to the stigma that they were faced with. The participants in this study learned to cope by employing a variety of strategies such as accommodation, acceptance and rationalization of inadequate care, as well as reduced expectations of care. Some of the participants did not recognize that dementia stigma may be a reason for their treatment. Similar to the findings of Legace et al. (2012), where their participants described legitimizing ageist treatment, the participants in this study, in addition to legitimizing the treatment they received, did not frame it through assumptions of ageism or stigma related to dementia.

Legace et al. (2012) pointed out that internalization of stereotypes into an individual’s identity is a subtle, yet likely impact, and when individuals believe the stigma is part of their reality, their actions or behaviour can confirm and reinforce such stereotypes (Whitbourne & Sneed, 2002). Findings by Legace et al. (2012) suggest that older people employ coping strategies that include accommodation in response to ageism that is also more indirect and subtle. Although the participants in their study did not provide explicit reasons for what they did, they appeared to cope with ageism by accommodating their health care provider rather than challenging them by expressing their own thoughts or needs in an interaction that was infused with ageist stereotyping. In addition, Whitbourne and Sneed (2002) further suggested that individuals who are being stigmatized based on their age may not engage in counteractive strategies representing a self-fulfilling prophecy and their inaction serves to strengthen those stereotypes. Although the participants in this study demonstrated the notion of a self-fulfilling prophecy to some degree in terms of ageism, there were also participants who described their resistance to the ageist treatment they received. These same participants however, did not confront the staff involved in the interaction, which I argue is a result of the combined effects of status loss due to stigmatization coupled with experiencing an acute illness. Becoming ill and being ill are also causes of uncertainty for individuals and those who are close to them, which affects strategies of coping to deal with an upheaval in one's health (Pierret, 2003).

Legace's study revealed that individuals used humour, avoidance of difficult interactions, and engaged in accommodative behaviours more often than engaging in confrontation when they felt stigmatized. They chose not to confront their care providers in incidents when they were made to wait for care or to ensure that their rights were respected similar to the participants in this study. Furthermore, Legace suggests that lack of confrontational strategies may explain how individuals have integrated negative stereotypes into their identity where they demonstrate feeling less valued by putting others needs before their own, being satisfied to wait for care, and showing very little demand for their needs. This behaviour also paradoxically reinforces further ageist attitudes and behaviours.

In the study by Levy and Banaji (2002), participants described greater use of accommodation strategies as opposed to using confrontation, which is quite similar to some of the participants in my study. Accommodation was also found by Levy and Banaji (2002) as the option of choice over confrontation as engaging in confrontation threatens critical social ties. In this study, the accommodation that occurred can also be viewed as response to fear of interfering with a relationship with a health care provider who holds a crucial position in the delivery of comfort, care, and healing.

The storied accounts reveal that although the participants consciously attempted to disregard stigma, attitudes, prejudice, and discrimination were still present and posed significant influence on care provided as well as the hospital experience. Since there were only few direct, named accounts of stigma reported by the participants, it may be considered that participants imposed strategies to either accommodate or employ overly positive self-evaluations, which being characteristic of normal human thoughts, promotes positive mental health. Both social and cognitive processing filters information in a positive light where negative information is isolated and perceived in the least threatening manner as possible (Taylor & Brown, 1988). People with Alzheimer’s disease have also previously reported higher degrees of affirmative reaction from others rather than negative emotion (Werner & Davidson, 2004). Although there may be few experiences of stigma reported, the patient experience through the acute care environment by all accounts, was clearly shaped by ageism and dementia stigma.

5.3 Hermeneutic Phenomenology, Dementia, and the Sick Role

It is important to consider that the participants in this study were all experiencing serious, acute health problems and I suggest that the identities of these individuals, being older, living with dementia, and experiencing an acute illness, or assuming a sick role, create multiple intersecting identities that impacts individual experiences related to the acute care experience as shown in figure 2. To assist in deconstructing these experiences, and to develop the potential emergent framework around these intersecting identities, I will extend the exploration through a phenomenological lens to further understand the perception and role of stigma.

The findings from this study articulate a variety of important concepts related to how the concurrent presence of age, dementia and illness may impact individual experiences related to the acute care experience. Findings identify concepts that are mirrored in relationality, corporality, spatiality, and temporality. As used in this study, hermeneutic phenomenology revealed understanding of the lived experience of stigma that closely examined the lived space of the hospital environment (spatiality), the lived body or physical care (corporality), the lived time in their experience (temporality), and how healthcare relationships exist through interactions that contribute to influencing and shaping individual experiences (relationality). These four structures sensitize others to the stigma through multiple dimensions where layers of stigma become larger with multiple and intersecting identities.

5.3.1 Relationality

The illness experience is influenced by multiple factors and how meaning in this experience is shaped, and how it impacts the sense of self, relies heavily upon the reaction of others (MacRae, 2011). Relationships, including the interactions between people are strong conveyances for stigmatic messages. The relational aspect in the hospital environments studied here was key in the development and interpretation of the hospital experience. Sabat (2001) argues that negative treatment by others contributes to amplifying the disability of those with Alzheimer's disease. Sabat further suggests that positioning of a person can lead to behaviour consistent with expectations. In this case, not only is there positioning within the relationships with identities attached to being old and having dementia, but also included is the position of sickness. These attributes become central to the social interaction as it is how others make judgment as to the identity of that individual (Karp et al., 2004, p.56). Interestingly, participants' experiences included both positive reactions, such as patience and genuine compassion, and negative reactions such as avoidance for example, in their relationships with their health care providers. Perhaps health care providers' sense of duty to provide compassionate care conflicts with the norms of stigmatizing older people with dementia and the structural constraints within the acute care environment. Situating the health care relationships in this way provides some clarity to understanding stigma in the participants' experiences.

5.3.2 Corporality

Corporality, or the lived body, helps to identify and understand the role that the sick body and the physical care of the body plays in the experiences of the acute care environment. The sense of self, and consequently how an individual makes sense of his surroundings, is not only located in the mind but also exists within the body (Kontos, 2003). As the majority of participants in this study were experiencing serious health concerns that necessitated their hospital stay, their delicate physical condition likely also contributed to how they perceived and interpreted the care they received. Managing pain, discomfort and the embodiment of care are physical aspects of how the body is intertwined with the social relationships in care. Constructing the illness experience includes the visibility of the symptoms or illness, the perceived severity and the extent to which it interferes with the person's life (Mechanic, 1978). The physical symptoms of illness can be all consuming and shape how a patient interprets care by knowing when their needs have been met. Pathologizing the body in physical care connects the body experience mainly to illness or disease specifically, rather than fully comprehending the lived embodied experience, resulting in further marginalization (Wiersma, 2007). The body would also be the physical manifestation of stigma where being treated differently in the physical sense could contribute perceptions of stigma. The nature of the hospital institution, and predominantly within acute care, viewing patients as a set of symptoms rather than a whole person is an approach that puts people with dementia at a clear disadvantage. (Webster, 2011)

When physical needs are not met, it contributes to how care is perceived. As some of the participants in this study talked about inadequate care, how they conceptualized this may be through their understanding of the care for the body, and when their physical needs were not met, it contributed to how care was perceived.

5.3.3 Spatiality

What is important to discuss is the connection between body and place, as place is the experiential world that is mediated through the body (Gieryn, 2000). The embodiment of the hospital environment consists of more than just the physical structure. It incorporates conscious and subconscious degrees of physical senses, associations with admission and discharge, expertise in specializations and staffing, patient care decisions, institutional management etc., which are all contributing constructs in experiencing place as social, cultural and quasi-material. The emergency department and its specific culture, for example, includes observable structure and arrangement, shared values and beliefs, and underlying assumptions that are present in the physical structure, design and organization of its department which impacts care of older individuals (Skar, Bruce & Sheets, 2015). Place lies between relationships and the greater structure of stigma as place also defines social relations (Dixon & Durrheim, 2000). Being ill and in the patient role varies depending on place.

The hospital institution, which provides treatment and healing, is the container in which experiences take place. For the participants in this study, they often referenced the hospital as ‘not the right place for a person with dementia’ connecting place and negative experiences together. Specific structures or features of the hospital, such as the waiting area, or being on a stretcher in emergency for example, can also affect how care is interpreted (Gesler, 1999). Perceptions of the hospital, as an acute care facility, are also likely to have been influenced, to some degree by the participant’s relationships with their health care providers within that environment. As these relationships were infused with age and dementia stigma, this can be incorporated into the meaning of the physical structure also being viewed as stigmatic. Legace

(2012) found that there was a significant association between ageism and resident's perceptions of the long term care residence in which they lived, as a physical assembly that disturbs their identities. Knowledge and beliefs can be based on cultural representations current in specific places and times (Pile and Thrift, 1995). The perception of the hospital place being unresponsive to the needs of people with dementia, underpins how individuals in this study experienced stigma within this specific setting.

5.3.4 Temporality

Integral to space is time as they are both, although not necessarily together, connected to forming the basis of hospital experience. Time, which is most often referred to, and understood as chronological or linear, neglects subjective and experiential dimensions of time (Baars, 2007; Wiersma, 2012). Temporality, or lived time is highly significant to an individual who is experiencing pain and suffering as a result of an illness or disease. The passage of time became embodied, or embedded, in the body (Wiersma, 2012). For the participants in this study, the lived time was often organized by the hospital environment. Although time is normally structured by the institutional culture of 'time and task' (Henderson, 1995), there are competing pressures between time related tasks and quality care being provided (Waterworth, 2003). The physical care of the body was reported as rushed as health care providers had limited time to provide care. In the emergency department particularly, older patients with complex issues did not fit with the speed at which priorities were set in the high-pressured culture, and the time required to solve challenging presentations was not always available (Taylor, Rush & Robinson, 2015). The participants themselves were also different from other patients as their presentation included slower speech, slower movement, and slower thought processes which conflicted with the need for rapid accomplishments within the hospital environment (Taylor, Rush & Robinson, 2015). Lack of time was also recognized by Webster (2011) as a major obstacle in not being able to commit to care that is person-centered, which would disregard dementia in a person's care. 'Good nursing care' for older patients was described by nurses as meeting physical, social and psychological needs on time (Bulut et al. 2015). Time, however, has been described as a 'commodity' in health care environments (Henderson, 1995). Although people who are unwell may not have an accurate concept of time, treatment course and consequence (Brannon & Feist, 2010), it is an important part of their care experience. Lived time also incorporates an individual's past, present and future that are also constructed with a person's temporal landscape (van Manen, 2011). This would include previous experiences of stigma influencing what is perceived in the present experience. Experiencing an illness, whether chronic or acute, is a course of ongoing adaptation and meanings that can also shift with time (Charmaz, 1991).

Understanding the unfolding of the experience of the participants is supported by the four structures of hermeneutic phenomenology. This theoretical perspective is developed through further understanding, and being sensitized to the experience of stigma through the lens of the body, place, relationality, and time that are intertwined. We must also consider the identities of age and dementia, and include in the intersection the identity of being ill, along with the multiple dimensions of stigma that all contribute to creating different experiences related to marginalization. As the illness experience, along with dementia and age stigma are socially constructed, their experiences do not just exist waiting to be discovered, but are created by how they participate in and toward their domain which bestows it with meaning (Conrad & Barker, 2010).

5.4 Limitations

In considering the implications of this study, it is important to keep in mind its possible limitations. Stigma is very difficult to detect and define. Components of stigma are also often vague yet are labelled to assist in understanding. It may be considered that the language commonly related to stigma, and used here to describe the essence of experiences of the participants, may be overly powerful and constricting in contributing to how experiences are understood as stigma.

This study is limited in that it lacks voices that reflect the diversity of the lived experience of individuals in an acute care environment. As the participants in this study included only older adults, the perspectives of younger individuals living with early onset dementia were not included. Expanding the research to include this group may have provided insight into dissecting ageism and stigma related to dementia, which this study was unable to provide. This study is also limited in that the sample primarily consists of men with dementia and spouses as care partners which is disproportionate to the higher prevalence of dementia in women and may also not clearly reflect the caregiving circumstances of others living with dementia which should be taken into consideration.

Reflecting on the motivation of those who provided their stories to this research where they felt it was their duty to speak of behalf of others that would otherwise be denied their contribution. It should be reiterated that the participants in this study were individuals who were very energetic, functional, and socially involved indicating that these participants shared a perspective more exclusive to those who may be more inclined involvement in their activities and surroundings in comparison to others. Arguably, the experiences discussed in this research are also shared mainly by those who are motivated to help others. Additionally, one could suggest that the type of participants in this study are those that may diminish, or even reject the notion of stigma which is evident in that it was seldom commented on, and only eluded to in their descriptions, but which could perhaps resonate with the experiences of others receiving care.

The findings of this study are also not limited to only those living with dementia as there were both people living with dementia as well as their care partners who participated. It is not possible to dissect and explore specifically how either group experienced stigma and that the findings can only reflect on a shared construction and interpretation of the lived experience. This study may have benefitted from an additional question developed to obtain a better understanding of the participant's knowledge and attitudes regarding stigma, or more specifically, stigma related to dementia.

In addition, these findings cannot be made beyond the participants and context of this study. Assumptions, or inferences to other situations may be possible as Lincoln and Guba (1985) suggest provided that there is an evident degree of similarity between the research context and the context of comparison which requires thick description and ample detail for context appraisal. Lincoln and Guba (1985) further propose that dependability in qualitative research involves using larger amounts of data to achieve saturation, spending more time with the participants with multiple interviews, and triangulating data. As this study did not integrate these methods the findings may also be viewed as slightly deficient in dependability.

Another conceivable limitation is the influence that my own experiences and beliefs have on the interpretation of the research. In particular, I chose this topic of investigation to study as I had a great deal of experience, and frustration, regarding the care older people received in the hospital, particularly when they had any difficulty expressing their needs. Being aware of my own background and preconceptions however, increased my sensitivity to ensure that I was present for the participants with an open mind, and I was attentive to how I might influence the participants or research position. Reflexivity allowed me to understand that meanings are produced not only through the participant's social, cultural and relational contexts, but how the research process also plays a role in interactive meaning-making.

5.5 Implications for practice

One of the main goals in this research was to address the limited research into the experiences of people with dementia in the acute care environment, with special attention to the role that stigma played within those experiences. Additional purposes of this study are to contribute in two dimensions. One is to further understanding of the experiences of people with dementia specifically within the hospital care context and secondly, to build on this knowledge to identify practical applications of the research to develop new approaches and new solutions in response to the current dilemma of dementia care in complex acute care environments.

The findings of this study point to hospital practices that may not address the needs of people with dementia accessing care and that misconceptions about both aging and dementia shape care experiences. Accordingly, the first major practical contribution of the present research is to provide hospital administration an insight and awareness of how people with dementia experience hospital care, and the opportunity to reflect on their experiences in the application of this knowledge in future policy development. A second important practice implication of this study originated from the relationships described in the findings and is to heighten the level of attentiveness of health care providers to the presence of the multiple and intersecting identities that lead to stigma. Approach and communication strategies with older people, and particularly those with dementia, require additional sensitivity, patience, and person-centered care. A third implication stems from the need to provide recognition, and acceptance, that people who are most familiar with the person with dementia—the care partners--can play a key role in supporting their well-being while in hospital since they are most knowledgeable and familiar to the individual receiving care. In their absence, expanding the circles of support for a person with dementia through designated staff should be considered a priority in assisting a person with dementia in their time of illness. Finally, this study provides implications geared toward the user groups, including people living with dementia as well as care partners in that it provides others with dementia and their care partners understanding of the current care system and provides direction and assistance to seeking care.

Although these findings do not provide the tools to support and foster change in a system of care, they help to illuminate the areas of need and provide guidance reflective of the perspective of people with dementia. Further, the intent, and relevance of this research, was to inform and stimulate the involvement of organizations, practitioners, advocates and user groups in improving the culture of dementia care.

The evidence and knowledge from the experiences of people with dementia is set distinctively apart from the knowledge that currently guides healthcare and can be a valuable information source and incite change in the progress of dementia care. Ultimately, the involvement of people with dementia and their care partners should be at all levels of the development of hospital care plans to ensure that services meet the needs that they feel most important.

5.6 Implications for future research

Although this study explored the experiences of a small number of participants, it presents an alternative perspective on the experiences of people with dementia in the acute care context. Further research should continue to explore the experiences of people with dementia in acute care environments, exploring differences between different areas of acute care (e.g., emergency department, medical units), and exploring differences between the perspectives of people with dementia and care partners. Recognizing that there are wide variations in care provincially, federally and globally, further research similar to this study would be highly useful in building a breadth of understanding from within different hospital organizational structures. This would help to elaborate on the novel findings here with further exploration and interpretation, and may identify alternative solutions.

Additionally, this study provides findings that broadly examined the environment, overarching management systems, care practices and relationships with health care providers. Other opportunities for future investigation would be to delve more deeply into each area individually and how each of these factors influences the care experiences of people with dementia. As the evidence in this study points to the negative influence of stigma in health care relationships, further research may be extended to exploring relationships specifically in greater depth to unpack how stigma is constructed within those interactions.

Lastly, additional research is necessary to elaborate on the influence of age and dementia related stereotyping, prejudice and discrimination on hospital policy and to explore the development and implementation of approaches in dementia care.

This study provides some further insight into the concept of stigma within the health care context. However, further research is necessary to explore the ways in which people with dementia and care partners understand and contextualize stigma, and offers the opportunity to further refine the concept of stigma in context. Further work is necessary to shed light on how knowledge can be effectively circulated and exchanged within these particular groups in order to change the path of care for people with dementia.

5.7 Conclusions

Although this data is from a very small sample, it suggests that current conceptualizations of stigma, whether age or dementia related, is poorly recognized and understood by the acute health care team. The insufficient understanding of stigma has implications in how older individuals living with dementia are commonly treated in the hospital environment. This study sought to explore the hospital experiences of people living with dementia and if and how stigma was present in these experiences. Aspects of stigma related to age and dementia has been shown to exist in the hospital environments in this study, and further reveals that illness can be a catalyst for individuals to experience further exacerbation of stigmatization. The themes that emerged from this study indicate that stigma can be felt as influential in policy development, practices, and care provided for both those living with dementia as well as their care partners. It also brings into question the level of importance of care partners and their involvement in the hospital care experience.

This research begins to address a significant gap in the literature where there has been limited involvement and contributions from those living with dementia. The stories and experiences shared here are conduits to creating a better understanding of the unique experiences of people living with dementia in the acute care environment. It is hopeful that the insights gained from the experiences shared by the participants in this research will gain the much needed attention to facilitate the process of change in the approach to care within the acute care system for people with dementia, recognizing that there is more that we need to yet understand about these experiences.

The findings of this research also bring attention to an additional factor including bed shortages, lengthy wait times, and delayed placement into long-term facilities within the hospital areas focussed on in this study. Shortages in long-term care beds and chronic hospital overcrowding currently exist in many Ontario hospitals. With the increased time spent in overstressed hospitals, increasing understanding of the experiences of people with dementia while in hospital can contribute to improving care in many ways. Since the abundance of previous research focused on experiences in long-term care facilities from the perspective of health care providers, the value of gaining an understanding of care treatment directly from those receiving care, along with focus specifically on the hospital environment, could not be more timely in adding knowledge toward possible solutions. I believe that this research opens opportunity for others to explore more purposefully stigma and its effects in specific environments.

In sum, this study has allowed for a more in-depth understanding of stigma related to dementia in the context the acute care environment. Stigma shapes people's experiences in various ways, even when people may not name these experiences directly as stigma. Understanding the ways in which stigma may shape experiences and care interactions can provide more opportunities to change these interactions. *"The timing is really critical now to get people on board and get their thinking changed" [Samantha]*

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Appendix A Information and Consent Form

Dear Potential Participant,

Thank you for considering participating in this research project titled "Stigma & Experiences of People with Dementia in Acute Care Environments". This research seeks to contribute to better understanding the acute care environment, and the influence that stigma may have, from the perspectives and experiences of people with dementia and their care partners.

This information and consent form will provide you with:

- Information about your involvement in the research project
- How the research information is gathered, recorded, stored and utilized while protecting the confidentiality of all participants.
- How information is shared while protecting the confidentiality of all participants.

Research Purpose:

The proposed research will seek to better understand and learn about the experiences of people with dementia and their care partners in acute care environments.

Discussion will involve questions related to:

- Your perceptions about the care you received.
- Your interactions with health care staff.
- What factors contributed to supporting your care and facilitating your recovery.
- How you feel having dementia was perceived.

The interview will take approximately 1-1.5 hours and will be audio recorded. I can either talk with you over the phone or we can meet at a place that is comfortable for you. No one else with be at the interview unless you would like them to be.

Your participation is voluntary and you may decline to answer any questions that you do not feel comfortable in answering or you may withdraw completely, at any time, without consequence to your rights, associations, or services you receive from the Alzheimer's Association now, or in the future. If you choose to withdraw during the focus group discussion, the researcher will be unable to withdraw your information from the information generated from the group discussion.

I am aware that you will be sharing personal and confidential information that you might feel uncomfortable talking about and you do not have to give any reason if you choose to not answer any questions or would like to discontinue the interview.

Your information is confidential as any discussion, audio recording, documentation or reports generated from this research will not contain names, or any other identifying information, of anyone participating. Your identity will be kept entirely confidential. Consent forms will be kept separately from electronic notes and all information will be kept in a secure location.

If you participate in a focus group, we will ask you and others in the group to keep in confidence any identifying information of other participants. We cannot however, prevent participants in the group from sharing information.

The information you contribute to this research will be beneficial by increasing awareness and understanding of the experiences of people with dementia within an acute care environment. Your contributions to this research can help to direct and improve health care for people with dementia and their families in the future.

You will receive a summary of the results by September, 2014. Findings will also be presented at the Alzheimer Society of Thunder Bay and the date/time will be announced. The findings will also be available at Lakehead University for anyone else interested to learn about our study.

If you have any further **questions** or **concerns**, please contact:

Shannon Ferguson

Master of Health Sciences Candidate

Lakehead University

(807) 627-5648

My Consent to participate:

- I have read (or it has been read to me) the information letter provided by Shannon Ferguson describing the purpose of the study.
- I understand the information in the study cover letter.
- I understand that my involvement includes an interview and an additional focus group discussion with others.
- I know that my participation is voluntary and I am free to choose to end my participation at any time without consequence.
- I am aware that all of my information and contributions will be kept confidential
- I have been given opportunity to ask questions and any questions I have asked have been answered to my satisfaction.

I________________________________ consent to participate in the research titled “The Experiences of People with Dementia in an Acute Care Environment”

Name____

Signature____

Date____

Signature of Researcher_______________________________

Appendix B Interview Questions

The interview questions are as follows:

1) Tell me a little bit about yourself.

2) Tell me a little bit about your dementia journey.

3) As you know, we are examining the experiences of people living with dementia/memory loss in acute care environments such as hospitals. Can you tell me a little bit about your experiences in the hospital?

4) Can you tell me about the reasons that caused you to require acute care hospital services?

5) What were your initial thoughts and feelings when you came to the hospital?

6) Tell me about the care you received. How do you feel about the care you received?

7) What are the factors that contributed to supporting and caring for you while you were hospitalized?

8) Tell me a little bit about your interactions with the staff. How would you describe your relationship with staff?

9) How do you feel that people with dementia are perceived by health care staff?

10) What do you feel matters the most in your hospital care?

11) How did you feel about the hospital environment?

12) How do you feel about your involvement in the decisions related to your care?

13) If you could change anything about your experiences in acute care, what would you change? What would you keep the same?

14) What advice would you give to the acute care facility to ensure that the best care is provided to people living with dementia?

15) Is there anything you would like to add about your experiences?

16) Do you have any questions?

Figure 1. Key Themes Identified in Findings

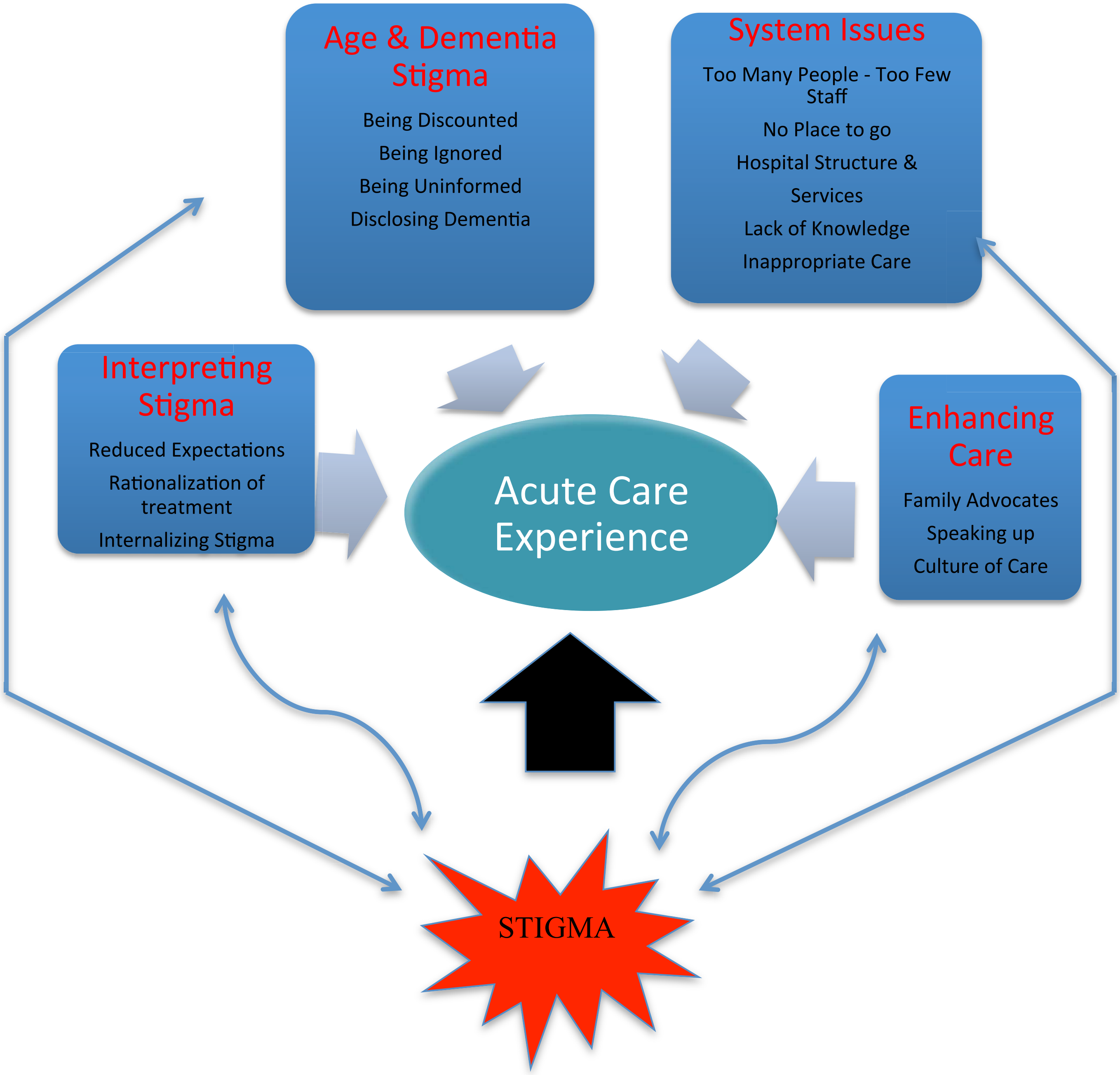

Figure 2. Phenomenology