

The Lived Experience of Dignity in Older Adults Living With Schizophrenia:

A Phenomenological Study

Darlene Robison

University of Prince Edward Island

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Abstract

There is a lack of nursing literature on the older adults' perceptions of dignity, and in particular those older adults living with schizophrenia. When older adults experience a lack of dignity, their sense of value is weakened and they are more likely to feel like a burden to others which can lead them to question their existence. With the aging of our population, mental health services and support for older individuals with schizophrenia will become a greater priority to ensure that they reach their optimal level of psychosocial functioning while maintaining human dignity and self-worth. The purpose of this phenomenological study is to describe the meaning of the lived experience of dignity for older adults with schizophrenia who reside in licensed community care facilities. A purposive sample of 8 older adults, aged 60 years and older living with schizophrenia and residing in licensed community care facilities, volunteered to describe their experience with dignity. Using a semi-structured interview guide and following Giorgi's (2009, 2012) phenomenological psychological method, all interviews were digitally recorded and transcribed. Over 500 large meaning units and 200 small meaning units were found and clustered into five essences or as Giorgi (2009, 2012) refers to as constituents. *Dignity is intrinsic, extrinsic and reciprocal. It is embedded in social relationships; can be eroded by ageism, stigma, discrimination, and alienation; is interrupted when the person is acutely ill, yet can be enhanced when the older adult and others embrace a recovery-focused relationship.* These findings have implications for mental health nursing in understanding and supporting dignity in the older adult living with schizophrenia.

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things in the world cannot be seen or even touched-they must be felt with the heart.” *Helen Keller*

CHAPTER 1

Background

Understanding the meaning of dignity can be challenging because it signifies different things to different people. However, when indignity is experienced, most people can identify dignity as that which is lacking when it is most needed (Shotton & Seedhouse, 1998). When older adults are not given the opportunities to demonstrate their capabilities, they experience a lack of respect, indignity, a weakened sense of value and worth, a burden to others and questioning of their own existence (Chochinov, 2007; Shotton & Seedhouse, 1998). Moreover, little is known about the experiences of dignity in older adults with schizophrenia. It is recognized that older persons with schizophrenia are subjected to stigma and labelling, discrimination, negative attitudes and behaviors, therapeutic nihilism, and ageist bias that can affect their self-esteem and self-worth (Collier & Sorrell, 2011; Murphy, 1998; Whitley & Campbell, 2014).

Cabness (2009) identifies that a lack of research in caring for older individuals with schizophrenia impedes their optimal level of psychosocial functioning. Having a sense of self and belonging is an essential component of quality of life, which if unfulfilled, can not only impact the course of an individual's psychiatric illness, but also undermine his/her self-esteem and psychological well-being (Depla, de Graaf, van Weeghel & Heeren, 2005; Leuterwyler, Chafetz, & Wallhagen, 2010). Cummings and McClure-Cassie (2008) recommend future studies on the effect of unmet needs on the well-being of the older adult with severe mental illness. Campbell and Sorrell (2006) and Sherrell, Anderson, and Buckwalter (1998) refer to mental health care as the most neglected area in long term facilities and suggest that the chronically ill elderly deserve to have treatment interventions tailored to their specific and individual needs.

Despite a person's age or illness, the preservation of dignity is important and is enhanced or diminished by the actions of others (Jacelon, Connelly, Brown, Proulx, & Vo, 2004).

The term dignity is derived from the Latin 'dignus,' meaning worthy (Clark, 2010; Maris, 1994) while the Oxford Canadian Dictionary defines it as the state of being worthy of respect (Barber, Fitzgerald, Howell, & Pontisso, 2005). Dignity is an abstract concept and notably there are inconsistencies in the nursing literature in relation to definitions of the concept (Clark, 2010; Griffin-Heslin, 2005; Haddock, 1996; Jacobson, 2007; Maris, 1994; Milton, 2008). In nursing, dignity has been referred to as a concept that describes a quality of being worthy, honored, or esteemed; whereas professional ethical codes compare the term to words such as respect, worth, integrity, uniqueness, and human rights (Milton, 2008). The term dignity is not always mentioned in the nursing literature, nonetheless is alluded to by using words such as discrimination, negative beliefs, negative attitudes, therapeutic nihilism, and ageist bias when caring for older adults with schizophrenia (Collier & Sorrell, 2011). Dignity is foundational to nursing ethics and supports the concept of autonomy but also intertwines the principles of beneficence, non-maleficence, and justice (Beauchamp & Childress, 2008). In summary, the literature views dignity as a state of physical, emotional, and spiritual comfort for every human being and believes that each individual is unique and deserves to be seen, heard, and understood, while maintaining self-respect and self-esteem (Fenton & Mitchell, 2002; Jacelon et al. 2004; Lindwall, Boussard, Kulzer, & Wigerblad, 2012; Maris, 1994).

Schizophrenia is defined as a mental disorder that is characterized by positive symptoms that include the active presence of delusions and hallucinations; and negative symptoms that refer to a loss of emotion, speech, or motivation (American Psychiatric Association, 2013). The prevalence of schizophrenia in the general population is approximately 1%, and the estimated

number of Canadians diagnosed with schizophrenia between age 60 and 90, is approximately 67,891 (Library of Parliament, 2011). With people living longer, this number is expected to double during the next 20 years (Cohen, Pathak, Ramirez, & Vahia, 2009; Cohen et al. 2008; Collier & Sorrell, 2011; Dixon, 2008), and mental health services and supports for older individuals will become a greater priority (Canadian Mental Health Association, 2007; Library of Parliament, 2011).

Approximately 85% of middle aged persons with schizophrenia were diagnosed in late adolescence or young adulthood; and are known to have ‘late life’ schizophrenia (Folsom et al., 2006), whereas all cases diagnosed after age 45 are known as ‘late onset’ schizophrenia and account for 15-20% of all cases. Cohen et al. (2008) identify another group known as ‘very-late-onset schizophrenia–like psychosis’ for individuals diagnosed after age 60. It has been argued that individuals with schizophrenia age more quickly and have a lifespan that is between 9-25 years shorter than someone without a severe and persistent mental illness, and experience a high prevalence of comorbid conditions (Leutwyler et al., 2010). Individuals over age 55 with schizophrenia are more likely to be diagnosed with multiple medical problems (e.g., cardiovascular disease, chronic obstructive pulmonary disease, gastrointestinal disease, liver disease, diabetes, and skin infections), compared to younger individuals with schizophrenia (Leutwyler et al., 2010). For this reason, as individuals with schizophrenia age, assisted living or long term care may be required.

Approximately 20% of all individuals diagnosed with schizophrenia reside in assisted living that provides supervised housing (Torrey, 2006). Prince Edward Island (PEI) leads the country with 9.2 % of the aging population living in either long term care or assisted living, also known as licensed community care facilities [LCCF] (PEI Department of Health, 2009). LCCFs

in PEI are licensed private establishments that offer services such as accommodations, housekeeping, supervision of the activities of daily living, meals, and personal care assistance in grooming and hygiene (Statistics Canada, 2011). There are presently 42 LCCFs in PEI with 22 of the facilities providing supervised housing to individuals with mental illness (Statistics Canada, 2011). For some, the experience of having schizophrenia and residing in assisted living can cause problems of stigmatization, loneliness, and negative attitudes that devalue the individual's dignity and autonomy (Granerud & Severinsson, 2003).

Literature that describes the life experiences or examines the outcomes in late life for individuals with schizophrenia is limited (Cohen et al., 2009; Collier & Sorrell, 2011). Presently, there is a lack of nursing research that examines the unique experience of dignity for this population, which creates an ethical challenge for nurses in recognizing the importance of preserving the dignity of the individuals and thus their intrinsic worth (Canadian Nurses Association [CNA], 2008). When caring for a person, it is important for nurses to examine attitudes and presuppositions towards the client and realize that perceptions may not reflect the client's reality (Chochinov, 2007). It is also pertinent for nurses to take into account the client's values and beliefs when making healthcare decisions and teach the importance of intervening and reporting when the dignity of a client is not being met.

Purpose

The purpose of this study is to explore the lived experience of dignity among older adults with schizophrenia.

Research Question

I sought to know, what are the essential elements of the lived experience as verbalized by the older adult living with schizophrenia and who resides in a LCCF? The following question guided me in understanding and describing the older person's experience with dignity when living with schizophrenia. What is the lived experience of dignity for the older adult with schizophrenia living in a LCCF?

Significance and Originality

Nurses must understand the meaning of dignity and know how to protect the client from experiencing indignity. Due to a lack of evidence and understanding regarding the lived experience of schizophrenia in the older adult, negative assumptions may be made by health care professionals that can lead to discrimination, indignity, and ageist bias (Collier & Sorrell, 2011). It is important that nurses reflect on their own perspectives and how these can affect their practice and ethical decision making, when caring for older adults with schizophrenia (Granerud & Severinsson, 2003) and regardless of the age or the illness, nurses have a professional obligation to ensure that all individuals in their care are treated equally and that their uniqueness and dignity are respected (Fenton & Mitchell, 2002).

Research has indicated that maintaining dignity of the individual is important, however, it is questionable whether this concept is the same for each person (Lin & Tsai, 2011; Maris, 1994). The literature has stressed the importance of health care professionals to preserve the client's dignity (Walsh & Kowanko, 2002), but the majority of nursing studies have focused on the importance and the professional duty of nurses to preserve and respect dignity of clients in acute hospital settings (Baille, 2009; Lin & Tsai, 2011; Matiti, Cotrel-Gibbons, & Teasdale, 2007; Reid, 2012). There are some studies on the older adult's perceived idea of dignity

(Woolhead, Calnaan, Dieppe, & Tadd, 2004). However, most of this literature has focused on the healthcare professionals' identification of factors essential to providing dignified care to the older client (Arino-Blasco, Tadd, & Boix-Ferrer, 2005; Bruton, 2012; Chochinov et al., 2002; Fenton & Mitchell, 2002). The literature is insufficient regarding the experiences of dignity for older adults with schizophrenia and almost non-existent for older adults with schizophrenia living in LCCFs. And researchers recognize that more research related to older adults with schizophrenia and their unique experiences is needed (Collier & Sorrell, 2011).

Phenomenological Perspective

In this study, I proposed to uncover and gain a deeper understanding of the meaning of dignity for older adults aged 60 years and older living with schizophrenia and residing in a community care setting on PEI. Most Canadian statistics describe an older adult as someone age 65 and older, whereas the United Nations uses the cut-off at age 60 (Touhy, Jet, Boscart, & McCleary, 2012). This research could help nurses preserve the dignity of older adults living with schizophrenia, while assisting nurses in developing the skills to care for this population. It also will allow nurses to examine their personal attitudes and assumptions towards older adults with schizophrenia. By interviewing older individuals with schizophrenia and allowing them to reflect on their experiences with dignity and analyzing the data using Giorgi's (2009, 2012) phenomenological psychological method, I attained a better understanding of the lived experience of this population. Giorgi's phenomenological psychological method aims to discover the meaning of a phenomenon, as experienced by a human through the identification of essential constituents (Koivisto, Janhonen, & Vaisanenm, 2002), which fits well with phenomena that are of concern to psychiatric-mental health nurses (McInnis & White, 2001). Using Giorgi's

approach gives a voice to individuals who need to be heard (Cohen, Kahn, & Steeves, 2000); in this case for older adults with schizophrenia.

Summary

Dignity is a complex concept and poorly understood in older adults living with schizophrenia. In this chapter, I have provided relevant background information and highlighted the significance of the current research study on the phenomena of dignity and older adults living with schizophrenia. I have also outlined how my study can uncover and gain a deeper understanding of the meaning of dignity for older adults living with schizophrenia who reside in LCCF's, by using Giorgi's phenomenological psychological method. Furthermore, I believe that the findings of this study are relevant for nurses in understanding the concept of dignity when they are caring for individuals living with schizophrenia.

CHAPTER 2

Review of Literature and Nursing Perspective

The purpose of this study was to describe the lived experience of dignity in the older adult who lives with schizophrenia and resides in a LCCF. In order to understand this lived experience of dignity, it is important to provide a background of the research and related literature on the phenomena of dignity, specifically in the older person living with schizophrenia. When exploring the research on the lived experience of dignity among older persons with schizophrenia, studies were reviewed to primarily understand the definition of dignity by exploring dignity in intrinsic and extrinsic terms, dignity as other-regarding and as self-regarding values, the values of absolute and relative dignity, to learn about the importance of dignity when growing old, to comprehend the older adult's perspective of dignity, to explore the meaning of dignity for the older adult with schizophrenia, to understand the effect of stigma and labelling on dignity for the older adult living with schizophrenia, and lastly, to emphasize the importance of nurses to understand the relevance of preserving the dignity of individuals with schizophrenia

I have divided this chapter into eight sections which are: (a) an overview of the commonly known definitions and dimensions of dignity; (b) dignity and the older adult; (c) an overview of dignity and the older adult living with schizophrenia; (d) older adults with schizophrenia residing in licensed community care settings; (e) the effect of stigma and dignity for the older adult with schizophrenia; (f) nursing care and older adults with schizophrenia; (g) nursing perspective and philosophical assumptions; and (h) summary of the literature reviewed.

Definitions and Dimensions of Dignity

Defining dignity is challenging, as it is a highly abstract and subjective concept that is difficult to measure (Baillie, 2009; Fenton & Mitchell, 2002; Griffin-Heslin, 2005; Haddock, 1996; Milton, 2008). The term 'dignity', although studied by many, (Backer-Condon & Hegge, 2011; Clark, 2010; Edlund, Lindwall, von Post, & Lindstrom, 2013; Gallagher, 2004; Griffin-Heslin, 2005; Haddock, 1996; Jacobson, 2007; Maris, 1994; Milton, 2008; Nordenfelt, 2004; Periyakoil, Noda, & Kraemer, 2010; Sulsmasy, 2013) still lacks a consistent agreed upon definition. Maris (1994) recognized the importance of maintaining dignity however, the concept meant something different to each person. To complete a concept analysis of dignity, Maris sought student nurses' understanding of dignity by interviewing 20 nursing students about their perception of dignity. Results indicated that nursing students perceived dignity to consist of respect, self, personal, privacy, feelings, individual, rights, beliefs, behavior, needs, esteem, embarrassment, pride, poise, and standards; which were further categorized into three critical attributes: maintenance of self-respect, maintenance of self-esteem, and appreciation of individual standards. The research described dignity as the capability of making choice and having control over decisions, that dignity was acquired through life experiences, and that dignity was a personal possession which was given little consideration unless an individual became vulnerable or could anticipate its loss. Future research in concept clarification of dignity was recommended.

Haddock (1996) used a concept analysis to further define dignity. Her research identified dignity as both a subjective and a shared belief among humanity, and that the effect of dignity within oneself affected the ability to maintain or promote the dignity of another. Dignity was viewed as an ability to feel important and valuable in relation to others, to communicate this to

others, and to be treated as such by others. For nursing, this study identified future concerns such as the importance of self-awareness, consideration of countertransference, the use of appropriate and thorough assessment of patients, and a deeper understanding of cultural values and meanings. Haddock (1996) further described the power that nurses had to maintain and promote dignity, by using themselves to understand patients and to treat them as valid, worthy, and important at a time when they were vulnerable. The researcher suggested further research on dignity, indignity, power in relationships, and patient empowerment. Griffin-Heslin (2005) also used a concept analysis to help define dignity, which further supports the work of Haddock by identifying dignity as a fundamental provision to effective nursing care, and the importance of respect, autonomy, empowerment, and communication as attributes of dignity. Furthermore, Griffin-Heslin (2005) expanded our understanding of dignity by highlighting that dignity is a complex concept with various attributes which can be portrayed in several ways. The researchers recommended using a conceptual framework as a way to increase knowledge, understanding, and to maintain dignity.

Gallagher (2004) described dignity as both a subjective and an objective concept where individual differences were taken into account in the former and human rights were taken into consideration in the latter. The researcher also considered that dignity had two key values known as: 'other- regarding', or respect for the dignity of others, and 'self-regarding', that encompassed respect of one's personal and professional dignity. Although these two values can be linked, the researcher recognized how there could be an imbalance of nurses and other health professionals respecting the dignity of themselves and others too much or too little and recommended that there be a comprehensive view of ethical competence that would include seeing, reflecting, knowing, doing, and being.

Clark (2010) referred to dignity as being a right, an experience, and something that could be bestowed on others, and further modified from Haddock's (1996) definition of dignity as both an objective 'right' and a subjective concept that could be experienced. The researcher described dignity as a fundamental human right with the expectation of feeling and or being regarded as important and valuable in relation to others. From this definition, a model of dignity was constructed that consisted of Gallagher's (2004) and Spiegelberg's (1970) notion of dignity having two dimensions, 'self-regarding' and 'other-regarding', and Clark (2010) also used Shotton and Seedhouse's (1998) idea that dignity had different levels, from 'dignity maintained' to 'devastating loss of dignity'. Clark concluded that the model needed to include these levels because dignity could be lost to both self-regarding and other-regarding.

Edlund's et al. (2013) study strived for a deeper comprehension of dignity by seeking out its meaning, scope, and nature by exploring the caring science knowledge of dignity and the concept of determination of dignity. An understanding of dignity was attained when these authors identified 'the values of absolute dignity'. These values represented the spiritual dimension characterized by holiness, human worth, freedom, responsibility, duty, and serving one's fellow-men; and 'relative dignity', that mirrored absolute dignity, but its values were influenced by culture and were hierarchical. While the intent was to preserve the experience of dignity, this study indicated the importance of health care professionals taking these values into consideration in order to meet the personal needs of the older person's changing attitudes, while helping the person to preserve what was important to him/her.

Nordenfelt (2004) researched a philosophical approach to the understanding of dignity and aging and identified four kinds of dignity: (a) dignity as a merit is connected to a person who holds rank and status in society and is related to rights and respect for social standing or

accomplishments. This type of dignity is unevenly distributed among human beings; (b) dignity as moral structure is dignity based on the thoughts and actions of the individual in order to maintain self-respect and can be easily reduced or lost due to immoral deeds; (c) dignity of identity is linked to the person's integrity and identity as a human being and is indicated as the most important, as this kind of dignity can be lost due to the actions of others, injury, illness, and age; (d) dignity of *menschenwurde*, a German word, referring to the human value of dignity that all humans have or are supposed to have because of being human. Given that humans are equal, this dignity should have the same value for everyone and no one should be treated with less respect than anybody else, and it cannot be taken from human beings as long as they are living.

Periyakoil, Noda, and Kraemer's (2010) study explored the provision of dignity at the end of life, by administering a survey that was used to develop a preservation of dignity card-sort tool (p-DCT) built on the themes that materialized from the data and the existing literature. The study classified dignity as: (a) everyone possessing intrinsic dignity; and (b) extrinsic dignity that remains outside the person and is influenced by the way a person is treated by others. Subthemes for intrinsic dignity included autonomy, self-respect, and spirituality; and when these themes were met, there was an experience of self-esteem and autonomy, and a sense of hope. A person encountered extrinsic dignity when physical and emotional needs were met, respect was experienced, and when privacy and confidentiality were made a priority. A proposed model for dignity was based on the survey responses that further classed extrinsic dignity into subthemes of respect and 'care-tenor', a term which describes the attitude expressed by caregivers when communicating with clients. Sulsmasy (2013) also discussed intrinsic dignity when defining dignity, as a value term that refers to worth, stature or value of some entity. In presenting a philosophical view of dignity, the researcher described how dignity falls into three categories

that included: intrinsic dignity as the value that human beings have by virtue of being human; attributed dignity which is the worth, status or value that individuals will choose to bestow upon each other by acts of attribution; and inflorescent dignity, that defines individuals who are flourishing by living their lives consistent with the intrinsic dignity of humans.

Dignity as an ethical and social concept was discussed in several studies. Jacobson's (2007) study identified dignity as having two dimensions; one that included human dignity as a fundamental human value and the second as social dignity that was grounded in human dignity and was experienced, bestowed, or earned through interaction in social settings. Jacobson profiled how human and social dignity was used in such areas as human rights, social justice, bioethics, and clinical care but also identified issues when using dignity, depending on how society acknowledged the value of every human being. The researcher suggests that conflicts between human and social dignity can occur when a certain social-economic class is devalued. Milton (2008) also viewed dignity as an ethical concept found in biomedical ethics nursing literature. She emphasized dignity from the nursing perspective, as compassion and respect for the essential dignity of every individual including the qualities of one being worthy, honored, or esteemed and agreed that dignity was based on definitions that described a human attribute or a right.

Backer-Condon and Hegge's (2011) study on human dignity was the result of an ethics course delivered to doctoral nursing students at South Dakota State University in 2010. The researchers sought to find out how often the topic of dignity was discussed in a graduate level nursing ethics course. By using Parse's (2010) 'humanbecoming' perspective in which human dignity consists of four ethical tenants, reverence, awe, betrayal, and shame, they found that dignity was frequently discussed, which supported their thesis that dignity is the cornerstone of

ethics. However, they found that novice nurses placed less value on dignity than the more experienced nurses. This research highlighted the importance of discussing dignity early in nursing education.

Dignity and the Older Adult

Dignity in aging is related to the process of becoming old and being subject to physical and mental deterioration (Anderberg, Lepp, Berglund, & Segesten, 2007). This process is also related to a feeling of vulnerability, loss of self-identity, and of being subject to negative attitudes (Moody, 1998; Woolhead et al., 2004). While maintaining dignity across the life-span is promoted in the literature, nonetheless, the experience of dignity can be somewhat different for the older adult. Black and Dobbs (2014) recognized that community-based older adults were living longer and that the majority would face declining health that could impact dignity while living in the community. Their study explored older people's understanding and experiences of dignity and three key components of dignity were identified: (a) "dignity as autonomy, was the most prevalent with participants crediting dignity as the ability to having choice and decision making in all aspects of their lives; (b) relational dignity, described the importance of having interactions and relationships with others; and (c) dignity as self- identity, pertained to self-identity that included, self-pride, personal acceptance, and appreciation of oneself" (p.1303). The researchers recognized that these themes reflected universally important aspects of ageing with dignity and suggested ways to enhance the dignity of ageing persons by supporting the themes that were identified.

Fenton and Mitchell's (2002) nursing study on growing old with dignity emphasized how dignity was an essential requirement in the care of older adults and was relatively unacknowledged in the nursing literature. The researchers completed a concept analysis of

dignity in the context of nurses caring for older adults. They further analyzed the concept of dignity as it related to older people receiving care and promoted the use of concept analysis to understand the complexities of working with older adults. The researchers highlighted the nurse's professional obligation of ensuring that the needs of the older client were not overlooked or forgotten within the demands of nursing practice; stressing that dignity was something to preserve and not to be undermined. The researchers believed that labels such as 'geriatric' or 'the elderly' were examples of how older people could be dehumanized and their dignity could be undermined.

In contrast to Fenton and Mitchell (2002), Jacelon et al. (2004) recognized that dignity of older adults was often discussed in the health care literature however, its meaning was not always clear. The researchers completed a conceptual analysis utilizing literature and qualitative data collected from five focus groups with a diverse sample of older adults. Three major themes were identified from the data: philosophical, attribution, and behavioral. The researchers used behavioral characteristics such as behavior of older adults and behavior of others toward the older adult as the basis for an operational definition of the concept. They concluded that "dignity is an inherent characteristic of being human, it can be felt as an attribute of the self, and is manifested through behaviour that demonstrates respect for self and others" (p. 81). The researchers suggested using the results of their study to develop an assessment tool for dignity, but identified that additional research was needed to explore their conclusions with other populations.

Arino-Blasco et al. (2005) investigated the moral implications of human dignity in the older adult by studying health professionals' views of dignity. This large study consisted of 85 focus groups involving 424 health professionals in six European countries. Only 13% of the

participants were men. The study identified the following factors that were essential to providing dignified care: promotion of autonomy and independence; a person-centered and holistic approach; maintenance of identity and encouragement of involvement; participation and empowerment; and effective communication and respect. Circumstances that constituted undignified care were: invisibility; de-personalization and treatment as an object; humiliation and abuse; and narrow and mechanistic approaches to care. The participants identified societal, structural and individual elements as possible barriers to providing dignified care. It was also recognized that personal skills, professional values, communication and behavior could impact the dignified care of the older adult. By completing this study, the researchers determined that education on human dignity, supported by policies and resources were fundamental to the development of appropriate professional attitudes to maintain dignity in older people.

Much of the research has described the importance of dignity for the older adult from the health care professional's viewpoint and from participants in a hospital setting. However, to identify whether dignity is being preserved, the perspective of the older adult must be acknowledged. Woolhead et al. (2004) examined older adults from different socio-economic backgrounds and levels of health and disability who live in institutional and community settings. The researchers used a qualitative method that applied both individual and focus group data collection methods to explore the concept of dignity from the older person's perspective. The sample included 72 participants over the age of 65. Results indicated that dignity was important to older adults and that dignity was perceived as an identity (e.g., self-esteem, self-respect, integrity, and trust), a human right (e.g., equality, choice, and human entitlement to dignity), and autonomy (e.g., independence, control, and freedom of choice). This study supported the concerns that dignity in the older adult was being lost or at risk, especially in the areas of health,

social care settings, human rights, and policies for older people. While this study offered valuable insight into how older adults perceive dignity, two limitations were the self-selection of participants and the under-representation of ethnic minorities.

A grounded theory study by Jacelon (2004) examined how older people perceived dignity while hospitalized. This was a small study with five volunteers who were all approximately 75 years old and hospitalized for medical reasons. Interviews were completed on admission, shortly after admission, and at discharge. In the early stages of admission, the participants agreed that receiving treatment in order to return home was more important than the maintenance of their dignity. Regardless, the longer they were hospitalized the more emphasis the participants placed on their own personal dignity. Throughout hospitalization, the participants reported how they felt that their dignity was negatively affected by the procedures to which they were submitted and by the staff who interacted with them. The researcher concluded that there was a necessity for future discussion and investigation of the importance of dignity to the older adult, and the relationship between dignity of older adults and their ability to manage their health.

Webster and Bryan (2009) used a phenomenological approach to explore the lived experience of dignity and the factors that promoted dignity in older patients who had been recently hospitalized. Purposeful sampling was used to recruit ten older adults aged 73 to 81 who had an unplanned admission and were discharged home. The data was collected by semi-structured interviews in the participants' homes, and concentrated on the experience of the hospital admission. Although the findings indicated a general satisfaction with the level of care received, the participants discussed issues around the promotion and maintenance of dignity that pertained to the following: privacy for the body, cleanliness, sufficient time from staff, attitudes toward older people, independence and being able to exert control, and communication. This

study suggested that the preservation of independence was the main determinant of dignity. Effective communication that conveyed concern and interest in the older adult was also a key factor in maintaining dignity. This study reflected a population of older adults who were relatively well and independent, but did not include older people with ethnic minority backgrounds, or more vulnerable older adults with cognitive and neurological difficulties. This study has strongly recommended that research is required on the preservation of dignity for vulnerable older adults.

Dignity and the Older Adult Living with Schizophrenia

In the literature, there was little documentation on the older adults' experience living with schizophrenia and no research was documented on dignity in the older adult with schizophrenia. However, literature was found on the experience of living with severe mental illness and being an older adult, which provides some preliminary insights of older people with schizophrenia and dignity. Cummings and McClure-Cassie (2008) conducted a study to determine the psychiatric, physical, and social services needs experienced by older adults with severe mental illness. The participants were recruited from a community mental health centre and were 55 years or older and had a diagnosis of schizophrenia, schizoaffective disorder, major recurrent depression, or bipolar disorder. This study had 75 participants between the age of 55 and 80, with 33.3% diagnosed with schizophrenia. Face-to-face interviews were conducted to gather data on the participants' needs and psychological and health status. Results indicated that psychological pain, physical illness, social contacts, looking after the home, and activities of daily living were priority needs. The researchers also addressed the consequences of aging with a severe mental illness and how this diagnosis could create additional physical and social barriers to receiving the

needed services. Although dignity was not formally discussed in this study, the authors argue for future research on the unmet needs of older adults living with serious mental illness.

Older Adults with Schizophrenia Residing in Community Care Settings

Among older adults with schizophrenia, there are individuals with higher needs who are unable to live independently and are required to live in an assisted living environment (Karim, Overshott, & Burns, 2004). Cabness (2009) examined the effect of integration into an assisted living facility on older persons with schizophrenia. The results showed that this population could experience social losses and cognitive decline that could affect their autonomy when faced with major change in their lifestyle. Cabness described the importance of staff to provide an empathetic and a facilitative environment when learning the capabilities of older adults with schizophrenia. The researcher remarked on the importance of human dignity and self-worth when helping individuals reach their optimal level of psychosocial functioning. The researcher determined the need for more research on older adults with schizophrenia and that there was a gap in the literature related to psychosocial interventions for this specific population.

Granerud and Severinsson's (2003) examined the integrity of people with mental illness living in either assisted living or independently in their own apartments. The data indicated that individuals with mental illness regarded their home as important for living a safe and independent life, where autonomy and dignity in their contact with others could develop. However, the participants had experienced stigma and a lack of acceptance when trying to meet people. The researchers believed that it was important for community mental health nurses to become familiar with the ethical problems that could occur for individuals with mental illness living in assisted living, in order to be able to know how to preserve their integrity. It was recommended that future research be considered on nurses' ethical decision making and their

responsibilities to persons with mental illness. The use of such research would enhance the care for older adults with schizophrenia and could assist nurses in determining what the concept of dignity means to this population.

Effect of Stigma on Dignity for the Older Adult with Schizophrenia

Although the literature describes the effect of stigma for individuals living with serious mental illnesses, there is little research on labelling and stigma of the older adult living with schizophrenia, and how it affects their dignity. However, it is evident that older adults living with schizophrenia experience labelling, stigma and discrimination when living in the community, especially when they feel unaccepted by society or receive little general public support to overcome adversities in their life (Depla et al., 2005). This results in “loss of self or belonging when not feeling accepted by society, and a lack of support in overcoming adversities in their personal life” (p.152).

Depla et al. (2005) completed a study with adults living in assisted living to determine the stigma experience associated with mental illness. A strong connection between quality of life and stigma was encountered; the more stigmatization the participants perceived, the less satisfied they were about their quality of life. The researchers found that stigma could undermine self-esteem, psychosocial well-being, social adaptation, and cause social withdrawal. They concluded that in order for individuals living with serious mental illness to experience a sense of belonging versus exclusion that could lead to an improvement in their quality of life, there needed to be a more concentrated focus on destigmatization.

Guimon (2010) also believed that individuals with serious mental illness, such as schizophrenia, deserved to be treated equally in dignity, regardless of their mental capability and should not have to experience stigma and discrimination. The researcher’s study focused on the

lack of respect for human dignity in psychiatric settings and how, historically, individuals with mental illness have experienced stigma that has affected their access to appropriate treatment. The researcher concluded that to make change and reduce prejudice in this population, a serious effort must be made to eliminate alienation that can occur among the mentally ill, in order to improve self-esteem, and create alternatives to hospitalization, and work activities that would in essence, give dignity in their life. Phelan and Link (2011) share the belief that labelling and stigma may endanger the lives of individuals diagnosed with serious mental illness, by not only diminishing their self-esteem but increasing the possibility of devaluation, discrimination, and exclusion. From their strong position taken on this issue, a theory on labelling and stigma has evolved that points to the importance of attitudes and beliefs of society and indicates that the negative stereotypes and social distancing responses have changed little and may have even strengthened over the years.

Nursing Care and Older Adults with Schizophrenia

While older adults with schizophrenia can be divided into two groups, those who develop symptoms later in life and those who have been diagnosed at an early age and have grown old, both groups have complex clinical needs. There is a compelling obligation by healthcare providers to develop care that is designed to meet the needs of this population (Karim et al. 2004). Health care professionals need to be aware of preconceptions regarding this population that would prevent practicing in a holistic manner when assessing and treating those aging with schizophrenia (Dixon, 2008). This obligation and awareness holds true with Moody's (1998) belief that dignity matters because of the sense of vulnerability and fear that older individuals may experience in the last stage of life. This belief is also consistent with much of the nursing research that stresses the importance of nurses to maintain dignity and to provide dignified care

to the older adult. While there is relevant literature regarding dignity in nursing when caring for the older adult, there is a lack of nursing research that examines the unique experience of dignity when caring for older adults living with schizophrenia.

Studies by Collier and Sorrell (2011) and Leutwyler et al. (2010) identified that living with schizophrenia placed the older adult at risk for unfounded negative assumptions. Both studies identified that nurses' beliefs about older adults with schizophrenia could affect practice and nursing interventions. Nurses are encouraged by these studies to reflect on how their own attitudes influenced their understanding of mental illness and the nurse-patient relationship. Because there is little known about the unique experiences of older adults living with schizophrenia, the researchers cautioned nurses to be careful in labelling older adults with mental illness and to attempt to create positive opportunities for interventions and personal development. Dignity in nursing care was not mentioned in both articles, however in Collier and Sorrell's study, relevant examples were provided that described indignity for older adults with schizophrenia including: discrimination from professionals on the basis of the age of the older adult with schizophrenia; nurses' negative beliefs and attitudes about people with schizophrenia; therapeutic nihilism by clinicians related to a lifetime of chronic symptoms and poor treatment response; ageist bias when caring for older adults with schizophrenia; financial bias due to the belief of some that the individual did not contribute to society, thus a reluctance to provide more expensive treatments; and an absence of constituency associated with the older person not having advocates or family to help. Leutwyler et al. concluded that if a positive connection were made between the nurse and patient, it could help the older adult with schizophrenia to feel at ease in other aspects of his/her life.

Nursing Perspective

Nursing is interested in the total person; body, mind, and soul. Nursing as a science has a goal to understand those individuals being cared for in order to know how to care for them. “Professional caring through the hands of nurses can be defined as activities that promote healing, preserve dignity, and respect the nature of holistic nursing practice” (Vandenhouten, Kubsch, Peterson & Murdoch, 2012. p. 326). The articulation and description of the human experience is foundational to nursing practice (Todris & Wheeler, 2001). “Phenomenology is a philosophical perspective which guides the researcher to explore and understand the everyday lived experiences of the person without pre-supposing knowledge of those experiences” (Converse, 2012, p. 28). “The philosophical underpinnings of phenomenological thought are consistent with the values of nursing practice including the uniqueness of the person, the importance of personal discovery and acceptance of life situations, the need for the exploration of meaning of experience, interpersonal relating, potential for personal growth, and the use of self as a therapeutic tool” (Edward, 2006, p. 237). By using a phenomenological approach as a way of knowing what the dignity experience is like for older adults with schizophrenia, the nurse may come to a better understanding of what promotes dignity and what degrades dignity. Giorgi’s (2009, 2012) phenomenological psychological method was used as it emphasizes an understanding of psychological phenomena and fits best with the psychiatric–mental health nurse perspective.

To a large extent, nurses are increasingly turning to phenomenology to explore the client’s lived experience of illness, and are using complex critical thinking to enhance their understanding of care (Earle, 2010). Phenomenology fits well within the scope of practice for psychiatric-mental health nurses as they work towards developing a therapeutic relationship with

clients in order to capture a better understanding of their experience of living with a mental illness (Kutney, 2006; Stubblefield & Murray, 2002). A phenomenological approach, such as Giorgi's (2009, 2012) enables outcomes to be known from the client's perspective as what is meaningful and what matters to the client (Kutney, 2006). Using a phenomenological method when caring for clients with mental illness also "promotes the construction of social reality from the perspective of the client rather than the perspective of the nurse" (Stubblefield & Murray, 2002, p.164). Furthermore, when nurses understand the client's experience, it can guide them to interact in ways that may differ from healthcare professionals who may lack this understanding (Cohen, Kahn, & Steeves, 2000), while aiding in the development of individualized outcomes based on the continued needs of the client.

Researcher's Presuppositions

Giorgi (2000) stressed the importance of understanding and articulating that, in essence, phenomenology is primarily a philosophy. However, it was essential for me as a psychiatric-mental health nurse, to acknowledge any pre-understanding of the phenomena in order to remain open and sensitive to the participants' lived experience, which is known as phenomenological reduction or bracketing, throughout the entire research process. Any belief or past knowledge that I had about the phenomenon needed to be acknowledged and set aside in order to prevent error; something that Giorgi (2000) cautions is possible when past knowledge is imposed on the research study. Therefore, in following steps outlined by Giorgi (2009, 2012), I have identified the following presuppositions that have influenced me and are important to be bracketed.

1. Dignity is a lived experience, has personal meaning, is a human right, and is universally important to all human beings.

2. Dignity matters because of the sense of vulnerability and fear that older adults may experience in the last stage of life (Moody, 1998).
3. The presumption of always being treated with dignity does not change despite increasing age.
4. There is little known about the unique experience of dignity in older adults with schizophrenia, specifically in the nursing literature.
5. People living with schizophrenia, are subject to discrimination and stigma that could be defined as undignified and dehumanizing (Collier & Sorrell, 2011).
6. Individuals with schizophrenia have been thought of as second class citizens and have experienced social losses and barriers (Cummings & McClure-Cassie, 2008).
7. Older adults expect to be treated with dignity and define it as promotion of autonomy, independence, empowerment, and respect (Arino-Blasco et al., 2005).
8. The older person who is more vulnerable may encounter undignified care that can make him or her feel invisible, treated as an object, humiliated, dehumanized, and abused.
9. There are many times in the health and social care settings when older adults are not being heard and are experiencing more situations where dignity is lost rather than enhanced.
10. Nursing is about caring, promoting healing, and preserving dignity (Vandenhouten et al., 2012).
11. Regardless of age or illness, nurses have a professional obligation to ensure that all individuals in their care are treated equally and that their uniqueness and dignity are respected (Fenton & Mitchell, 2002).

12. Nurses must understand the meaning of dignity and know how to protect the client from experiencing indignity.

Summary

While the concept of dignity in the older adult and the importance of preserving a person's dignity are well documented, there is a lack of research on the perspective of dignity for the older adult living with schizophrenia, and no documentation exists in the nursing literature. Moreover, researchers who have described the dignity agree that it is difficult to define (Clark, 2010; Griffin-Heslin, 2005; Haddock, 1996; Jacobson, 2007; Maris, 1994; Milton, 2008) and many question whether dignity means the same thing for each person (Lin & Tsai, 2011; Maris, 1994). It can also be argued that the concept is complex and difficult to understand and may be taken for granted with the risk of losing some of its meaning (Edlund et al., 2013; Shotton & Seedhouse, 1998) and acknowledgement.

The need for greater clarity of the phenomenon of dignity as experienced by the older adult living with schizophrenia warrants a research approach that allows for a clearer understanding of the definition of dignity by exploring dignity in external and intrinsic terms, dignity as other-regarding and as self-regarding values and the values of absolute and relative dignity, the importance of dignity when growing old, the older adult's perspective of dignity, the meaning of dignity for the older adult with schizophrenia, the effect of stigma and labelling on dignity for the older adult living with schizophrenia, and lastly the importance of nurses' understanding of the relevance of preserving the dignity of individuals with schizophrenia. Knowledge of dignity, as it is lived, will allow new understandings of dignity and insights on how one can maintain and/or enhance dignity.

CHAPTER 3

Method

The purpose of this chapter is to describe the research method chosen to address the question: What is the lived experience of dignity for older people with schizophrenia living in a LCCF? In order to understand this, one must try to obtain the individual's experience as described in everyday life. To do so, I used a descriptive qualitative research design to study the phenomenon of dignity in the older person living with schizophrenia. Giorgi's (2009, 2012) phenomenological psychological approach was chosen as the method to uncover the meaning of dignity in the older adult living with schizophrenia and residing in a LCCF.

Giorgi's Descriptive Phenomenological Psychological Method

For this research study, I chose Giorgi's (2009, 2012) phenomenological psychological method, which is a modified Husserlian approach that focuses on intentionality. This method, with roots in philosophy and psychology, focuses on the lived experiences of individuals (Polit & Tatano Beck, 2012), specifically examining human experiences through the descriptions provided by the individuals involved (Nieswiadomy, 2008). This phenomenological method of inquiry, as described by Giorgi (2009, 2012) was used to explore the experience of dignity in older adults living with schizophrenia. Giorgi's phenomenological psychological method aims to discover the meaning of a phenomenon as experienced by a human through the identification of essential constituents (Koivisto et al., 2002), and fits well with phenomena that are concerns to psychiatric-mental health nursing (McInnis & White, 2001). Using Giorgi's method gave a voice to individuals who needed to be heard (Cohen, et al., 2000); in this case the lived experiences of dignity for older adults living with schizophrenia who resided in LCCFs.

To use Giorgi's method, there was a phenomenological attitude taken that supports phenomenological reduction, which means that I resisted from positing as existing, whatever object or state of affairs that was presented (Giorgi, 2012). I concentrated on the given information as a phenomenon, and everything that was said about the phenomenon was based upon what is given, and refrained from bringing in past knowledge to help account for whatever was being presented (Giorgi, 2009). It was imperative that my pre-understanding of the phenomenon as a psychiatric-mental health nurse was made explicit and bracketed in order to remain open and sensitive to the phenomena throughout the entire research process. Giorgi (2009, 2012) cautions that error is a possibility if past knowledge is imposed on the phenomena under study. It was recommended that my psychological perspective be clearly identified before and during the research process, and that the specific data analysis steps as outlined by Giorgi (2009, 2012) were followed. Reflective journalism was suggested. This phenomenological research design was an appropriate fit to explore the essential elements of the lived experience of dignity for older adults with schizophrenia living in assisted living and to describe the meanings of the phenomenon made by the person experiencing it.

Participants

I used a purposive sample of eight older adults who were diagnosed with schizophrenia and were willing to describe the phenomenon of dignity while living in LCCFs in PEI. Although equal representation from both men and women was sought with the assistance of community mental health nurses and licensed community care facility managers who are involved in the care of the participants, seven males and one female volunteered to be involved in this study. Participants met the inclusion criteria of: being at least 60 years of age; diagnosed in late adolescence or in young adulthood; presently mentally stable; oriented to person, place, time and

circumstance; able to speak, hear, and understand the English language; and willing to share their experience of dignity.

After ethical approval was received from the University of Prince Edward Island (UPEI) Research Ethics Board (REB) and the Prince Edward Island (PEI) Health and Wellness Research Ethics Board, permission to conduct this study and access to health care personnel that cared for older adults with schizophrenia in the community, was requested from the Executive Director of Community Hospitals and Primary Health Care and the Director and Manager of Mental Health and Addictions, PEI Health and Wellness (See Appendix A). Assistance was then requested from the senior mental health resource team (SMHRT) in Queens County, the community mental health outreach teams in Queens, Kings, and Prince Counties and managers of licensed LCCFs in Queens County, to identify possible participants living in PEI LCCFs (See Appendix B & C). Participants were recruited by an invitation letter (See Appendix D) through the community mental health clinics and the LCCFs in Queens and Prince Counties. In the letter, I outlined the purpose and the procedure of the study, the criteria for the participants' eligibility to participate, explained that participation was voluntary and that participants could withdraw at any time, the choice of location of the interview, and my office phone number, email address, and mailing address. The letter of invitation also included a pre-stamped addressed envelope that could be used by the interested participant to return the letter of invitation, indicating how he or she would like to be contacted by me. I also informed the Director of both Queens and Kings County community mental health clinics about the purpose and procedures involved in the proposed study.

Pilot Study

A pilot study consisting of three interviews was undertaken to ensure and increase my ability to gather information on the phenomenon using bracketing and to determine the adequacy of the research methods and procedures. One interview was completed at a community mental health clinic, and two were completed in the participants' homes, using the interview guide in a semi-structured interview prior to the larger study. To assist in ensuring proper use of Giorgi's (2009, 2012) method, a nurse expert in phenomenological methods of inquiry reviewed my results of the pilot interviews and was my adviser. No changes were required after the pilot study and these three interviews were included in the results in the larger study.

Data Collection

After I had screened the participants in person for eligibility, the purpose and procedures of the proposed study were reviewed, followed by participants' completion of a demographic information form (See Appendix E) and signing a consent form to participate in the study (See Appendix F). I completed one unstructured interview with each participant that was approximately one hour, which was digitally recorded and transcribed verbatim. Questions during the interview included broad questions (See Appendix G). Participants were asked to describe their experiences of dignity while residing in a LCCF. The participants were encouraged to narrate freely, and I restricted questions to requests for clarification, elaboration, and reflection. All interviews took place at a mutually agreed location to provide privacy for the participant being interviewed.

Data Analysis

Data were analyzed using Giorgi's (2009, 2012) method which included: (a) reading the entire description to grasp a preliminary understanding of the lived experience of the

participants; (b) re-reading the description and identifying the meaning units from a psychological perspective and focusing on the perception of dignity for each participant; (c) the meaning units were transformed from everyday language to a psychological language, emphasizing the most descriptive meaning units of the perception of dignity for individuals with schizophrenia living in long-term care; and (d) synthesis of all the transformed meaning units into a consistent statement of structure of the participants' experiences living with schizophrenia in long term care and their perception of dignity. When following Giorgi's (2009, 2012) method, reduction, intuiting, and the use of free imagination in the analysis of the data promote reliability and validity of the study, by bridging the gap between the facts described by the participants and the essential meaning of the lived experience. I ensured this by becoming totally immersed in the phenomenon as described by the participants and continually addressing personal biases and assumptions, and setting aside personal beliefs in order to obtain the purest description of dignity in older adults with schizophrenia. Descriptive statistics were used to analyze the collected demographic data and a written report of the experiences was compiled.

Ethical Considerations

Since this project was a fully developed research study that was considered beyond the experiences that the participants may have experienced in everyday life, ethics approval for this proposed research study involving human participants was submitted for full review by the UPEI Research Ethics Board and the PEI Health and Wellness Research Ethics Board. Prior to the onset of data collection, written informed consent was obtained from all participants living in community care facilities. For confidentiality purposes, each interview received an identification number and recorded interviews were erased following transcription. All transcribed data was locked in a filing cabinet at the University of Prince Edward Island, School of Nursing with only

the supervisory committee and myself having access to this data. Due to the vulnerability of this population, I reassured the participants that they could withdraw from the interview at any time, and if they became upset during the interview, I would stop and resume only if the participant was willing to continue. I have 16 years of experience as a psychiatric-mental health nurse caring for individuals with severe and persistent mental illness such as schizophrenia. I also achieved certification by the Canadian Nurses Association as a certified psychiatric-mental health nurse in 2001. From 2000 to 2005, I held the position of an executive member on the PEI Schizophrenia Society Board of Directors. I am presently a clinical nursing instructor at UPEI School of Nursing for psychiatric-mental health nursing in the classroom and in the acute and community setting. Information about appropriate resources, including counselling, was provided to all participants.

Confidentiality

All transcribed data were analyzed after each interview and locked in a filing cabinet at the University of Prince Edward Island, School of Nursing with only myself and supervisors having access to this data. All materials will be kept for a period of 5 years after publication, at which time they will be destroyed. The consent and demographic forms that contained personal information were stored in a locked filing cabinet separate from the transcripts.

Anonymity

All measures were taken to ensure that the participant would not be identifiable to other participants in this study or identifiable in any dissemination activities. In no way was it possible to link the responses to the participant. Names were not used in any transcripts or reports, including use of direct quotations from interviews in reports related to the findings of this study. All personal identifying information was removed from the transcripts, and a code number was

used. The digital recording of this interview was transferred electronically to a universal serial bus (USB) memory flash drive and used by the researcher to transcribe the interview into an electronic document. At this time, all personal identifying information was removed. Once the document was completed, the original recording was deleted and a unique number was assigned to the transcript. I used this number to distinguish the difference between the interviews during data analysis and in no way was it to provide a means to link the transcript to the participant's identity.

Phenomenological Trustworthiness

To determine the trustworthiness in qualitative studies, I needed to utilize strategies that would enhance both reliability and validity. Trustworthiness, from a phenomenological stance depended on the rigor of the questions put to participants and the extent that participants' experiences were taped; and the consistent use of bracketing of prior knowledge helped to ensure the pure description of data (Streubert & Carpenter, 2011). Complete agreement among phenomenologists on what actually constitutes trustworthiness, is lacking. Despite this challenge, some guidelines have been suggested to ensure that good qualitative work is produced. For the purpose of this research, Giorgi (2009, 2012) and Guba and Lincoln's (1989) guidelines for trustworthiness were used.

Giorgi (2012) believes that the use of phenomenological reduction and intuiting in the analysis of the data is intended to establish the reliability and validity of the study and Guba and Lincoln's (1989) classic work is used to address issues of trustworthiness. Guba and Lincoln developed a framework using five criteria for developing the trustworthiness of a qualitative study: (a) credibility that refers to the confidence in the truth of the interpretations of the data; (b) dependability which describes the reliability of data over time; (c) confirmability that

describes the objectivity or the potential for congruence; (d) transferability that explains the potential for extrapolation; and (e) authenticity, which is the degree to which one fairly and faithfully demonstrated a range of realities (Guba & Lincoln 1989; Polit & Tatano Beck, 2012).

To ensure credibility of my study, after I screened my participants in person for eligibility, the purpose and procedures of this study were reviewed, followed by participants signing a consent form to participate in the study (See Appendix E). I conducted all interviews in order to build a trusting relationship and make it easier for the participants to tell their stories and reflect on their lived experiences of dignity. I completed a semi-structured interview with each participant that was approximately one hour, as lengthy interviews produce rich data (Corrigan, Samuelson, Fridlund, & Thome, 2007). Each interview was digitally recorded and transcribed verbatim. This was the main source of data for my study, however, secondary sources were obtained from my interpretation of notes of unstructured observations and reflective journaling while in the field.

I spent approximately 8 months collecting data in order to get an in-depth understanding of the lived experience of the participants. As a mental health nurse who has cared for older adults with schizophrenia, I understand the importance of taking into account personal beliefs and feelings regarding dignity for this population, in order to understand the lived experience from the older adults' vantage point. Giorgi's (2009, 2012) phenomenological reduction or bracketing was evident as I identified all presuppositions or assumptions about the phenomena of dignity, older adults with schizophrenia and nursing care of the older person with schizophrenia. A reflective journal of my personal experiences, reflections, and progress was maintained to assist in effectively bracketing and dealing with the data in its pure form. The

completion of a pilot study with supervision provided by my supervisory committee allowed me to demonstrate bracketing and intuiting skills.

According to Giorgi (2009, 2012), validity is enhanced when the researcher uses intuiting as the means to identify the phenomena of interest, which ensures that the true constituents are being identified. In addition to bracketing, I used the process of intuiting, which is the signifying, fulfilling, identifying acts, and the use of free imaginative variation during the analysis of the participants' lived experience (Husserl, 1970). Guba and Lincoln (1989) refer to confirmability as the criteria of objectivity of this proposed study, and authenticity or the rich identification of the lived experience of the participant. I had repeated discussions with my supervisory committee regarding the meaning of the data to ensure that the findings reflected the participants' voices and the conditions of the inquiry, and not my biases, motivations or perspectives (Polit & Tatano Beck, 2012). The fifth criteria considered in developing trustworthiness, was transferability or applicability in other settings or groups. It was anticipated that the findings of this proposed study would have meaning to other individuals experiencing dignity with mental illness or for other individuals interested in making use of the findings in others settings or groups (Polit & Tatano Beck, 2012).

Dissemination of Results

A written report of the findings of my study will provide nurses and other healthcare providers with knowledge of the lived experience of dignity for older adults with schizophrenia living in LCCFs and identify any critical issues that might need to be addressed in the delivery of care. All participants were asked, at the time of their interview, if they would like to be sent a copy of a summary of the results. In the future, I will present the findings of my study to groups

in settings that would be interested in the experience of dignity in older adults living with schizophrenia who reside in a LCCF.

Summary

In this chapter, I presented the methodology used in my study. A description of the Giorgi's (2009, 2012) phenomenological psychological method was provided. Access to participants and the importance of ethical considerations were identified. Steps to ensure phenomenological trustworthiness using the Giorgi's (2009, 2012) phenomenological psychological method were reviewed. Data collection, analysis, and utilization of a pilot study were provided. How I will disseminate final results was identified.

CHAPTER 4

Research Findings

The purpose of this study was to explore the essential elements of the lived experience of dignity in the older adult who lives with schizophrenia and resided in a LCCF. I sought to find out “What are the essential elements of the lived experience as verbalized by the older adult living with schizophrenia and who resides in a LCCF?” A descriptive, qualitative research design following Giorgi’s (2009, 2012) phenomenological psychological method of inquiry was employed. In this chapter I will address the: (a) demographic data, giving a basic description of each older adult who participated in the study; (b) descriptive findings from the interviews with the participants; (c) meaning units and clusters that were extrapolated from the participants’ raw descriptions of their experiences of dignity; and (d) general structure of the synthesized themes of the participants’ lived experience of dignity restated from a psychological perspective.

Description of Participants

Eight older adults living with schizophrenia and residing in LCCFs participated in my study. The eight participants (See Table 1) comprised of seven males and one female: all of the Caucasian race; with the age range being between 60-68 years; living with schizophrenia for an average of 39 years; and residing in a LCCF for an average of 18 years. With respect to marital status, six participants were single, one separated and one divorced. Seven of the participants had a high school education, one achieved grade seven, one had completed university credits, two had undergraduate degrees, and two had diplomas from a community college. Most of the participants had work experience. In order to protect the identity of the participants, Giorgi’s (2009, 2012) phenomenological psychological method recommends the use of pseudonyms that

include a number. For my study, I have used pseudonyms (See Table 1) that are described as participant (P)1 to (P)8 to identify the quotes and to protect the participants' anonymity.

Table 1

Demographics of Participants

Parameter	P1	P2	P3	P4	P5	P6	P7	P8
Gender	M	M	M	M	M	M	F	M
Years residing in a LCCF	29	10	14	34	22 mos.	25	20	8

Phenomenological Psychological Analysis Results

In this section, I present the results of the phenomenological psychological analysis which revealed the constituents and meaning structures of the phenomenon of dignity from the perspective of older persons living with schizophrenia. I identified over 500 large meaning units in the transcribed interviews that were transformed into 200 smaller meaning units of the essence of dignity. Five essential constituents emerged from the narratives and represent the meaning structure of the phenomena of dignity for the participants. The following constituents emerged: (a) dignity is an intrinsic or self- regarding experience; (b) dignity is a reciprocal extrinsic, others regarding experience, which is embedded in social relationships; (c) dignity can be eroded by ageism, stigma, discrimination, and alienation; (d) dignity can be interrupted when the positive and negative symptoms of schizophrenia are present and misunderstood by others; and (e) dignity can be enhanced when self and others embrace a recovery-focused relationship that optimizes psychosocial functioning of the person living with schizophrenia.

Each of the five constituents will now be presented along with the related meaning units (See Table 2). The analysis process produced five structures which are highlighted by quotes from the interviews although the themes and subthemes in the typology sometimes overlap or are interwoven.

Table 2

A Typology of the Lived Experiences of Dignity of the Older Adult with Schizophrenia

Constituents	Meaning Units
Constituent 1: Dignity is an intrinsic or self-regarding experience.	<p>1.1 Participants identified that when experiencing dignity, they were being treated with self-respect, were treating others as they would treat themselves, and were receiving respect of others such as family, friends and society.</p> <p>1.2 Participants described dignity as a sense of feeling happy, self-confident, helped, understood, and being able to hold their heads up high.</p> <p>1.3 Participants described how the importance of being able to think independently and having the opportunity to make personal decisions were vital to having a sense of autonomy and self-determination.</p> <p>1.4 Participants believed that experiencing dignity was a result of being treated as an equal in every aspect of daily life, which in turn made them feel good about themselves.</p> <p>1.5 Participants verbalized that dignity is an attribute of the self-expressed as values and virtues that must be maintained in their lives in order to feel good about themselves.</p>
Constituent 2: Dignity is a reciprocal extrinsic, others regarding experience, and is embedded in social relationships.	<p>2.1 Participants expressed the importance of being accepted as a human being by others through not being ignored, ridiculed, and/or humiliated.</p> <p>2.2 Participants experienced dignity when strangers acknowledged them as a person rather than someone living with a mental illness.</p> <p>2.3 Participants described experiencing a sense of self when they felt accepted versus being excluded by others.</p> <p>2.4 Participants described feelings of tolerance and belonging when family and friends understood and accepted their mental illness.</p> <p>2.5 Participants described how someone in their lives, whether it was family, friend, health care staff, or a higher power, gave them support.</p>
Constituent 3: Dignity can be eroded by ageism, stigma, discrimination, and alienation.	<p>3.1 Participants identified that their lived experiences of dignity were compromised when they endured derogatory labels that were a result of having schizophrenia.</p> <p>3.2 Participants experienced feelings of alienation when others knew they lived with mental illness.</p> <p>3.3 Living with the stigma of mental illness for many years led to some participants believing that they did not deserve to experience dignity.</p>
Constituent 4: Dignity can be interrupted when the positive and negative symptoms of schizophrenia are present and misunderstood by others.	<p>4.1 Participants living with the symptoms of schizophrenia recognize how mental illness can permanently affect their sense of self, sanity, and wellbeing.</p> <p>4.2 Participants expressed having fragmented relationships due to lack of support especially when the participants were experiencing acute symptoms of hallucinations, delusions, bizarre behavior, and or changes in mood.</p>
Constituent 5: Dignity can be enhanced when self and others embrace a recovery oriented relationship that optimizes psychosocial functioning of the person living with schizophrenia.	<p>5.1 Participants expressed the need for support of others to ensure that hope was instilled and dignity was experienced.</p> <p>5.2 Participants described feeling empowered, experienced personal growth, and accomplishment when others treated them as an equal.</p> <p>5.3 Participants experienced dignity when they were included in meaningful social activities.</p>

Typology of the Lived Experience of Dignity in the Older Adult with Schizophrenia

The following are examples of the five constituents of the lived experience of dignity along with supportive narratives that emerged from the digitally recorded interviews of older adults living with schizophrenia.

Constituent 1. Dignity is an intrinsic or self-regarding experience.

MU 1.1 Participants identified that when experiencing dignity, they were being treated with self-respect, treating others as they would treat themselves, and were receiving respect from others such family, friends, and society. The recognition of the importance of personal values enhances the experience of dignity of older adults living with schizophrenia. The following verbatim statements suggest some of these perceptions. P1 expressed this theme in the following narrative:

Dignity means to me ... I guess self-respect for yourself and respect for that person and being treated with some kind of ... dignity is a word that is used a lot all the time ... being treated with some kind of respect and some sort of level of sanity of some sort ... you would treat yourself ... the golden rule 'do on to others as they do onto you' ... that sort of thing.

Similarly P2, shared the following about self-respect and labelling: "Well it means a feeling of self-respect, yah, being respected as a person. I don't know, you're a human being. I don't know ... called by your own name and not being called crazy." A third participant P3 supported the theme in the following narrative:

It's a part of your estimation of yourself or your self-esteem and people want the respect of others. People want it ... let's face it, you know? We live every day, we work, we

work, we play, we travel, we go to school, we do all kinds of things, we want the respect of others.

MU 1.2 Participants described dignity as a sense of feeling happy, self-confident, helped, understood, and being able to hold their heads up high. P3 also shared how important the feeling of being treated in a dignified manner was by sharing the following:

I spoke from the pulpit at church in association with a boy's club. I felt very dignified.

Just being up on the pulpit and speaking to the congregation, you know? And the whole feeling, you know? I felt very dignified. I ... just gave my speech, and I sat down, and ... the response, the response was good, it went over well. It makes you feel good.

A second participant, P4 voiced the following about being understood: "Well I ... I have a friend of mine. She takes me out for dinner now and then as a friend, not as a lover, but as a friend. She understands the situation, we talk and we remain friends."

MU 1.3 Participants described how the importance of being able to think independently and having the opportunity to make personal decisions were vital to having a sense of autonomy and self-determination. P5, who completed high school at night school after being unable to continue school after he became mentally ill, described how this endeavor helped him to feel like he had been successful in accomplishing something despite his diagnosis of schizophrenia and described this mastery in his life as a personal experience of dignity:

I felt good that I finished my grade 12 and got that much done. Well I felt like I accomplished something. Most would not bother. I felt better and that I accomplished something with my parents that had opinions of me which were not very pleasing to me, that they would not go a long with my sexuality problems, my nerves and my depression and so on, I was.. I found they did not understand that it was my health ... they thought it

just the way I was and I wasn't like that they thought I was. My parents they didn't quite understand me my health, my issue, it wasn't that they could understand, they couldn't deal with it.

A second participant, P2 verbalized hope and his perspective of dignity in his daily life: "I think another word for dignity I would use for dignity would be, ah ... taking one's freedom to live and to do as one pleases. That's what I believe. There's more to dignity you know? A lot more to dignity." P2's perception of the everyday lived experience of dignity evolved as he recognized that it was an important aspect of his daily life:

I think it's a very positive thing, yes, a very positive thing dignity, it's a very healthy thing it is important aspect of everyday life. Well, I tell ya it's how ya conduct yourself you know, how you react to ah ... to situations I suppose, or to ah ... to other people ... ah ... um ... I ... I would think it's associated with self-esteem, a large part of self-esteem, especially when you're older. Well ... ah ... how you carry yourself ... carry yourself ... ah, the way you dress, ah, your manner, ah ... your personality, you know, ah, it would be part of your personality, ah ... um ... and how you address people you know and how you interact with people and so on. I guess you know, yeah it should be a part of everyday life and just ordinary, you know just ordinary guys like us living together we should, we should treat each other with dignity.

MU 1.4 Participants believed that experiencing dignity was a result of being treated as an equal in every aspect of daily life, which in turn made them feel good about themselves. P1 described how he felt accepted by family and staff:

When I came back here there were roots here and my brother is here. Roots has a lot to do with dignity ... it has roots. When you have roots there is dignity to that. It's tied into

roots as well I had some roots then you know that you are accepted. Anyway I would say since I have got here I have been treated with royalty. This is a lovely house to live in and this house treats you with dignity in this house. And they don't treat you with bad treatment or bad temper; they have really good temper here ... or by the tone of voice ... they never shout at you they tell you in a soft way ... and that is very nice.

A second participant P5, shared how his experience of dignity had changed for the better when he was feeling well:

I've been treated pretty good at the lodge for all ... down there where I live. They have their moments, but most of the time, it's usually my own fault. I have said some things I shouldn't. They can treat you good ... sometimes it is great there. Everyone has an illness and the staff does the best they can. And some days it gets to you, usually when I am not feeling well or something is going on.

MU 1.5 Participants verbalized that dignity is an attribute of the self, expressed as values and virtues that must be maintained in their lives in order to feel good about themselves. When asked to describe his experience of dignity, 61 year old P1 expressed the following about honor:

You feel elated, you feel happy and you feel ... I don't know where the words are, I just can't get the words out ... let's see now ... What's a good word to use ... honour ... something to do with honour ... something to do with honourable ... and means something else to do ... as being accepted as a person.

A second participant, P4 described how his personal faith had helped him maintain a sense of self:

As far as dignity is concerned other in my life, as far as dignity is life experiences as my...my motto is, I take the good with the bad, the bitter with the sweet, the rose with the thorns, the bull by the horns. But I also believe that it's with strong faith that if you have faith must proceed to move many mountains ... You know it's faith, hope, love, and charity, you know. I think love covers all dignity and respect ... love. And love covers many areas, you can love people and give 'em gifts, you'd be imminent with them, you can share things, you can care ...

A third participant P3., who was a former teacher, spoke of the importance of being recognized for his performance as an educator and how much it meant to him:

I was teaching overseas. I worked for four years teaching high school and at the end, at the end of my term, of work there, the principal came up to me with a, with a cup, and an award, and everything, and presented it to me. And ... ah ... I felt terrific and dignified at that time, you know? It was a positive very positive thing.

P6 correlated his purpose in life to his personal beliefs, shared the following:

There's another way of looking at it at dignity is that your family members you know and ah you have love for them and there's dignity in that but most importantly when you think about God, dignity comes from God. And his ah, his death on the cross proved to us that he loved us ... Well see with my illness I can't really describe it the way I'd like ... to. I try to see ... ya see we are all meant to become holy but how holy we are is a matter of question ... ah depends on how much ya pray ... it depends on how much ya love ... or forgive you must forgive ... and, ah to me that's wholeness, I'm whole ... as a person ...

Constituent 2. Dignity is a reciprocal extrinsic, others regarding experience, and is embedded in social relationships.

MU 2.1 Participants expressed the importance of being accepted as a human being by others and, not being ignored, ridiculed, and/or humiliated. For most of the participants being accepted by others was an important aspect of dignity. P1, who had been professionally employed prior to his diagnosis of schizophrenia, explained the importance of acceptance in order to experience dignity by sharing the following:

I guess it is appreciation ... it's tied into appreciation. I say dignity is tied into appreciation ... I say it is tied into it all. I would say that appreciation and dignity are almost the same. When you are appreciated and you are dignified you have true dignity ... you are appreciated.

P1 discussed further the importance of having people treat him with dignity regardless of his diagnosis of schizophrenia and the fact that he had to live in a LCCF. He described how the staff members made him feel like a human being in the following narrative:

I would say since I have got here I have been treated with royalty. This is a lovely house to live in and this house treats you with dignity in this house. And they don't treat you with bad treatment or bad temper; they have really good temper here ... or by the tone of voice.... they never shout at you they tell you in a soft way ... and that is very nice ... It's tied in with the voice, tied in with a soft voice and a nice clean direct way about you and that's what they like ... very direct. C. is direct and she treats you with dignity and she is angry some days; she may be not as dignified that day and if she is angry there is no dignity to that but you get chewed out now and again and that's how you know you are human. Sometimes the staff and sometimes I get angry too. Sometimes I am out of sorts.

P4 supported the theme by commenting on how stigma could affect the experience of dignity and explained:

It means respect of other people, consideration of my feelings, my thoughts, my actions ... acceptance and understanding the sick person, that they are human like anybody else, they want to be loved and treated and handled with pet gloves. And to understand that it's like I have cancer or paralysis; it's a mental disease and that is not curable but is treatable.

MU 2.2 Participants experienced dignity when strangers acknowledged them as a person rather than someone living with a mental illness. Positive and respectful social engagement and social inclusion were essential in this theme. The behavior of the person living with schizophrenia and that of others was important to the experience of dignity as was other thoughts, feelings, attitudes and behaviors towards the person living with schizophrenia. It was also evident throughout the interviews with the participants, that inclusion by society contributed to their wellbeing and allowed them to feel accepted and valued. In the following dialogue, P1 described how a simple acknowledgement led to an experience of dignity:

Maybe it's the whole attitude here, everyone knows each other and you get on a bus and you say hello and they say hello back to you and that is being like true to dignity or you are going on the bus and getting on the bus and there are two or three people ahead of you and they let you go on ahead of them that's like why would they do that? It must be a thing with dignity.

P4 expressed the following about how others in his life gave him a sense of self and dignity:

I think it's people that gives you encouragement and gives you hope, ya know? Rather than downplaying ya or downrolling ya, or letting you down, someone you could trust eh ... There's very few we can trust in this world today. Sometimes I can't even trust myself

to be honest with ya. But well I loved my grandmother, every time I lived, brought up by both my grandparents and whenever I went to the clubs say two or three in the morning, she would be at the window watching for me to come home to make sure I come home safely. The Mounties drove me home, they said will you take him in or put him in jail, he's drunk. She's say 'no he's a lamb, I can look after him'. So she was always very protective, so being protected by my grandparents in my younger youth is one of utter remembrance about goodness ... a good being.

P3 shared in the following narrative how an event he attended as a news reporter made him feel included by others:

Dignity is something associated with an important event, it seems to me and you think and act in a dignified manner. I remember one time I was working with as a reporter for the paper, and there was a sports dinner and it was the sporting community of Souris you know. And I was just the reporter. I was one and they were many you know, so I thought I had to act in a very dignified manner to get their respect and attention. And I did.

MU 2.3 Participants described experiencing a sense of self, when they felt accepted versus being excluded by others. P4 supported the theme by commenting on how acceptance can affect the experience of dignity and explained:

It means respect of other people, consideration of my feelings, my thoughts, my actions... acceptance and understanding the sick person, that they are human like anybody else, they want to be loved and treated and handled with pet gloves. And to understand that it's like I have cancer or paralysis; it's a mental disease and that is not curable but is treatable.

P2, expressed this theme in the following narrative when describing how strangers he met on the street, staff at the licensed community care facility where he lives and staff at the clubhouse he

attends and volunteers treated him “Sometimes they: call me dear ... I like that. And they say hi to you and they talk to you yah, it's a good feeling Well it means you are being respected. It makes me feel good.” P7 shared her perception of dignity by the actions and behaviors of others towards her in the following narrative:

Well not being treated like a kid. I'm sixty-three, I mean really ... one night I got up cause I couldn't sleep and I put my nightgown housecoat on, should say, I put my housecoat on, and my slippers and went out to the, went out to the living room up there and just sat there and drank some water and then actually A. came along one of the other residents I should say, came along and he was sitting there too and one of the staff night staff came along, and she was gonna shoo him out and she saw me there and shooed us both out ... I kinda thought she treated us, one of the residents kinda like a kid ...

P4 expressed the following about being diagnosed with schizophrenia having the capability to live his life with dignity and a sense of normalcy:

Dignity could mean four things: giving a person a job that he is capable of doing and endure to pass the time away, to have a library at the clubhouse, a library to read books, to ... to have, ah ... association with other members because all I visit with dignity is four people that's got bipolar or schizophrenia. I visit their homes and as community together we understand, we accept one another as a family you know, as friends. And sometimes your friends can be closer than your own family.

P3, who was required to live in a LCCF due to his diagnosis of schizophrenia, discussed how living together with others who had mental illness aided in respecting each other:

Yeah, yeah I think it, ah ... I think it can a part of everyday life ... it should be a part of everyday life. We all treat each other with dignity here. I think maybe in a, in a situation

like this just about living together with the same bunch of people over a number of years, ya know? It calls for treating each other with dignity.

He also explained that his freedom of making personal decisions was also hinged on the acquired dignity that had developed from understanding each other:

Well you know if I give a guy a smoke; I give you a smoke, again a little later in a couple of hours times, you know I loaned one of the guys ten dollars, you can pay me back in a week's time and I expect to be paid back in a week's time And I get paid back in a week's time, certainly ... and always do ...

MU 2.4 Participants described feelings of tolerance and belonging when family and friends understood and accepted their mental illness. P3 also realized the importance of tolerance and acceptance when he recognized that at times he had not been experiencing dignity.

... I haven't been treated with dignity at times ... and it hurts of course, it hurts ... you know, you feel it ... it hurts your feelings. There are people in town of course who I use the term, give you a hard time over mental illness you know. But I'm used to that it doesn't make too much difference ... Because it's ... ah ... childish you know ... it's childish.

He also explained that he understood the importance of experiencing dignity and treating others as he would like to be treated. This is what he had to say about living in assisted living with others and the staff:

If someone treats you with dignity, you treat them with dignity and dignity is something that you draw upon in order to ... alleviates a tense situation. We respect each other and communicate fairly well, pretty well, together and there's no fighting, there's no fighting of any kind. There might be criticism, and so on, but actually not much of it, really.

P7 discussed her perception of dignity and described how she felt when she was not understood or respected by family and staff: (family) “Being understood, being believed. Yah, my sister doesn’t always believe me about things. It’s not a very good feeling that makes me feel weird. I feel frustrated. I just wish she would believe me, we’re sisters for Pete’s sake, I don’t lie.”

MU 2.5 Participants described how someone in their lives, whether it was family, friend, health care staff, or a higher power gave them hope and encouragement to carry on when feeling rejected by others. For most of the participants dignity was related to the hope and encouragement from others. P4 voiced the importance of being treated as human being and to be given encouragement from others in the following:

I think dignity means, ah, dignity means ... being helped by somebody who understands the illness and being talked to and having confidence and having guidance and words of wisdom and understanding with one another and association if somebody talks when ya solves your problems over, talk your problems over with.

P6 described how the experience of dignity involved accepting each other as he described the following about his friends who also lived with mental illness:

Well if you have friends ... Some are good friends but sometimes they have a weakness though and don't understand perfectly what their problems are. And the only way I can look at that is I hold them in high esteem because I love them. My friends, yes ... and they mean something to me ... Well, ah say for example there's a misunderstanding ... they ...they ...they lash out at ya because they don't understand ... that's not dignity ... that's a mistake, that's sin ... that's a mistake. In the same token if it happens you forgive them anyway, you know ... that they're only human.

P1 described how family instilled hope despite living with mental illness:

Yeah when I was younger and I was out west for the first year or two or so, my brother commented that I was going to do well ... He thought I was going to go some places ... yeah when I was out there he thought I was going to go places ... yes he was very nice to me ... very nice ... he was the only one who really thought I was going to go places. When he came back and told me that I was going to do well for myself, that made me feel dignified, it made me feel happy or gave me self- confidence ... it gave me more confidence in myself that I could get beyond what I was doing.

P2 described how being involved in volunteer work had increased his self- confidence and gave him the power to carry on. In this narrative he described how the staff has treated him: "... the staff say hi to you and they talk to you and the relationship between us is pretty good. It makes you feel good. Well it means you are being respected and it makes me feel satisfied ... yah, it's a good feeling."

Constituent 3. Dignity can be eroded by ageism, stigma, discrimination, and alienation.

MU3.1 Participants identified that their lived experiences of dignity were related to not having to endure derogatory labels that were a result of having schizophrenia. Throughout this theme, persons living with schizophrenia experienced vulnerability, felt devalued, were excluded and alienated by society, and could relate to a loss of self- identity. P5 related to this theme in the following:

They say things they shouldn't ... they say something bad ... not bad ... things they shouldn't say. Sometimes they take it the wrong way or the wrong meaning if you do or say something ... if it ain't the way they think it should be done, they will say something

to you. “You done bad, you done wrong, you didn’t do what I told you to do, it’s not what I wanted you to do.

However, he also recognized when he was not being labeled by others for having a mental illness:

I have a paper route in the morning ... I do a paper route at 5:45am, 18 people. They are pretty nice, they tip me well, they are good to me. They tip me, not only that they don’t push me, or get on my case if the paper is late, they are pretty good. It gives me something to feel good about and get my own way a bit. The people are good to me. They are good people. They tip me so they must be satisfied with my delivery. Yeah, I am able to do something.

P4 described the discrimination that has occurred in his lifetime related to being mentally ill:

Well other than people talk behind my back, and saying bad things about me, and saying I was an idiot, that I was ah ... crazy lunatic, and that, ah ... ah ... you know that I ... I ... my brains was burned out and that I was, ah ... well they say I'm better off dead than alive, that nobody come to my funeral if I die, and all those things. I mean those things are the opposite of dignity, its disrespect.

MU 3.2 Participants experienced feelings of alienation when others knew they lived with mental illness. P4 expressed the importance of being understood and not condemned for having mental illness:

A lot of people around town, ah ... think that I shouldn't have my own room here that I should be in a mental hospital. I don't care where they put me. They're not in my position they're not in my boots. Yes, it curses my dignity, it goes against everything I believe, all my beliefs, and all my concerns, and interests. It's falling away, you know, it's judgment

like people can pass good judgment or bad judgment. But most mental health patients have by the feeling and the stigmatic attitude toward people in the public is, ah ... either one of three things. They don't give a damn about ya, they think that we're lunatics ... we're not. They think that we're ... we're ... we should be on an island all to ourselves by ourselves, left alone to ourselves and isolated and many other things they believe in.

P1 who had been professionally employed prior to his diagnosis of schizophrenia explained the importance of acceptance versus alienation in order to experience dignity by sharing the following:

Being accepted as a person who has certain qualities and that person should be able to express themselves in a certain way and get their ideas across and that person should be able to ... ah ... find employment in his area or some kind of ... not be left behind ... not be left behind ... and noticed and not to be ignored ... not to be humiliated or ridiculed too much and if you are then know when you are being ridiculed or humiliated ... and if that's okay with you ... it's like putting your head on the line every time you go out and talk with someone ...you put your neck out.

He also described in the following narrative the experience of alienation:

Most of my troubles were away. I did not belong out there and they did not want me out there. Even my relatives told me we don't want you out here. They said that to me "we don't want you out here." I didn't feel good about that. I would see them more often, too much maybe, and then they would disappear on me and wouldn't show up and I would be left stranded.

MU 3.3 Living with the stigma of mental illness for many years led to some participants believing that they did not deserve to experience dignity. P3 initially associated dignity with a higher class of person than himself in the following narrative:

You know in my life, in my life, you know I'm an ordinary fella and you know I don't know not a whole lot in my life. No I haven't had a lot of you know, I ... I ... associate with, with a class of person that's higher than I am, you know? I'm not a high class person. I just get up in the morning and have breakfast and, and ... um I take a shower, and ...uh maybe go down to the coffee shop, and you know these aren't important, these aren't important things, you know? Dignity is something associated with an important event, it seems to me. The common place fella, the common place fella doesn't get a lot of dignity. The ordinary joe, the ordinary joe doesn't act in a dignified manner, you know? He might, he might you know, wipes his hands on his clothes or he might blow his nose and throw the tissue in ... in ... in the garbage or something. These are things of just ordinary kind everyday occurrences, you know? But the ordinary fella it seems to me ... dignity is something that's situated with ... ah ... to me at least more important members of society.

He also believed the following about age and dignity: "I think being older ... it seems to be ... would be common place to say you want to be dignified ... I am sure that it's (dignity) something that's just a part of being older." P1 described the negative impact of stigma on self-concept in the following narrative:

... I didn't have self-respect for myself and I didn't know that I could of got further than I did as I dropped it. I am almost like a drop out in society, I copped out, I copped out kind of thing. I don't know how to engage myself into the main stream again. I am in the

outside looking in. You either in or you are out and I am out and I don't know how to get in again

Constituent 4. Dignity can be interrupted when the positive and negative symptoms of schizophrenia are present and misunderstood by others.

4.1 Participants living with the symptoms of schizophrenia recognize how mental illness can permanently affect sense of self, sanity, and wellbeing. Throughout this theme, most persons with schizophrenia have described how they have been judged for their bizarre behavior related to their mental illness, lacked the necessary support to enhance recovery, and how self-concept was permanently affected. P4 described how he believed he was misunderstood and labeled for having a mental illness in the following description:

Well I've been spoke to different times up town there. I was crazy to be served, locked up forever and every time I speak religion in Hillsborough or Unit 9 they put me in the side room. They don't want me speaking about the bible or ... but preachers in churches that protecting the churches. But I speak to people on the street they say I'm scaring people. People tell me that I'm scaring them by preaching about God. I speak about the judgment, eh ... I feel offended, I don't ... don't scare them intentionally. I just say quit drinkin', or quit the drugs, or quit cursing, or quit stealing, quit breaking the law, quit becoming a criminal because ... sometimes a jail instead of rehabilitation people makes them more criminalized ... A lot of people around town, ah ... think that I shouldn't have my own room here, that I should be in a mental hospital. I don't care where they put me.

P1 also discussed how he believed he was misunderstood because of having a mental illness and how difficult it was at times to express his point of view and be taken seriously in the following:

I try to communicate but I am not very good at it. So I couldn't teach school because they told me I couldn't get my ideas across. It's those thoughts in my head I can't get them out. I can't get those ideas out of my damn head out into the open ... I was teaching school first two years, they were terrible. Oh I had a rough time with the principal who didn't like me at all ... school principal didn't like me and the kids didn't like me because I was warped in my thinking. They were harsh and they didn't treat me right and brought them that hatred to me in the classroom.

He also described how his experience with mental illness affected sense of self:

Yeah around the time I got ill, in my 20's I was hearing voices; that's part of schizophrenia. It made me feel a bit worse on my dignity side. I thought I would never get anywhere; didn't make me feel good; my self-esteem was bad. My dignity ... I didn't have a lot of dignity in my life; it was all downhill.

P6 described preconceived ideas by others about his mental illness that had occurred since he was diagnosed with schizophrenia and shared the following on how he felt when he was being judged:

When the schizophrenia flaring up ... they didn't understand ... they didn't quite understand what the nature of my illness was ... they didn't have it diagnosed I had been in the hospital for about 9 months, 6 months. Yah and that was really hard on me ... I ... I felt demeaned, you know. It was the illness ... it wasn't anyone's fault ... it was my illness. Yah there was times when some of the workers that were there didn't understand my nature, my nature of my illness ... they would de-ride me ... Well they'd sit there or stand there and say "oh you're nothing but a queer" or something like that you know ... I'd just

say to myself he doesn't understand the nature of my illness to say that. I don't know if I lack dignity, but I feel my illness gets in the way...

P3, who had taught school and worked in journalism described how living with schizophrenia had affected his wellbeing by being unjustly called names by others and how he accepted it in the following comments: "They'd just shout insults and criticisms and ... ah, you know, name calling, you know. Oh nasty names, you know? Crazy or cuckoo ... it's all right, you know."

MU 4.2 Participants expressed having fragmented relationships due to a lack of support especially when the participant were experiencing acute symptoms of hallucinations, delusions, bizarre behavior, and or changes in mood. P3 also described how the symptoms of his illness affected the treatment he received when he was ill:

I've had sickness in my life and I think of a time when I got in trouble with the law as a matter of fact ... over a dispute with some people and they certainly didn't treat me with dignity, everything but, you know ... they treated me nasty ... poor treatment, and I reacted, and I got in trouble, and then again there have been a few times when I've been treated poorly ... treated very poorly, but ... ah, they can't pull you down you know, they can't pull you down ...

Successfully completing high school at night school after being unable to continue school after he became mentally ill, P5 described how he lacked support from family:

I felt good that I finished my grade 12 and got that much done. Well I felt like I accomplished something. Most would not bother. I felt better and that I accomplished something with my parents that had opinions of me which were not very pleasing to me, that they would not go a long with my sexuality problems, my nerves and my depression

and so on, I was ... I found they did not understand that it was my health ... they thought it just the way I was and I wasn't like that they thought I was. My parents they didn't quite understand me my health, my issue, it wasn't that they could understand, they couldn't deal with it.

Constituent 5. Dignity can be enhanced when self and others embrace a recovery oriented relationship that optimizes psychosocial functioning of the person and living with schizophrenia.

MU 5.1 Participants expressed the need for support of others to ensure that hope is instilled and dignity is experienced. In this theme, participants spoke favorably about people in their lives that have helped them maintain stability while living with schizophrenia by supporting, encouraging, accepting and respecting them as a person with a mental illness.

P1, who spoke highly of the LCCF staff where he lived, explained:

Well C. treats me with dignity here ... and so does W; and when R. was here she treated me with dignity too. And she wouldn't let me give up and she wouldn't let me quit. Yeah ... when people around you say don't give up ... they are great ...

He also verbalized how someone in his life had been an encourager that helped him to have hope:

She wouldn't let me fold in and say well quits call quits ... she wouldn't let me do that and she said you are not a quitter you're a fighter when I wanted to quit half way through a job and half way through the experience of being treated for mental illness ... She wanted me to keep going.

Another participant P5, described how important it was to him to have his sister's support and understanding of his diagnosis of schizophrenia:

She understood ... she was a nurse ... she was a LNA ... she was more understanding ... both of my sisters were LNA's and she was more understanding than my parents ... my parents just thought I was a fool ... my sisters were more aware what was going on with me more so than my parents were. Well my parents just didn't ... they found it hard to accept that I had schizophrenia with depression on top of it. My sisters, they seemed to know me better. I was younger; I was just 18 or 19. I had just grown out of my teen years. And they seem to understand what I was going through and what schizophrenia and depression was. I was getting deeply depressed and I thought I was the anti-Christ and all this stuff and that is why they put me in hospital. It was the only thing they could do at the time.

He also believed that the care that he had received from health care professionals while hospitalized was pivotal to his ability to live in the community.

Dr. P., she was my doctor at the time ... and she seem to know it ... see I went into a deep depression when I first got sick ... for months before I had treatment ... see they let it go for a long time before I went into hospital for treatment and that sort of cause me a prolonged and more intense depression and illness at the time. Dr. P gave me shock treatment I felt comfortable with her. It was an experience of dignity, I felt comfortable and relaxed and that is dignity. That's where Dr. P. came in. She seem to know what to say and what to do and tell me what to do and how to act. That helped me through it all.

A third participant P4, gave recognition to family and friends who were supportive and made him feel accepted and experience dignity:

The only dignity I experienced was in hospital when I had my family and friends visit me and sit down in the chair and see how I'm doing when I'm gettin' out, when I'm gettin'

well and wish me well, but, ah ... kinda of ... ah ... consider anothers' feelings toward the illness and accept it. I think that covers it pretty well ... ah ... I have my ministers come to visit me and preach to me and console me.

P3 also agreed that it was others in his daily life that have helped him to experience personal growth and stability in his mental illness.

We all treat each other with dignity here ah ... I don't know how familiar you are with the lodge, but the lady that owns the place, has the place running as smooth as silk, you know, and we all treat each other with dignity, you know.

MU 5.2 Participants described feeling empowered, experienced personal growth, and accomplishment when others treated them as an equal. P4 voiced the importance of being treated as human being and to be given encouragement from others in the following. He also described what gave him hope to continue:

What it is I have ... I pray for is, courage, patience, perseverance, endurance, faith, hope and love. Well another world for dignity I use is, ah, serenity and solitude. I come here when I get all worked up and my ... my mind's racing, I'll go for a walk or walk it off or talk off, but I lay in bed here on my back and thank the Lord for a pillow to lay, and a comfortable bed to rest, and meditate, and contemplate God's word eh ... so that gives me dignity and respect. That helps me with my dignity and those things. But I think it's people that gives you encouragement and gives you hope, ya know?

P8 shared how his experience of dignity involved personal accomplishments that had increased self-confidence and gave him a reason to hold his head high in the following: "Going to church regularly and having friends there; be chosen to be a Mason; graduating from college; and for the last three or four years I had to go get a driver's test, every six months and I passed every time."

Another participant, P2, described how he is treated when he is out in public:

When you walk past the place and they're strangers, but they say 'how are you yah', people just say hello and how are you. It makes me feel good and accepted. Well one time I was in the pub and I asked if they had .5% beer and they're sorry they were all out of it, but this girl came, with she came, it was a hot day and she came and she said to not get dehydrated and she gave me a glass of water. That was really nice of her.

MU 5.3 Participants experienced dignity when they were included in meaningful social activities. P4 described how important it was to him to have friends who did not live with mental illness in the following:

Well I ... I have a friend ... she takes me out for dinner now and then as a friend, not as a lover, but as a friend. She understand the situation, we remain friends. So, I met her about a year ago and that's dignity, and then she ... we talk, we have bible studies together every Tuesday at the mall.

Another experience of dignity for P4 was when he had an opportunity to attend a church camp retreat.

Well, the only dignity that I felt was when I was in Augustine Cove in Camp Abegweit retreat for elig ... for Christianity retreat camp and site ... That's back about 20 years ago. I went to Fredericton retreat over on the mainland, as the title Man is Not Alone and I was up there, Man is Not Alone, that's the motto. And when I was there with nature, and the flowers around the banks there, the smell of the animals and the birds ... there's a tranquility solitude, ah, feeling you know? And, ah, you know that gave me dignity of nature, the love of nature, and the understanding that nature's more important to life than just mechanical or physical items, eh. With nature and ... and ... and, with the sunshine

and the sandbars. We were out there doing community standing around in a circle on the sand bar, that was different.

P3 described how he had wanted to experience inclusion and dignity in the following:

You want someone to treat you a certain way and they don't treat you a certain way, you know ... your dignity might be affected ... it's just ... ah you agree to meet someone for a coffee and they don't show up, you know or they show up late just nothing that took my dignity away completely, kinda thing, you know ... It makes you feel bad, you know but for a little while, but I don't feel bad for a long while with these things..

P3 also recounted how he had experienced dignity and respect through meaningful activities and at his work.

I was working and I was busy at something ... I was always active and ... ah going from one thing to another ... I worked for many years as a reporter and then as door-to-door newspaper delivery. Oh I enjoyed that and people were good to me.

P6 commented on how he had a friend outside his home at the LCCF whom he described as someone who treated him with dignity and helped him experience a feeling of inclusion.

She lived at the house that I lived not here another place. She's a kind gentle person.

There's dignity in her, a lot of dignity, yah ... My relationship with her is great. She gave me dignity, gave me dignity. Well she was a friend that's all we weren't going steady or anything.

Summary

In this chapter, I presented the experience of dignity for eight older adults living with schizophrenia who resided in LCCFs. Demographic data was provided to give a brief description of those who participated. I used Giorgi's (2009, 2012) phenomenological psychological method

to uncover the meaning of dignity in older adults living with schizophrenia. There was a range of meanings and influences that impacted the lived experience of dignity for the older adult with schizophrenia. In this study, participants described their experiences of dignity as an intrinsic or self-regarding experience; as a reciprocal extrinsic, others regarding experience, which is embedded in social relationships; being eroded by ageism, stigma, discrimination, and alienation; being interrupted when the positive and negative symptoms of schizophrenia are present and misunderstood by others; and enhanced when self and others embraced a recovery-focused relationship that optimized psychosocial functioning of the person living with schizophrenia. A discussion of findings will now be addressed.

CHAPTER 5

Discussion

The purpose of my study was to explore the essential elements of the lived experience of dignity as verbalized by older adults living with schizophrenia and who reside in LCCFs. I used a descriptive, qualitative design following Giorgi's (2009, 2012) phenomenological psychological method to uncover the meaning of dignity for older adults living with schizophrenia. I will provide a summary of my findings, followed by an overview of the constituents and psychological descriptions of the experience of dignity in the context of existing literature.

An Elaboration of the Experience of Dignity of the Older Adult Living With Schizophrenia

By using a phenomenological analysis, I was able to reveal the constituents and meaning structures of the phenomenon of dignity from the perspective of eight older adults living with schizophrenia and who resided in LCCFs. The participants were predominantly male, over the age of 60, had been diagnosed with schizophrenia for approximately 36 years and resided in LCCFs for an average of 18 years. All of the participants were able to identify a personal experience of dignity and willingly shared their experience.

The findings of this study indicate that dignity remains a complex concept and is individually understood in older adults living with schizophrenia. Dignity is enhanced when the personal values of the older adult living with schizophrenia are recognized. Being accepted by others is an important aspect of dignity for participants of this study. The findings reveal that the behaviors of the person living with schizophrenia, and that of others, is important to the experience of dignity and indignity, as are other thoughts, feelings, attitudes, and behaviors towards the person living with schizophrenia. It is also evident throughout the interviews, that

inclusion by society contributes to the participants' well-being and allows them to feel accepted and valued. Dignity is related to the hope and encouragement from others, however, many of the participants felt vulnerable, devalued, excluded, and alienated by society, which led to loss of self-identity. Many participants described how they have been judged because of their bizarre behaviors which are a result of their mental illness, lacked the necessary support to enhance their recovery, and how their self-concept was permanently affected. All the participants identified that dignity was enhanced when the participant and others embraced a recovery oriented relationship, one that optimized the psychosocial functioning of the older adult living with schizophrenia.

Discussion of the Meaning of Dignity in Older Adults Living With Schizophrenia

Dignity is an Intrinsic or Self-regarding Experience

Participants identified that when they experienced dignity, they were being treated with self-respect, were treating others as they would treat themselves, and were receiving respect of others such as family, friends and society. This experience provided a sense of happiness, a feeling of being understood and increased self-confidence that provided the participants with a reason to hold their heads high. In essence, this recognition of the importance of personal values enhanced the older adult's experience of dignity when living with schizophrenia. One participant described a feeling of sanity when he was experiencing dignity and that gave him the hope to persevere while living with schizophrenia. Literature supports that dignity is intrinsic, with all people being born with the possession of dignity, autonomy, self-respect, and spirituality (Gallagher, 2004; Periyakoil et al., 2010; Spielberg, 1970; Sulsmasy, 2013). Similarly to my findings, Maris (1994) viewed dignity as being individualized, important to be maintained, exemplified when the person makes his or her own choices, is acquired through life experiences,

and that dignity is given little consideration unless a person became vulnerable or could anticipate its loss. Moreover, Haddock (1996) identified dignity as both a subjective and a shared belief among humanity, and that the effect of dignity within oneself affects the ability to maintain or promote the dignity of another. Griffin-Heslin (2005) viewed dignity as an ability to feel important and valuable in relation to others, to communicate this to others, and to be treated as such by others. Dignity is important to older adults and is perceived as an identity (e.g., self-respect/esteem, integrity, trust), a human right (e.g., equality, choice, human entitlement to dignity), and autonomy (e.g., independence, control, freedom of choice (Woolhead et al., 2004).

In my study, participants described the importance of being able to think independently and have the opportunity to make personal decisions, to have a sense of autonomy and self-determination, and to be treated as an equal in every aspect of daily life, which made them feel good about themselves. These findings are congruent with Chochinov's (2007) and Shotten and Seedhouse's (1998) who believed that when older adults are not given the opportunities to demonstrate their capabilities, they experience a lack of respect, indignity, a weakened sense of value and worth, a burden to others and questioning of their own existence. Additionally, Clark (2010) described dignity as a fundamental human right with the expectation of feeling and/or being regarded as important and valuable in relation to others. In my study, participants acknowledged a sense of mastery in their life and that personal dignity was experienced when they were treated in a dignified manner or being successful in accomplishing something despite being diagnosed with schizophrenia.

Furthermore, participants verbalized that dignity was an attribute of the self, expressed as values and virtues that must be maintained in their lives in order to feel good about themselves. Acceptance by self and others resonated throughout the interviews of participants living with

schizophrenia. And when feeling accepted, the participants described situations where they felt honoured, recognized, and were given a purpose in life. These findings support the work of Edlund et al. (2013), in which they developed the values of ‘absolute dignity,’ which represents the spiritual dimension characterized by holiness, human worth, freedom, responsibility, duty, and serving one’s fellow-men; and ‘relative dignity,’ that mirrors absolute dignity, but its values are influenced by culture and are hierarchical. Personal faith is also an attribute that helps participants to feel accepted and maintain a sense of self. Furthermore, Nordenfelt (2004) identified dignity of *menschenwurde*, which refers to the “human value of dignity that all humans have or assume to have because of being human” (p. 70). Given that humans are equal, this dignity should have the same value for everyone and no one should be treated with less respect than anybody else and it cannot be taken from the human being as long as he or she is living. Nordenfelt also views dignity as moral structure and dignity that is dependent on the thoughts and actions of an individual in order to maintain self-respect.

Dignity is a Reciprocal Extrinsic, Others Regarding Experience, and is Embedded in Social Relationships

Participants expressed the importance of being accepted as a human being by others and not being ignored, ridiculed, and/or humiliated. For most of the participants who were all diagnosed with schizophrenia and lived in LCCFs, being accepted by others and included in positive and respectful social engagement and social inclusion was an important aspect of dignity. Extrinsic dignity can be thought to remain outside the person and can be influenced by the way the person is treated by others (Gallagher, 2004) and is preserved when a person’s physical and emotional needs are met, when he/she is treated with respect, and when attempts are made to maintain privacy and confidentiality (Periyakoil et.al., 2010). These findings

collaborate with Nordenfelt's (2004) perception of dignity as an 'identity', which is attached to the person's integrity and identity as a human being, but can be lost due to the acts of others, injury, illness, and age. Jacobson (2007) identifies dignity as having two dimensions; one that includes human dignity as a fundamental human value, and the second as social dignity that was grounded in human dignity and is experienced, bestowed, or earned through interaction in social settings. However, this all depends on how society acknowledges the value of every human being.

Nordenfelt's (2004) work supports the older adult's desire for acceptance and the need to be recognized as a person and not for their illness. One participant, who described himself as a 'sick person', stressed how important it was for him to be understood, accepted, and treated like a human being in order to experience dignity. He went on to recount that having schizophrenia was not curable but it was not a death sentence either. Dignity in the older adult is at risk of being lost, especially in the care practices of health, social care settings, disregard for human rights, and the lack of senior focused policies (Woolhead et al., 2004). This study supports the concerns that are described by participants of this study, with when dignity (intrinsic or extrinsic) is not met, the person does not experience self-esteem, or autonomy, and loses a sense of hope (Periyakoil et.al, 2010). Similarly, Arino-Blasco and colleagues (2005) found that circumstances that constitute undignified care of the older adult are: invisibility; de-personalization and treatment as an object; humiliation and abuse; and narrow and mechanistic approaches to care. In their study, participants identified societal, structural and individual elements as possible barriers to providing dignified care.

Participants described experiencing a sense of self when they felt accepted versus being excluded by others. This held true for participants who described feelings of tolerance and

belonging when family and friends understood and accepted their mental illness and gave them hope and encouragement to carry on when they were feeling rejected by others. The behavior of the person living with schizophrenia, and that of others, is important to the experience of dignity as are other thoughts, feelings, attitudes, and behaviors towards the person living with schizophrenia. It was also evident throughout the interviews that inclusion by society contributed to the participants' well-being and allowed them to feel accepted and valued. Participants described a loss of self and a diminished perception of dignity when they felt misunderstood, not believed or respected by family or staff of LCCFs. Another participant described how he was subjected to ridicule and criticism by strangers related to his mental illness. However, his response to this treatment was to accept it, as he had become used to the negative comments and stigma that he had endured for most of his life.

Dignity can be Eroded by Ageism, Stigma, Discrimination, and Alienation

All participants described an experience of feeling vulnerable and devalued, excluded and alienated by society, and could relate to a loss of self-identity associated with living with schizophrenia. Dignity was connected to not having to endure derogatory labels that were a result of having schizophrenia. It is recognized in the literature that older persons with schizophrenia are subject to stigma and labelling, discrimination, negative attitudes and behaviors, therapeutic nihilism, and ageist bias that can affect their self-esteem and self-worth (Anderberg et al., 2007; Black & Dobbs, 2014; Collier & Sorrell, 2011; Granerud & Severinsson, 2003; Leutwyler et al., 2010; Moody, 1998; Murphy, 1998; Whitley & Campbell, 2014).

Labelling and stigma were experienced by the older adults living with schizophrenia leading to experiences of alienation when others knew they lived with mental illness. During the

course of this study, the importance of being understood and not condemned for having a mental illness was voiced. One participant described how he had been told by strangers that he did not deserve to be living outside a psychiatric hospital. He strongly believed that there was no regard for individuals living with mental illness, and that he and others living with schizophrenia were thought of as lunatics who should be isolated from the rest of society. This concurs with Depla and colleagues (2005) who believed that older adults who are living with schizophrenia lack the support to overcome life's adversities, endure labelling, discrimination and are not accepted by society, resulting in a loss of self or belonging. The researchers also stressed the importance of destigmatization to prevent social withdrawal when participants are experiencing more stigmatization and less satisfaction quality of life; resulting in a undermining of self-esteem, psychosocial well-being, and social adaptation. Moreover, Phelan and Link's (2011) study linked labelling and stigma of individuals diagnosed with serious mental illness to a decrease in self-esteem and the possibility of an increase of devaluation, discrimination, and exclusion. Their theory on labelling and stigma indicated the importance of attitudes and beliefs of society and they suggest that the negative stereotypes and social distancing responses have changed little and may have even strengthened over the years.

My findings revealed that living with the stigma of mental illness for many years resulted in some participants believing that they did not deserve to experience dignity. Participants downplayed their personal existence by identifying themselves with words such as: 'ordinary', 'common place', and 'not a high class of person'. Another participant described the negative impact of stigma on self-concept by recounting how he had a lack of self-respect and thought of himself as a 'drop out in society' and 'on the outside looking in'. This collaborates with the research reported by Guimon (2010) on the lack of respect for human dignity that individuals

with mental illness experience. Results showed that individuals with a serious mental illness, such as schizophrenia, deserve to be treated equally in dignity and right, regardless of their mental capability and should not have to experience stigma and discrimination. Guimon suggested that to reduce prejudice in this population, improve self-esteem and dignity, a serious effort must be made to eliminate alienation.

Dignity can be Interrupted When the Positive and Negative Symptoms of Schizophrenia are Present and Misunderstood by Others

Noiseux and Ricard's (2008) grounded theory study on recovery indicated that participants living with schizophrenia described their symptoms of illness as "a sense of having their souls invaded and of being trapped in an extended descent into hell" (p. 1153). The researchers also described how the participants' symptoms of schizophrenia have a permanent impact on their hopes and dreams, and how they experience ostracism by family and friends. The participants in my study recognize how mental illness can permanently affect their sense of self, sanity, and well-being. They also express having fragmented relationships due to lack of support especially when the participants are experiencing acute symptoms of hallucinations, delusions, bizarre behavior, and changes in mood. One of the participants described how he was labelled and misunderstood by others and was told on different occasions that he was crazy, scaring people, and that he should be 'locked up forever'. He recognized his own personal symptoms of illness and when he verbalized increased religiosity, it caused him to experience isolation and negative consequences.

My findings support the experiences of Lee (2005), who lives with schizophrenia, describes how his positive symptoms such as auditory and visual hallucinations and thought disorder, led to confusion, delusional thinking, and inappropriate behaviour that could elicit

emotions, feelings, and reactions that are not usual responses to a real external influence. Lee (2005) also commented on the stigma that he and others with schizophrenia endure and that their work still needed to ensure that the person's environment changes by becoming more functional or that the person feels accepted in society. Tsai, Lysaker, and Vos (2010) concurred that the stigma of negative symptoms of schizophrenia are a significant barrier to function as these symptoms can cause impairment in attention and decrease the ability to express emotion, experience pleasure and to initiate involvement in their environment resulting in social withdrawal. Their findings suggest future research on how the effect of negative symptoms and attention dysfunction can lead to an ongoing negative coping cycle for the person with schizophrenia. A cycle in which the person feels that he or she is unable to cope with stress, therefore ignoring daily life issues, unable to problem solve, which enables worrying about daily activities, and eventually develops into seeing social situations as a source of embarrassment.

In my study, one participant described how he felt misunderstood and had difficulty at times expressing his point of view or be taken seriously. Disorganized thinking impacted his ability to work in his chosen profession, while experiencing hallucinations affected his sense of self, self-esteem, and dignity. Similarly, Reavley and Jorm (2011) revealed that perceptions of discrimination, social distancing, a preference to not employ, dangerousness, and unpredictability are the general beliefs about individuals living with schizophrenia. The researchers' work resulted in advocating for anti-stigma interventions in Australia.

Other participants in my study described preconceived ideas about their mental illness by others that made them feel judged, ridiculed, and thus lacked support from family friends, and society. Because of this treatment, the participants' well-being was affected. Noiseux and Ricard (2008) also identified that persons with schizophrenia experience ostracism by family and friends

usually due to the persons' attitudes, bizarre behaviours, and a misinterpretation of the symptoms of schizophrenia being experienced. They articulate the importance of assistance of a support network to ensure that recovery is possible and successful.

Dignity can be Enhanced When Self and Others Embrace a Recovery Oriented Relationship that Optimizes Psychosocial Functioning of the Person Living with Schizophrenia

The participants in my study spoke favorably about people in their lives who have helped them maintain stability while living with schizophrenia by supporting, encouraging, accepting, and respecting them as a person with a mental illness. They also expressed a need for support from others to ensure that hope was instilled and dignity was experienced. Participants described the support that they had received in comments that included: 'wouldn't let me give up', 'wouldn't let me quit', 'she said I was fighter not a quitter'. It was important for the participants to know that someone not only believed in them but recognized their potential when they could not. According to the American Psychological Association (2012), recovery is considered to be self-directed and person-centered that empowers clients to take responsibility for their journey, focuses on the clients' strengths, while they are receiving peer support and respect. Living in an environment where most participants had described themselves as 'second class citizens', having someone in their lives who encouraged and believed in them was pivotal for them to maintain stability in their illness and recovery of schizophrenia.

Lysaker and Buck (2006) described how the goal of treatment for persons with schizophrenia should not only be stability, but recovery if not fully, over time. The researchers recognize that the exact definition of recovery is unclear, however, it is generally used to "talk about adaptive changes in people's appraisals of themselves and their future potential that

promotes a holistic movement towards health” (p. 29). The Mental Health Commission of Canada (2009) also believed that the focus of recovery is allowing individuals to make their own decisions about their mental health and well-being, changing the way society views mental health and mental illness, improving health outcomes and enhancing quality of life for persons who live with a mental illness. Kaewprom, Curtis, and Deane (2011) identified hope, illness acceptance, self-responsibility, and supportive environments as some factors that facilitated recovery and well-being in the person living with schizophrenia and negative public attitude and stigma as primary barriers. The researchers recognized the importance of a change of attitude and a need for increased knowledge for nurses regarding the importance of recovery of clients with schizophrenia.

Participants in my study described feeling empowered and experiencing personal growth and accomplishment when others treated them as an equal. The importance of equality was conveyed by the participants sharing experiences of being treated as a human being, given encouragement from others, and when they achieved personal accomplishments that increased their self-confidence while giving them a reason to hold their head high. It was the little things that most people take for granted that the participants of this study used as examples of experiences of dignity in their personal life. One participant described an experience of dignity that related to how good he felt about himself when someone would simply greet him when he was walking on the street or when he entered a public place. Another participant described his appreciation of having a comfortable bed to lie on to meditate and pray about all the good things that he had in his life that helped him to feel empowered to go on each day. These findings are consistent with Noiseaux and Ricard (2008), who identified that persons living with schizophrenia are constantly trying to find a way to fit into society through ongoing interactions

with their social and physical environments. However, this is only possible with the support of peers, family, and health professionals who believe in them and treat them as an equal, but also if the person will accept this support. In turn, persons with schizophrenia begin to develop a greater well-being, self-awareness, and understanding of their limitations and begin to work through the recovery process. Similarly, Lee (2005) recognized the recovery process for persons with schizophrenia as a retainable goal but describe it as an individual path, as each person is mentally and socially skilled, financially adept, and spiritually driven differently.

The participants of my study emphasized the importance of being included in meaningful social activities in order to experience enhanced dignity and to be able to embrace recovery. Perry, Henry, Sethi, and Grisham (2011) explored how social exclusion affects persons living with schizophrenia and identified the possibilities of ostracism related to the stigma associated with mental illness. Their study also examined the social isolation and lack of involvement in social activities that occur for persons with serious mental illness related to social distancing by society. This is primarily due to a lack of understanding of mental illness and preconceived ideas by society, that persons with schizophrenia can be dangerous and unpredictable. Perry et al. (2011) recognized the seriousness of this problem as they identified that persons with schizophrenia, who are chronically exposed to social rejection, may begin to accept alienation and isolation, and give up on seeking social relationships which, in turn, further isolates them.

Conclusion

Interviewing older adults with schizophrenia not only allowed them to reflect on their experiences with dignity, but by using Giorgio's (2009, 2012) phenomenological psychological method to analyze the data, I was given a better understanding of the lived experience of this population. In reviewing the participants' narratives, I could see both similarities and differences

which reflected the complexity of understanding the experience of dignity for the older adult living with schizophrenia. Despite this complexity, the men and woman who participated in my study have given me an understanding and meaning of dignity in their lives and the influence of dignity on their lives. The literature strongly supports that dignity is an experience that is intrinsic, extrinsic, reciprocal, and embedded in social relationships. However, little is documented on the effects of ageism, discrimination, stigma and labelling on the dignity of individuals living with schizophrenia. Further research is required on how dignity can be interrupted when the positive and negative symptoms of schizophrenia are present, misunderstood and permanently affects sense of self, sanity, and well-being. The literature is also sparse on how dignity can be enhanced when a recovery oriented relationship, that optimizes psychosocial functioning of the person living with schizophrenia, is embraced.

CHAPTER 6

Researcher's Journey, Limitations, and Implications

The purpose of my study was to explore the essential elements of the lived experience of dignity in the older adult with schizophrenia who resides in a LCCF. A research design using Giorgi's (2009, 2012) phenomenological psychological method was chosen to further understand the essence of dignity experienced by the older adult with schizophrenia. This chapter presents the researcher's journey and limitations with the dignity experience using Giorgi's method, implications for practice, recommendations for future research, and conclusion of this study.

Researcher's Journey and Limitations Using Giorgi's Phenomenological Psychological Method

As a novice researcher, I am aware of the limitations of my understanding and use of Giorgi's (2009) phenomenological psychological method, however, every attempt was made to assume a phenomenological attitude, determine the essence of the phenomenon of dignity, and describe the psychological perspective as accurately as possible. It was imperative that my pre-understanding of the phenomenon as a psychiatric mental health nurse was made explicit and bracketed in order to remain open and sensitive to the phenomena of dignity throughout the entire research process. Therefore, to prevent error from my past knowledge being imposed on this study, and in following steps outlined by Giorgi (2009), I identified numerous presuppositions that influenced me and were foundational for my research. I bracketed my past knowledge about dignity in order to focus on the present experience of this phenomenon, and used the method of free imaginative variation to apply to the phenomenon of dignity so that the

essence could be discovered, and lastly when the essence was determined I carefully described it (Giorgi, 2009).

Kleiman (2004) agrees that the richness of phenomenology lies in the raw data descriptions to justify articulations of both the essential meanings and the general structure. As a novice researcher, I did my best to ensure that all of the findings were substantiated in the raw data. Kleiman also mentions that some theorists have added a step to Giorgi's (2009) phenomenological psychological method, of returning to the participants to confirm the analyses. However, Giorgi believes that the completion of the phenomenological analyses is the responsibility of the researcher, and not the participants. Thus, in keeping with the steps of Giorgi's phenomenological psychological method, I did not incorporate this extra step. The analysis of my phenomenological data on the experience of dignity for older adults living with schizophrenia relied on my interpretation and there could be a difference in themes if another investigator was critically analyzing my data. However, Giorgi suggests that this is not peculiar for phenomenological research and that if I have read my participants' descriptions without prejudice and thematised the transcripts from their perspective, the quality of the findings is neither impaired nor contaminated.

Englander (2012) describes the occasional difficulty of finding participants for a phenomenological study. Although it was challenging to access participants, I was able to interview eight older adults, seven men and one woman all who have experienced dignity. More men than women who have a diagnosis of schizophrenia live in licensed care facilities, which may have influenced the accessibility of men over women. Also, there is a tendency for more women to marry or have a partner and thus are able to live in the community versus a licensed care facility. In future research, I would consider accessing an equal number of women in order

to determine if there were any gender differences in the experience of dignity. In regards to the number of participants, Giorgi's (2009) phenomenological psychological method requires at least three participants to ensure that there is variation in the raw data. I had eight participants, but only one was female. It is questionable if the raw data would have had more variation if there had been equality in the gender of my participants.

Lastly, the demographics of my participants for this study, who had lived with schizophrenia for a mean of 36 years and resided in LCCFs for at least 18 years, could be considered a limitation to my study, as the perspective of dignity for individuals outside these demographics could be viewed differently for someone who was newly diagnosed or had late-onset schizophrenia. The same could be said about the lived experience of dignity for individuals living independently or living in a nursing home. The essence of dignity may also be experienced differently for individuals with schizophrenia who were in relationships, have children, are successfully maintaining employment, in a higher social-economic status, or a different culture.

These are all areas suggested for future research. Despite the limitations of my research, there are many implications for nursing practice, theory, education, and research. The implications of my research will now be addressed.

Implications

The findings of this study have brought to light how older adults with schizophrenia living in LCCFs have experienced dignity and this is reflected in five main constituents: (a) dignity is an intrinsic and a self-regarding experience; (b) dignity is a reciprocal extrinsic, other regarding experience embedded in social relationships; (c) dignity can be eroded by ageism, stigma, discrimination, and alienation; (d) dignity can be interrupted when the positive and negative symptoms of schizophrenia are present and misunderstood by others, and (e) dignity

can be enhanced when self and others embrace a recovery oriented relationship that optimizes psychosocial functioning of the person and living with schizophrenia. Essentially, dignity is affected if the older adult is not experiencing self-respect, autonomy, being treated as an equal or accepted as a human being. Dignity is also influenced when the older adult is supported by others versus being excluded by society, creating an experience of sense of self. Dignity for older adults has been compromised by having to endure derogatory labels, feelings of alienation and living with stigma of mental illness for many years. Living with the symptoms of schizophrenia can also permanently affect their sense of self, sanity, and well-being and lead to fragmented relationships. However, dignity can be enhanced when older adults receive the needed support that ensures hope, empowerment, and personal growth, and when they are included in meaningful social activities. The findings of this study which have implications for the discipline of nursing in practice, theory, and education, will now be presented.

Implications for Practice

To practice holistic nursing and to enhance the quality of life, nurses are required to incorporate the client's perspective of dignity into their care, especially when working with clients who are living with schizophrenia. However, in order to be effective in the delivery of care that promotes dignity and respect, nurses must reflect on their own personal values, behaviour, and attitudes which play a large role in the quality of care that they deliver (Chadwick, 2012). To improve the dignity of the client with schizophrenia, the nurse must be aware of the constant rejection, alienation, derogatory labelling, and stigma that they have experienced. Noiseux and Ricard (2008) stress the importance for nurses to decrease the stigma that clients with schizophrenia must endure, by considering the potential of the client rather than focusing on the negative and positive symptoms of the illness. It is also vital for nurses to help

clients to identify their own well-being, support their sense of self, identify sources of motivation, and support restoration to a state that the client was in before the disease.

The development of a therapeutic nurse-client relationship, centred on trust and acceptance of the person as a worthy human being, is also essential in order to enhance dignity in persons living with schizophrenia. Nurses need to focus more on recovery rather than illness for clients with schizophrenia. Furthermore, focusing on recovery rather than the illness needs to begin with the development of skills and knowledge for nurses, in order to recognize ways to increase quality of life and to support clients who are in recovery. Therefore, by advocating for change that addresses the barriers that prevents clients from exercising greater choice and control, while negatively impacting their hope and dignity, nurses have the opportunity to assist clients in experiencing a life that they can choose and value. Nurses can achieve this by enhancing hope in clients and helping them to see how they can have a more active role in the self-management of their lives; by empowering clients in order to reduce low self-esteem and stigma while improving quality of life. Nurses can teach clients how to increase self-efficacy by helping them to recognize their strengths and abilities to attain personal goals, assisting clients to develop a sense of self and helping them to see themselves beyond their mental illness (Mueser, et al. 2002), while also supporting them in expanding their social networks (South London and Maudsley National Health Services [NHS] Foundation & South West London and St .George’s Mental Health NHS Trust, 2010).

Implications for Theory

Through nursing research, new nursing knowledge can be applied to the nursing curricula. There is a lack of nursing research involving the phenomena of dignity in older adults living with schizophrenia. More specifically there is limited nursing research on the importance

of preserving dignity, addressing stigma, and focusing on recovery rather than illness when caring for clients with schizophrenia. This study offers nurses the opportunity to increase critical thinking and nursing knowledge that can be used in practice to enhance the quality of life, preserve dignity, and support the recovery of clients with schizophrenia in their care.

Using phenomenology research to guide nursing practice allows the opportunity for nurses to question custom and trends of nursing. When using a phenomenology framework, nurses can also consider the essences of care that they are providing by incorporating their clients' perception of their illness (Edward, 2006). Psychiatric-mental health nursing is a specialized area of nursing that can be complex in practice and care for individuals with mental illness (Canadian Federation of Mental Health Nurses [CFMHN], 2014). Specifically, when providing nursing care for older adults with schizophrenia, there needs to be ongoing education and utilization of research to ensure that nurses are aware of the importance of alleviating stigma and discrimination, enhancing the recovery of individuals with mental illness rather than focusing on their illness, and lastly, understanding the essence of dignity for the older adult living with schizophrenia.

Implication for Education

Educationally, there is a need to prepare nurses to take into account how clients with schizophrenia are no different than any other human being and deserve the same treatment, respect, and dignity. It is also vital to educate nurses on the importance of using psychiatric-mental health nursing theory, research, and corresponding interventions. Furthermore, it is important that the nursing curricula include teaching nursing students the importance of developing a therapeutic nurse-client relationship to ensure that the dignity of clients with schizophrenia is enhanced while focusing on recovery rather than their illness.

While the concept of dignity is complex and poorly understood in older adults living with schizophrenia, the findings of this study have added to the knowledge already known about dignity by uncovering a range of meanings and influences that have impacted the lived experience of dignity in older adults with schizophrenia. This study has implications to expand education and improve practice in psychiatric-mental health nursing by identifying the importance of nurses continuing to uphold the dignity, beliefs and values of clients with schizophrenia. Participants in my study described their experiences of dignity embedded in social relationships; being eroded by ageism, stigma, discrimination, and alienation; being interrupted when the positive and negative symptoms of schizophrenia are present and misunderstood by others; and enhanced when self and others embraced a recovery-focused relationship that optimized psychosocial functioning of a person living with schizophrenia. These are all areas that psychiatric-mental health nurses can advance their knowledge by using evidence informed research to ensure best practice. To foster recovery and to begin to remove the barriers experienced by older adults with schizophrenia, there also needs to be ongoing evaluation of nursing policy, continuing evolution of nursing research and nursing practice that is focused on guaranteeing that older adults with mental illness are seen as human beings rather than their illness (Mental Health Commission of Canada, 2012).

Recommendations for Future Research

In this study, I explored the complexities of the concept of dignity and the lived experience of dignity in eight older adults living with schizophrenia and residing in LCCFs. That is not to say that another phenomenological study with a different age group of adults with schizophrenia would yield the same results. The participants in my study had lived with schizophrenia for most of their lives and lived in LCCFs for an average of 18 years. Perhaps the

results of a study with young adults with schizophrenia who are living independently might uncover totally different true meanings of dignity, or explore dignity in young adults with schizophrenia living at home and supported by family. Their lived experience may be quite different than the participants in my study. Possibly middle aged adults with schizophrenia who live independently, are employed, and in a relationship, would also share much different experiences. Interviewing a much older cohort of older adults, who reside in a LCCF or a long-term care facility such as a nursing home, may present with different findings. Also, adults diagnosed with late onset schizophrenia could possibly have a different experience of dignity than the population used for this study. My study also had a majority of male participants. I would like to determine if the lived experience of dignity in older female adults with schizophrenia would be perceived differently. Consideration of those older adults who come from a higher social-economic or a different cultural background, are all suggestions for future research. Furthermore, there has been sparse research documented on the effect of ageism, discrimination, stigma, and labelling in the dignity of persons living with schizophrenia. I also believe that there is a need for further research on how dignity can be interrupted when the positive and negative symptoms of schizophrenia are present, misunderstood, and permanently affect sense of self, sanity, and wellbeing of the person with this severe mental illness.

Conclusion

A review of the researcher's experience and limitations of using Giorgi's phenomenological psychological methodology was provided. The implications for practice, theory, education, and limitations were presented. Suggestions for future research are recommended.

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Appendix A

Letter of Permission to Conduct Study from the Department of Health and Wellness

Ms. Deborah Bradley
Executive Director of Community Hospitals and Primary Health Care
PEI Health and Wellness
P.O. Box 2000
Charlottetown, PE C1A7N8

Ms. Margaret Kennedy
Director of Mental Health and Addiction
PEI Health and Wellness PEI
P. O. Box 2000
Charlottetown PE C1A7N8

Dear Ms Bradley and Ms. Kennedy,

I am a graduate student in the Master of Nursing program at the University of Prince Edward Island. A partial requirement for the degree is the completion of a research study. This letter is to explain the purpose of my study and to seek your approval for my study.

The purpose of my study is to explore the lived experience of dignity among older persons with schizophrenia. The goal is to add to the body knowledge related to dignity for the person with schizophrenia. Allowing this population the opportunity to reflect on their experiences with dignity has the potential to enhance the knowledge of nurses in preserving the human dignity of older adults living with schizophrenia; while assisting nurses in identifying whether they have the skills to care for this specific population. This research will also allow nurses to examine their personal attitudes towards the older adult with schizophrenia.

This is a qualitative research study, which will involve one interview lasting approximately 60 minutes with approximately 10 participants. The interviews will be digitally recorded and transcribed verbatim. With the assistance of my supervisory committee, I will then analyze the transcripts. A research report will be provided to you following completion of the data analysis. There will be no names or distinguishing characteristics in the report. The UPEI Research Ethics Board and the PEI Research Ethics Board will review the proposed study and I will confirm approval to you prior to the start of the study.

With your approval, I am seeking your assistance in obtaining contact with community mental health care professionals who are caring for older adults with schizophrenia living in community care facilities on PEI and meet the following eligibility criteria of the study: (a) at least age 60 (b) diagnosed with schizophrenia in late adolescence or early adulthood (c) presently mentally stable (d) oriented to person, place, time, and circumstance (e) speaks, hears, and understands the English language, and (f) willing to share their experience of dignity. I am asking for health care professionals to give potential participants a letter of invitation for this study. The provided information will also give individuals information on how to contact me if they wish to do so.

I ask that you might consider my request. Your assistance is central to the success of obtaining participants for my study. Should you require further information or have any questions, please contact me. I look forward to your reply.

Sincerely,

Darlene Robison
djobison@upei.ca
902-620-5212 (work)

Appendix B

Cover Letter to Health Care Professionals and Community Care Facility Managers in the Recruitment of Potential Participants

Date_____

Dear _____,

My name is Darlene Robison and I am a graduate student in the Master of Nursing program at the University of Prince Edward Island. A partial requirement for the degree is the completion of a research study. The purpose of my study is to explore the lived experience of dignity among older persons with schizophrenia living in community care facilities on PEI.

The goal of my study is to understand dignity and add to the body of knowledge related to dignity for the person with schizophrenia. Allowing this population the opportunity to reflect on their experiences with dignity has the potential to enhance knowledge in preserving the human dignity of older adults living with schizophrenia.

The eligibility criteria for participants in this study includes: at least age 60; diagnosed with schizophrenia in early life; presently mentally stable; oriented to person, place, time, and circumstance; and are able to complete the interview in English.

I am seeking your assistance in providing information that I will supply, to potential participants that fit the criteria. This letter of invitation explains the study and gives information for them to contact me if they wish to do so. I have also provided a written script for you to explain the research study to individuals that fit the criteria of the study.

I ask that you might consider my request. Your assistance is central to the success of obtaining participants for my study. Should you require further information or have any questions, please contact me. I look forward to you reply.

Sincerely,

Darlene Robison

djrobison@upei.ca

902-620-5212(work)

Appendix C

A Script for Community Mental Health Staff and LCCF Managers

A script for community mental health staff and licensed community care facility managers to explain the proposed study with potential participants before giving out the letter of invitation

Darlene Robison is a graduate student at the University of Prince Edward Island School of Nursing. She is doing a research study to better understand the experience of dignity for older persons with schizophrenia living in community care facilities on PEI. She is interested in learning about your experience with dignity so that nurses and other caregivers can better provide for your health care needs.

If you want to learn more about the study, here is some information about the study and how to contact Darlene.

Appendix D

University of Prince Edward Island School of Nursing,

“Participants” Letter of Invitation

Title: “Dignity in Older Adults Living With Schizophrenia: A Phenomenological Study

Researcher: Darlene Robison R.N.

You are invited to volunteer to participate in a research project that is part of my University of Prince Edward Island (UPEI) graduate nursing program. This study will help nurses and other caregivers understand your experience of dignity so that they can better provide for your health needs. You are invited to be interviewed if you are at least age 60, you were diagnosed with schizophrenia in early life and you live in a licensed community care facility on PEI.

If you choose to do this, I will audio-record my interview with you about your thoughts and experiences about dignity, while living with schizophrenia in a community care facility on PEI.

The interview will be held wherever you choose and will take about an hour. Before the interview, I will answer any questions you have and you will sign a form giving your permission to be part of the study. You will also fill out a short form about yourself so I can describe the people I interviewed. I will make sure that no one knows that you were part of my study.

Whether you take part in this study is completely up to you and you have the right to stop the interview at anytime, or to answer only some of the questions.

If you want to do this, or if you just want to learn more about my study, you can phone me at 902-620-5212, email djrobison@upe.ca. If you would rather, you can fill out the form that is enclosed and mail it to me in the envelope provided.

The Letter of Invitation will include a pre-stamped addressed envelope for interested individuals to return the following information:

I am interested in being interviewed or learning more about the study on dignity that Darlene Robison is doing at UPEI.

Name: _____

I would like you to contact me by (check one):

_____ Phone. My phone number is: _____

_____ E-mail. My E-mail address is: _____

_____ Mail. My mailing address is: _____

Appendix E

Dignity in Older Adults Living With Schizophrenia: A Phenomenological Study

Demographic Data

1. Diagnosed with schizophrenia in _____ by _____
2. How long have you resided in a community care facility? _____
3. You are Female _____ Male _____ Age _____
4. Highest level of education _____

Appendix F



CONSENT FORM

Title: Dignity in Older Adults Living with Schizophrenia: A Phenomenological Study

You are invited to volunteer to participate in a research project that is part of the requirements of my UPEI Master of Nursing Program. This study will help nurses and other caregivers understand your experience of dignity so that they can better provide for your health needs.

Here is my contact information and the contact information of my supervisors:

Darlene Robison: Master of Nursing student at UPEI

Phone: 902-620-5212, Email: djrobison@upei.ca

Dr. Gloria McInnis- Perry: Co-Supervisor and Associate Professor, School of Nursing at UPEI

Phone: 902-628-4301, Email: gjmcinnis@upei.ca

Dr. Lori Weeks: Co-Supervisor and Associate Professor, Department of Applied Human Sciences. UPEI

Phone: 902-566-0528, Email: lweeks@upei.ca

You are invited to be interviewed if you are at least age 60, you were diagnosed with schizophrenia in early life, are able to do the interview in English, and you live in a licensed community care facility on PEI.

If you choose to do this, I will be audio-record your interview about your thoughts and experiences about dignity while living with schizophrenia in a community care facility on PEI. The interview will be held wherever you choose and will take about an hour. Before the interview, I will answer any questions you have and you will sign this form giving your permission to be part of my study. You will also fill out a short form about yourself so I can describe the people I interviewed. I will make sure that no one knows that you were part of my study. Whether you take part in this study is completely up to you and you have the right to stop the interview at anytime, or to answer only some of the questions. I will interview about 10 people in total. Risks are minimal to you taking part in this study but if you become upset, I will stop the interview and will not continue unless you agree. If you decide to take part in this study, your experiences and thoughts about dignity will help nurses and other caregivers make positive changes in providing for your health needs.

If you agree with the following and wish to participate, please sign this consent form.

- I have read and understood this consent form and that any questions I have were answered by Darlene Robison.
- I understand that it is up to me whether I take part in this study.
- I understand that I have the freedom to not answer any question or to stop the interview at any time.
- There will be no consequences for me if I decide to not take part in the interview or not answer any question.
- If I choose to not be involved, I will tell the researcher and all information collected up to the date of my decision not be involved, will not stay or be included in the study.
- I understand that anonymity cannot be guaranteed, but I understand that my name or anything else that could identify me will not be included in the results.
- I understand that anything that I said in the interview can be used as a quotation.
- I give permission for the interview to be audio-recorded.
- The researcher will do everything possible to keep my personal information confidential within the limits of the law. I understand that all audio-recordings and information related to this study will be kept locked in a filing cabinet at the UPEI School of Nursing for 5 years after the end of the study.

If I have concerns about how this research was conducted, I can call the UPEI Research Ethics Board at (902) 566-0637 or by email reb@upei.ca; and Una Hassenstein, Chair of the PEI Research Ethics Board at (902) 569-0576.

Name of Participant: _____

Participant Signature: _____ Date: _____

Researcher Signature _____ Date: _____

If you would like a summary of the results of this study, please write your mailing address and/ or email address below and I will send you a copy.

Name _____

Address/or E-mail Address _____

Appendix G

Dignity in Older Adults Living With Schizophrenia: A Phenomenological Study

Interview Guide

1. What does dignity mean to you?
2. Can you think of an experience of dignity?
3. Do you remember an experience of dignity?
4. Please describe with as much detail as possible a situation of dignity.
5. Can you remember a time that you were not treated with dignity? (Tell me about it)
6. Is there anything else you would like to share?