Ways of Decision-Making Used in the Care Decisions of Individuals with Dementia

by

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Abstract

An understanding of the ways that rural community dwelling individuals with dementia (IWDs) are, and prefer to be, involved in their decision-making could help caregivers maximize IWDs' contribution to their decisions and could thus improve their care. This qualitative secondary analysis used an interpretive descriptive approach to inductively analyze 30 semi-structured interviews, which included 5 IWDs and their 6 informal caregivers (ICGs). Interviews were conducted over a year at the baseline, 6 months, and 12 months. Five ways of decision-making were identified: (a) independent, (b) collaborative, (c) guided, (d) delegated, and (e) directed. Contrary to IWDs' preference for independent decision-making, they most often made guided decisions. Guided decision-making was used when IWDs did not recognize their need to make the specified decision, and when the IWD or their ICG perceived that the IWD needed guidance in their decision. Involvement of IWDs in their decision-making was maximized when their decisions were guided.

Preface

This thesis was a secondary analysis of data collected by Dr. Dorothy Forbes, for the study “Developing Dementia Care Decisions through Knowledge Exchange in Rural Settings”. Chapter 2 of this thesis has been prepared for publication submission to the Canadian Journal on Aging. I, Emily Thiessen, was responsible for this thesis study’s research design, literature review, methodology, data analysis, and manuscript composition. As mentioned above, Dr. Dorothy Forbes, the supervisory author, collected the data used for this secondary analysis, of which I formed no part. Ethics approval for this thesis study was received from the University of Alberta Research Ethics Board, Project Name “Care Decision Preferences of Individuals with Dementia”, No. Pro00044994, on January 10, 2014.

Dedication

This thesis is dedicated to my loving husband whose tireless support helped me achieve my goals. His constant encouragement, well-prepared meals, and many gracious acts of self-sacrifices gave me the strength and tenacity to continue to where I am today. Further, I would like to thank my parents and sister for their encouragement and prayers that provided me with ongoing support and inspiration. Thank you, to everyone who was there to listen and support me throughout this journey.

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I would like to thank Dr. Dorothy Forbes, my thesis supervisor, for embracing my enthusiasm for this research topic, and for the support provided throughout the thesis process. Her thoughtful and inquisitive feedback provided me with guidance in the thesis design, analysis, and manuscript composition. She was readily available to discuss findings and provided timely feedback throughout the thesis process. Dr. Forbes' passion for improving the care of individuals with dementia has been inspirational and is one that I strive to emulate.

Finally, I would like to thank my committee members, Dr. Wendy Duggleby and Dr. Belinda Parke, whose well-phrased questions and insightful discussions provided guidance throughout the thesis process, and contributed greatly to the final scholarly product.

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Chapter 1: Background

Alarmingly, the number of Canadians with dementia is expected to increase by 2.5 times over the next 20 years. In fact, by 2038 there is expected to be 1.1 million Canadians suffering from dementia (Alzheimer's Society of Canada [ASC], 2010). In addition, the service needs of individuals with dementia (IWDs) are anticipated to shift from long-term care to community care; and it is projected that, by 2038, over half a million IWDs will live in the community in Canada (ASC, 2010). With the prevalence of dementia increasing with age (Lobo et al., 2000), and the population of seniors in rural areas of Canada aging faster than urban areas (Dandy & Bollman, 2008), an understanding of the care needs of rural community dwelling IWDs is essential. Indeed, the perceptions, of IWDs care needs, by rural dwelling IWDs and their informal caregivers (ICGs) have markedly differed between IWDs and their ICGs (Edelman, Kuhn, Fulton, & Kyrouac, 2006). Often times, ICGs have made substitute decisions for IWDs resulting in poorly predicted care preferences (Horton-Deutsch, Twigg, & Evans, 2007; Mesman, Buchanan, Husfeldt, & Berg, 2011). Without a doubt, IWD's perspective about their care needs should be included in their care planning to ensure that the care provided to them reflects their needs (Bossen, Specht, & McKenzie, 2009; Van Der Roest et al., 2009) and desires. Despite IWDs' preference to be involved in their care decisions (Hanmann et al., 2011) and their capability to contribute meaningfully in their decision-making (Hirschman, Joyce, James, Xie, & Karlawish, 2005b; Karlawish, Casarett, Propert, James, & Clark, 2002), they are not consistently included in discussions regarding their care (Tyrrell, Genin, & Myslinski, 2006). Ethically, IWDs have the right to be involved in their care decisions (Bartlett & O'Connor, 2010); and health care providers (HCPs) of IWDs must refrain from assuming that dementia sufferers are not capable of contributing to their care plans due to their diagnosis alone (O'Connor & Purves, 2009). It is pertinent for IWDs to be involved in their healthcare decisions because it has been significantly and positively related to their quality of life (Menne, Tucke, Whitlatch, & Feinberg, 2008). An understanding of the ways that IWDs are, and prefer to be involved in their care decisions could guide ICGs and HCPs on how to optimally include IWDs in their decision-making. Consequently, this understanding could contribute to the provision of care that better reflects the IWDs needs**.**

Thesis Overview

This thesis-based paper has three chapters. In chapter one, the specific purpose, aims, and key concepts of the research study are articulated. Following this, the thesis literature review and research study methodology are discussed in detail. The literature review and methods section are presented in chapter one to provide the reader with a deeper understanding of the research study than can be captured in the chapter two research study manuscript. The literature review section of the first chapter begins by outlining the search strategy and the inclusion criteria utilized for locating the appropriate research studies. This is followed by a discussion about the literature review findings and gaps related to the purpose of this thesis. Moreover, since this thesis research study is a secondary analysis of data collected from the primary study titled "Developing Dementia Care Decisions through Knowledge Exchange in Rural Settings", by Dr. Forbes, a summary of the primary study's data and consent procedures are provided prior to the discussion of the thesis research methodology. The discussion of the thesis research study methodology includes a presentation of the (a) sample selection procedure, (b) data analysis method, (c) research credibility, and (d) ethics approval, respectively.

Chapter two has been formatted according to the submission guidelines of the Canadian Journal on Aging, as it will be submitted to this journal for publication. The second chapter begins with an abstract, which is followed by an overview of the current literature and research gaps related to the study. Next, the study's purpose and aims, research methodology, statement of ethics approval, findings, and limitations are presented respectively. Following this, there is a discussion about the results in relation to what is known in the literature.

Chapter three provides a detailed discussion about the findings in relation to the current literature, followed by a methodological discussion of the strengths and limitations of the research associated with the secondary analysis approach. Lastly, implications for practice, teaching, and future research are discussed.

Study Purpose

The purpose of this study was to explore the ways that rural community dwelling IWDs were involved in the decision-making for their care decisions.

Specific Aims

1. To develop a conceptual description of the ways that rural dwelling IWDs were involved in their decision-making.

2. To explore the ways of decision-making that were preferred by rural dwelling IWDs and how these preferences varied between care decisions.

3. To describe the contextual factors that impacted the decision-making of rural dwelling IWDs.

Key Concepts

In order to provide the reader with a greater understanding of the terms *dementia*, *rural*, *ICGs, and care decisions* as used in this study, the following definitions are provided.

- *Dementia,* is defined as an irreversible syndrome that is characterized by ongoing decline of short term and long term memory, with an accompanying impairment in judgement, abstract thought, higher cortical function, or a change in personality (American Psychiatric Association, 1995; McKhann et al., 1984). This definition of dementia is currently the most widely recognized (Robillard, 2007). In this study, IWDs were all diagnosed with Alzheimer's disease by a general practitioner or geriatrician (Forbes et al., 2012; Forbes et al., 2013).
- *Rural,* in this study, was characterised by communities in south western Ontario that were outside of an urban center, and whose population were no greater than 10,000 in population (Du Plessis, Beshiri, & Bollman, 2001). Rural participants from south western Ontario identified themselves as living on or in "farms and small towns surrounding London", in their own publication (Ontario Ministry of Agriculture, Food and Rural Affairs, 2012).
- *ICGs* in this study referred to family members and relatives who provided informal care to the IWDs (Alecxih, Zeruld, & Olearczyk, 2001).
- *Care decisions* include any decisions that IWDs in the study identified as impacting their care.

Literature Review

A literature review was conducted to gather an understanding of the research related to ways that IWDs are, and prefer to be involved in their care decisions. Presented subsequently are the search strategy, inclusion criteria, and findings from the literature review.

Search Strategy

In consultation with the University of Alberta, Faculty of Nursing librarian, the following search engines were used to review the literature: Medline, CINAHL, Abstracts in Social Gerontology, Proquest, and Scopus. The following key words were used: alzheimer, dementia, lewy bodies, decision, decision-making, preference, desire, care decision, care preference, choice behavior, participant, patient, patient preference, patient participant, personal autonomy, advanced directive, living will, capacity, rural, and competency. Key words and search strategies changed slightly between databases (see Appendix A).

Inclusion Criteria

Included articles were: (a) written in English, (b) a research study, and (c) included participants who were diagnosed with dementia and were over the age of 65. In addition, the research studies included had at least one of the following aims: to explore IWDs' decision-making capability and autonomy; to explore the care decision preferences of IWDs; or to describe the ways IWDs are, or prefer to be involved in their care decisions.

A broad search strategy was implemented, and the initial literature review search yielded 2,094 articles. After the removal of duplicates, 1,599 articles remained. After the review of the abstracts of these articles, 168 remained. After a full review of the 168 articles, 31 articles were deemed relevant to this review. An additional 14 relevant articles were retrieved after searching the reference lists of the included articles, using the Scopus search engine. Thus, a total of 45 articles were included in this literature review.

The findings of this literature were categorized into six groups as follows: (1) the capability of IWDs to communicate their care decisions, (2) the capacity and competency of IWDs to make care decisions, (3) the care decision autonomy of IWDs, (4) ICGs' understanding of IWDs' preferences in their care decisions, (5) ways of decision-making used by IWDs, and (6) the characteristics of rural IWDs. Following these categories, a summary of the research gaps and justification for this research study were provided.

Capability of IWDs to Communicate their Care Decisions

Interestingly enough, IWDs were able to provide meaningful opinions regarding their lives (Mozley et al., 1999), and were able to be involved in their care planning (Karel, Moye, Bank, & Azar, 2007). Overtime, research has consistently found that individuals with mild to moderate Alzheimer's disease could consistently and accurately respond to questions on facts about themselves, including their involvement in their daily decisions (Clark, Tucke, & Whitlatch, 2008; Feinberg & Whitlatch, 2001), and their subjective states (Brod, Stewart, Sands, & Walton, 1999; Clark et al., 2008). Furthermore, over 90% of individuals with mild to moderate dementia could consistently report their current and future health care preferences (Dawson et al., 2008); and they could even identify a surrogate decision maker (Feinberg, & Whitlatch, 2002; Whitlatch & Feinberg, 2003). Individuals with mild dementia were equally as capable, as those without dementia, in their ability to respond to questions about their health care decisions (Karel et al., 2007). In addition, IWDs have demonstrated a capability to (a) articulate and explain reasons for their care decisions (Horton-Deutsch et al., 2007; Karel et al., 2007; Smebye, Kirkevold, & Engedal, 2012; Whitlatch, Feinberg, & Tucke, 2005a), and (b) communicate their thoughts regarding their present and future care preferences (de Boer, Dröes, Jonker, Eefsting, & Hertogh., 2012; Dening, Jones, & Sampson, 2013; Feinberg & Whitlatch, 2001, 2002; Hanmann et al., 2011; Tyrrell et al., 2006; Whitlatch & Feinberg, 2003). Further, IWDs were able to express their beliefs and values associated with their decisions (Whitlatch, Feinberg, & Tucke, 2005b). They were even able to make decisions based on societal norms (Bosch-Domènech, Nagel, & Sánchez-Andrés, 2010). It was feasible to ask IWDs about their decision-making preferences (Karel, Guerrera, Hicken, & Moye, 2010).

Importantly, even though individuals with severe dementia were able to communicate their preferences (Cahill & Diaz-Ponce, 2011; Godwin & Waters, 2009; Goodman, Amador, Elmore, Machen, & Mathie, 2013), as their cognitive impairment worsened, the consistency and accuracy of their responses lessened (Clark et al., 2008); and they had greater difficulty considering their future and end-of-life care needs (de Boer et al., 2012). In a one year longitudinal study, individuals without dementia were found to be more reliable than IWDs in their responses to their care preferences overtime (Carpenter, Kissel, & Lee, 2007). However, in this study, there was a large amount of inter-individual variability in each group, regardless of cognitive status, suggesting that preferences of individuals need to be regularly assessed, as they are subject to change overtime (Carpenter et al., 2007).

Capacity and Competency of IWDs to Make Care Decisions

The capacity of those with cognitive impairment to make decisions has been found to be impacted by their ability to understand the information required to make a decision, provide reasons for their decision-making choice, and understand the consequences of their final decision (Moberg & Rick, 2008). Capacity has not been thought to be about the right choice, but rather about the process of decision-making and the ability of an individual to make a decision (Moberg & Rick, 2008). Competency differs from capacity, as competency is a decision made by a profession about an individual's capability to make decisions (Moberg & Rick, 2008). More specifically, legal competency is established when the decision is made by a "judge" or a "legal professional" in court (Moberg, & Rick, 2008, p. 404). Regardless, specific criteria for the standard of decisional capacity (Kim, Karlawish, & Caine 2002) and competency is lacking (Moberg & Rick, 2008).

Capacity of IWDs to make decisions. The level of involvement of IWDs in their decision-making was influenced by their capacity to understand care decisions (Hanmann et al., 2011; Smebye et al., 2012). As cognitive impairment worsened, the ability of individuals to name a proxy (Sansone, Schmitt, Nicholas, Phillips, & Belisle, 1998), to reliably respond to question about demographics and preferences (Whitlatch et al., 2005a), to make consistent decisions (Teasdale, 1994), and to understand and provide reasoning for their treatment decisions decreased (Moye, Karel, Gurrera, & Azar, 2006). Over a nine-month period, Moye et al. (2006) examined the changes in the capacity of individuals with and without dementia using the MacArthur Competence Assessment Tool Treatment (MacCAT-T) and neuropsychological batteries. This research found that all individuals with mild to moderate dementia were able to clearly convey their treatment choice; however, these IWDs did have significant declines in their capacity due to decreases in their reasoning and understanding (Moye et al., 2006).

Ways to increase IWDs capacity to make decisions. IWDs have expressed a desire to use strategies that could improve their short-term memory and enhance their capacity to make decisions (Conde-Sala, Garre-Olmo, Turro-Garriga, Lopex-Ppusa, & Vilalta-Franch, 2008; Kim et al., 2002). Interventions that could help maximise reasoning and understanding by supporting IWDs' memory could help improve their capacity (Kim et al., 2002; Moye et al., 2006). For example, individuals with mild to moderate dementia were able to provide strong reasoning for their decisions by expressing the relationship between their values and their decision-making choices (Karel et al., 2007). In addition, Karel et al. (2010) also examined the relationship between IWDs' value-based reasoning and capacity to make treatment decisions. This research found that IWDs' logic based rationale was significantly inferior to those with no cognitive impairment. However, when IWDs provided rationale for their decisions based on their values and beliefs, their reasoning ability was comparable to those without cognitive impairment. With the use of a value-based rational approach, IWDs were able to provide a rationale for their health care decisions (Karel et al., 2010). Furthermore, overtime, IWDs were able to state values that were as consistent and stable as those without dementia (Karel et al., 2007). To date, instruments used for structured evaluation of decisional capacity have not taken into account the impact of value-based reasoning on decision-making (Karel et al., 2010). As a result, the rationale of IWDs, whose decisions were strongly influenced by their values and beliefs, may be underestimated by current decisional capacity instruments (Karel et al., 2010).

MMSE. In search of a tool that is time efficient and widely used in assessment of cognition, researchers have evaluated the correlation of Mini Mental Status Examination (MMSE) scores to the decisional capacity of IWDs. Gregory, Rokes, Jones, and Patel (2007) studied the usefulness of the MMSE to screen for the capacity of IWDs, with Alzheimer's disease, to create an enduring power of attorney. This study used a cross-sectional design and examined the capacity of IWDs to create an enduring power of attorney using non-validated structured interviews that assessed the four legal criteria of capacity. Capacity of the participants was then determined by a blinded independent assessor, who listened to the audio taped interviews. The results found that a score of 18 or greater on the MMSE had the highest sensitivity and specificity for determining the ability of IWDs to create an enduring power of attorney (Gregory et al., 2007). Gregory et al. (2007) found the MMSE to be a useful screening tool to determine the capacity of IWDs to create an enduring power of attorney. At the same time, they warned that the MMSE should not be the sole assessment tool utilized in the assessment of an individual's decision-making capacity (Gregory et al., 2007).

Karlawish, Casarett, James, Xie, and Kim (2005) researched the decision-making ability of IWDs regarding the use of an Alzheimer's disease slowing medication. Findings suggested that IWDs who had a MMSE greater than 23 were likely to have the capacity to make a decision about whether to take Alzheimer's disease slowing medication. Whereas, those with a MMSE less than 19 were likely to lack the capacity to make this decision. Nevertheless, the MMSE was not found to be a sensitive measure of the capability of individuals' with mild to moderate dementia to make decisions about their daily care and to state their care preferences (Feinberg & Whitlatch, 2001). Further, Teasdale (1994) found the MMSE to be a poor screening tool for determining capacity of older adults to create an advanced directive. However, this finding may be due to the discrepancy between the domains measured in the MMSE scale and those required to create an advanced directive (Teasdale, 1994).

Instruments for measuring decisional capacity. The most commonly used instruments for measuring decisional capacity of IWDs include: the MacCAT-T, the Hope Capacity Assessment Interview (HCAI), and the Capacity to Consent to Treatment Instrument (CCTI) (Moberg & Rick, 2008). Challenges with these three measures have been related to their modest validity with older adults and their differences in their definitions and measurements of capacity (Kim et al., 2002; Moye, Karel, & Guerrera, 2004b). When used to measure overall capacity for treatment decisions in individuals with mild to moderate dementia, the three instruments only had a "fair to good agreement beyond chance" (Guerrera, Karel, Azar, & Moyle, 2007, p.171). In addition, Moye, Karel, Azar, and Gurrera (2004a) also found a discrepancy between the three instruments when they were used to assess the capacity of IWDs compared with an individuals without dementia to consent to treatment For example, the CCTI reported that IWDs were impaired in appreciation; however, these finding were not replicated in the MacCAT-T and HCAI instruments (Moye et al., 2004a). In addition to these concerns, a poor agreement between physicians' capacity assessments has also been found (Marson, McInturff, Hawkins, Bartolucci, & Harrell, 1997). Agreement between physicians' capacity assessments can be maximized through the use of standardized instruments (Kim et al., 2002); however, physicians themselves are "rarely trained to conduct capacity assessments and assessment methods are heterogeneous" (Skelton, Kunik, Regev, & Naik, 2010, p. 300). As a limitation, a raters' personal values and biases have a tendency to interfere with their capacity assessments (Guerrera et al., 2007).

Decision-making competency. Competency has been associated with the IWDs' awareness of their symptoms, diagnosis and prognosis (Karlawish et al., 2005). Even though instruments used to assess decision competency are important and useful, it is imperative to acknowledge that a global lack of competency determined by one instrument is not possible because an individual may lack competency to make one decision despite having full competency to make another (Holm, 2001). The most frequent error made by clinicians in their assessments is viewing an individuals' competency as being globally affected (Grisso & Appelbaum, 1998). Unfortunately, a dichotomized view of competency has been found to be prevalent in community home care agencies (St-Amant et al., 2012). It is essential for clinicians to consider decision-making autonomy of IWDs as a "process" in which IWDs have different "degrees" of involvement in each stage of their treatment decisions (Hirschman et al., 2005b, p. 386). IWDs were most optimally involved in their care decisions when their values, capacity and competency to contribute to a decision were accurately assessed (Smebye et al., 2012).

Care Decision Autonomy of IWDs

IWDs indicated that they would like greater autonomy in their decision-making (Smebye et al., 2012), and appreciated the opportunity to discuss their daily care preferences (Feinberg & Whitlatch, 2001). They expressed a desire to be treated as "normal persons" and to maintain interdependence in their life, despite experiencing an increased reliance on others (Bamford & Bruce, 2000, p. 559). IWDs preferred to have as much independence (Menne, Kinney, & Morhardt, 2002) and choice in their care plans as possible (Dening et al., 2013), and they wanted services that would help them maintain their values (Conde-Sala et al., 2008). IWDs' valued the ability to maintain influence over the services that were provided to them (Bamford & Bruce, 2000; Clare, 2002). IWDs preferred that their ICGs played a secondary role in their care decisions, and they often desired more decision-making power than their ICGs were willing to allocate to them (Hanmann et al., 2011). The preference of IWDs to be involved in care decisions were significantly related to their confidence in their decision-making ability (Hanmann et al., 2011). Therefore, IWDs with a higher MMSE were significantly more likely to prefer greater decision-making involvement in their health care decisions (Hamann et al., 2011). As IWDs' cognition decreased, their desire to participate in their decisions also declined (Hanmann et al., 2011). It is possible that as the dementia of the individuals progressed, that their awareness of their disease decreased; and they no longer had an accurate appreciation of their abilities to be involved in their decision-making. For example, Forbes et al. (2012) found that rural IWDs often denied the presence of their disease.

ICGs' Understanding of IWDs' Preferences in their Care Decisions

Three types of incongruence were found to exist between ICGs' understanding of the care preferences of IWDs: "knowledge incongruence", "agreement incongruence", and "behaviour incongruence" (Whitlatch, 2001, p. S22). "Knowledge incongruence" occurred when the ICGs were unaware of the care preferences of the IWD. "Agreement incongruence" occurred when ICGs inaccurately perceived the preferences of the IWD. In addition, "behavioral incongruence" reflected a discrepancy between the care preferences of the IWDs and the actions and decisions made by their ICGs on their behalf (Whitlatch, 2001, p. S22).

Knowledge incongruences. Often times, ICGs and HCPs did not accurately know the care preferences of IWDs (Horton-Deutsch et al., 2007; Whitlatch & Feinberg, 2003). In spite of an awareness by ICGs that individuals with mild to moderate dementia had clear care preferences, ICGs often avoided these care discussions (Feinberg & Whitlatch, 2002). Also, ICGs who reported a better understanding of the values of IWDs had included them in their decision-making (Reamy, Kim, Zarit, & Whitlatch, 2011).

IWDs, who were aware of their memory difficulties, often lacked confidence in their ability to contribute information about their care preferences to their HCPs and ICGs (Goodman et al., 2013). For example, Ayalon, Bachner, Dwolatzky, and Heinik (2012) found that one third of IWDs had not discussed their end-of-life care preferences with their spouses. HCPs have encouraged the participation of IWDs in their decisions through the creation of safe spaces for IWDs to communicate their care needs (Goodman et al., 2013). When HCPs invited IWDs to participate and engage in their decisions, IWDs were enabled to express their care preferences (Helgesen, Larsson, & Athlin, 2010).

Agreement incongruences. ICGs' and IWDs' perspectives of IWDs' care needs have differed from each other (Bamford & Bruse, 2000). ICGs and HCPs have been inaccurate in determining the values (Reamy, Kim, Zarit, & Whitlatch, 2013) and preferences of IWDs (Mesman et al., 2011; Whitlatch, Piiparinen, & Feinberg, 2009). For instance, in end-of-life hypothetical vignettes, the ICGs' perspective of the IWDs' end-of-life care preferences differed from the IWDs (Ayalon et al., 2012). In some cases, ICGs' knowledge of IWDs' care preferences were no better than chance, while in other cases, the ICGs' knowledge of the IWDs' care preferences were moderately accurate (Carpenter et al., 2007). Relying solely on the input of ICGs in the decision-making process for IWDs has resulted in a provision of care that does not reflect their care needs (Bamford & Bruce, 2000). Therefore, HCPs should avoid the assumption that ICGs are able to provide accurate information about the care needs of IWDs (Carpenter et al., 2007).

Behavioural incongruences. Community dwelling individuals with mild to moderate dementia, and their ICGs, have had poor congruence in IWDs' care decisions (Horton-Deutsch et al., 2007). At times, ICGs have overrode the wishes of IWDs, regardless of their degree of cognitive impairment (Horton-Deutsch et al., 2007). Horton-Deutsch et al. (2007) revealed that 30% of ICGs were willing to choose a treatment that they believed the IWDs would not have chosen**.** Further, as time passed, ICGs de-emphasized the importance of the IWDs' values, and were increasingly unable to accurately represent their care decision preferences (Reamy et al., 2013).

The characteristics of ICGs' and IWDs' impacted the involvement of IWDs in their care decisions (Menne et al., 2008). For instance, when ICGs were younger, married, and female, they were significantly more likely to have reported involving IWDs in their treatment decisions (Menne et al., 2008). Whereas, ICGs who were male, older and unmarried were less likely to involve IWDs in the decision-making process (Hirschman et al., 2005a). IWDs who were involved in their decisions were characterized as being younger, female and educated; they also valued autonomy, desired not to be a burden, had less challenges with daily activities, had less symptoms of depression (Menne & Whitlatch, 2007; Menne et al., 2008), and did not suffer from severe dementia (Hirschman et al., 2005a). The majority of individuals with mild dementia who had a MMSE greater than 19 were largely involved in their medical decisions (Hirschman, Xie, Feudtner, & Karlawish, 2004; Karlawish et al., 2002).

IWDs found that as their ICGs' burden increased, that they felt less supported in communicating their care needs, they had greater psychological distress (Van Der Roest et al., 2009), and a decreased quality of life (Menne et al., 2008). Also, ICGs who reported a greater caregiving burden were more likely to report the use of directed decisions (Hirschman et al., 2004; Karlawish et al., 2002). Moreover, IWDs were significantly more likely to report that their ICGs did not know their daily care preferences when their ICGs were experiencing financial distress (Feinberg & Whitlatch, 2002). Contrarily, ICGs were more likely to involve IWDs in their care decisions when they had less strain in their dyadic relationship, were experiencing less depression, and were experiencing an overall higher quality of life (Reamy et al., 2011).

Systems Impact on Decision-Making in Dementia

In the home care system, practices that excluded IWDs from decision-making were reinforced (St. Amant et al., 2012). The home care system's culture promoted "deterministic" decision-making, in which the voices of the IWDs were excluded and a "paternalistic" pattern of decision-making was reinforced (St. Amant et al., 2012, p. 431). This approach limited both the choice and involvement of the IWDs and their ICGs in the care decisions of IWDs (St. Amant et al., 2012). Therefore, it is not surprising many IWDs reported having limited freedom to participate in their care decisions (Tyrrell et al., 2006); and 75% of IWDs experienced a stigma associated with their diagnosis (Batsch & Mittelman, 2012). The most common complaint reported by IWDs was a feeling that their thoughts and opinions were dismissed and even ignored (Batsch & Mittelman, 2012). One third of IWDs reported that they were not informed or given an opportunity to express their opinion in their care decisions, and were not listened to amply (Tyrrell et al., 2006). Understandably, IWDs resented being excluded from the decision-making process and expressed a desire to maintain their involvement in their decisions, as long as they were capable (Fetherstonhaugh, Tarzia, & Nay, 2013). Further, IWDs appreciated strategies that aided their involvement in their decisions (Fetherstonhaugh et al., 2013). In order to empower IWDs in their decision-making, HCPs need to recognize these "paternalistic" practices and proactively collaborate with IWDs and their ICGs in the decision-making process (St. Amant et al., 2012, p. 431).

Ways of Decision-Making Used by IWDs

Smebye et al. (2012) identified five decision-making ways employed by IWDs in their care decisions: autonomous decision-making; pseudo-autonomous decision-making; shared decision-making; delegation of decisions; and non-involvement (Smebye et al., 2012). Out of the five ways, shared decision-making was the preferred way to make decisions (Karel et al., 2010) and occurred most commonly, while fewer decisions were made autonomously (Smebye et al., 2012). IWDs valued being able to contribute to their decisions and appreciated "subtle" support in their decision-making; however, they found it frustrating when ICGs attempted to take over their decisions (Fetherstonhaugh et al., 2013). Non-involvement of the IWDs in their care decisions occurred most often when there was limited availability of choices provided to them, and limited opportunities for them to participate in their decision-making (Smebye et al., 2012). Decisions became more dominated by ICGs as the severity of the individuals' dementia increased (Hirschman et al., 2004).

Samsi and Manthorpe's (2013) phenomenological study examined the decision-making of 12 community dwelling dyads, from London, UK. Each dyad included an IWD and their ICGs. Data on the decision-making dynamics of the dyad were collected over a year, with interviews held every three months. Overtime, IWDs became gradually less involved in their decision-making, and the decisions, made by the dyads, occurred less often in a mutual way, and were more often directed by the ICGs. Initially, IWDs expressed a greater desire to be involved in their decisions, and often the dyads made decisions together. As decisions became more difficult for the IWDs, the dyad together restricted their decisions through living a more simple life that required less daily choices. Overtime, the dyads decision-making became more reductive in nature; and IWDs allowed their ICGs to make decisions on their behalf (Samsi & Manthorpe, 2013). As the severity of dementia progressed, ICGs began to make retrospective decisions based on their perceptions of the desires of the IWDs. In the final stages, ICGs took over decision-making, and they made decisions that reflected what they thought would be best for the “interconnected” dyad (Samsi & Manthorpe, 2013).

Characteristics of Rural IWDs

Rural IWDs may provide a different perspective on decision-making in comparison to those who reside in urban areas, as they have a unique set of values and perceptions of health care (Gessart, Elliot, Peden-McAlpine, 2006). Overall, individuals living in rural areas have reported a more stoic view of life than those residing in urban centers (Forbes et al., 2008). Perhaps, rural individuals’ stoic view on life has impacted the reported difference between the end-of-life decisions made for rural dwelling IWDs, by their ICGs, as compared to IWDs who resided in urban centers (Gessert et al., 2006). For example, ICGs in rural areas pursued far less aggressive end-of-life medical care for IWDs, and were less likely to be hospitalized when compared to their urban counterparts (Gessart et al., 2006). The less aggressive end-of-life care decisions of rural dwelling ICGs for IWDs, may have reflected their acceptance of death as a natural course of life, as contrasted to urban ICGs' view of death as a tragedy (Gessart et al., 2006).

Rural dwelling IWDs were reluctant to seek medical assistance (Thorpe, Van Houtven, Sleath, & Thorpe, 2010); and they would delay seeking medical care longer than IWDs dwelling in urban centers (Bull, Krout, Rathbone-McCaun, & Shreffler, 2001). This difference may have been related to the decreased accessibility and availability of resources in rural areas (Casy, Klingner, & Moscovice, 2002; Forbes, Morgan, & Janzen, 2006; Forbes et al., 2008; Innes, Morgan, & Kostineuk, 2011; Mason, Blackstock, Cox, Innes, & Smith, 2005), or may have reflected rural individuals' deeply ingrained sense of self-reliance and desire to protect one's dignity (Forbes et al., 2008; Morgan, Semchuk, Stewart, D'Arcy, 2002).

Rural dwelling IWDs reported being excluded from health care decisions and expressed a desire to contribute to their care discussions (Forbes et al., 2011). In rural areas, the stigma of dementia often negatively impacted how community members and families interacted with IWDs (Morgan et al., 2002). Rural IWDs and ICGs expressed a desire to learn new ways to improve the communication of their care needs (Edelman et al., 2006). Nevertheless, to the author's knowledge, there have been no research articles that have directly explored the ways that rural dwelling IWDs are, and prefer to be involved in their care decisions.

Summary

The majority of the literature examined focused on the *ability* of IWDs to be involved in and communicate their care decisions. To the researcher's knowledge, there were no studies that explored IWDs' preferred way of decision-making, and only one research study focused on the strategies employed where IWDs were involved in their decisions (Smebye et al., 2012). Moreover, Smebye's et al. (2012) hermeneutics interpretive study explored how IWDs were involved in their care decisions, through interviews of ICGs and HCPs, and through observations of how the HCPs facilitated the care decisions of IWDs. In this study, the data were collected over a period of one to two days. The sample consisted of 10 IWDs, 10 ICGs, and 10 HCPs from three municipalities in Norway. IWDs included those who lived independently and those who lived in nursing care homes (Smebye et al., 2012). Smebye et al. (2012) did not ask IWDs directly how they were involved in their care decisions. Further insights on the decision-making process could be found by capturing the voice of IWDs through the use of interviews. Similarly, there is a need to examine the perspective of IWDs from wider socio-cultural contexts (O'Connor et al., 2007). To the author's knowledge, this thesis study was the first research study that explored decision-making of IWDs from the perspective of those living in rural communities. The results of this study could be used to guide ICGs and HCPs on how to best involve rural community dwelling IWDs in their care decisions.

Overview of Primary Study

This study was a secondary analysis of the primary study titled "Developing Dementia Care Decisions through Knowledge Exchange in Rural Settings", by Dr. Forbes. The primary study inquired about the knowledge that IWDs, ICGs, and HCPs needed regarding dementia. Further, it sought to understand how IWDs, ICGs, and HCPs obtained knowledge, and engaged in the knowledge exchange process overtime. The primary study collected data, using a grounded theory approach, from the years between 2009 and 2011.

Participants were identified as networks, which included IWDs, ICGs, and HCPs. Nine dementia care networks were recruited for this study, with a total of 5 IWDs, 14 ICGs, and 14 HCPs (see Table 1.1). A convenience sample was recruited from the following collaborating partners: the Alzheimer Society of London, the First Nations Council, the South West Community Care Access Centre; and local Victorian Order of Nursing in south western Ontario. Participants included in the study: (a) spoke English, (b) lived in a rural area with a population no greater than 10,000 people, and (c) were diagnosed with dementia by a general practitioner or geriatrician, or were caregivers of the IWDs. Theoretical sampling was used to test and refine the primary study theory. Data collection and analysis occurred simultaneously.

Demographic information was collected on the participants' age, sex, level of formal education, marital status, length of residence in community, services available in the community, employment status, total income, and subjective health state. In addition, IWDs' diagnosis, date of diagnosis, type of dementia, and medications were collected. In-depth semi-structured interviews were conducted and field notes written after each interview with the IWDs, ICGs, and HCPs (see Appendix B and Appendix C for guiding questions). Data were collected at three time points: baseline, 6 months, and 12 months post enrollment (see Table 1.1). The duration of the interviews ranged from 60 to 90 minutes. A total of 80 interviews and 80 field notes from nine networks were collected (see Table 1.1). Audio-recorded interviews were transcribed verbatim, and field notes were compiled. Field notes were written by each interviewer after they conducted each interview. The field notes contained information on the description of: (a) the environment, including the people present for the interview and activities that were occurring simultaneously, (b) the informal

Table 1.1

Interviews Conducted in the Primary Study

		Interviews			
Network	Interviewee	Baseline	6 Months	12 Months	Total Interviews
Network 1[a]	IWD	√	√	-	2
	ICG	√	√	√	3
	HCP	√	√	-	2
	HCP	√	√	-	2
Network 2[a]	IWD	√	√	√	3
	ICG	√	√	√	3
Network 3[a]	IWD	-	√	-	1
	ICG	√	√	√	3
	HCP	√	-	-	1
Network 4	IWD	-	-	-	0
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
	ICG 3	√	√	√	3
	HCP	√	√	-	2
Network5[a]	IWD	√	√	√	3
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
Network 6	IWD	-	-	-	0
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
	HCP	√	√	-	2
Network 7	IWD	-	-	-	0
	ICG	√	√	√	3
	HCP	√	√	-	2
	HCP	√	√	-	2
Network 8	IWD 1	-	-	-	0
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
	HCP	√	√	-	2
	HCP	√	-	-	1
Network 9[a]	IWD	√	√	√	3
	ICG	√	√	√	3
	HCP	√	√	-	2
Multiple Networks[b]	HCP 1	√	√	√	3
	HCP 2	√	-	-	1
	HCP 3	√	√	-	2
	HCP 4	√	√	-	2
Sum of Interviews	IWD	4	5	3	12
	ICG	14	14	14	42
	HCP	14	11	1	26
Total Interviews		32	30	18	80

Note. The table outlines the interviews of each individual with dementia (IWD), informal caregiver (ICG), and health care provider (HCP) in the primary study.

[a] Networks that were included in this study [b] HCPs interviewed for multiple network

conversations that occurred, and (c) the nonverbal behaviour of the participants. All identifying information was removed from the transcripts and field notes (Morse, 2012). This data has remained current and reflective of the state of knowledge in this population (Hinds, Vogel, & Clarke-Steffen, 1997).

Consent of IWDs in the Primary Study

Consent for IWDs to participate in the primary research study was not based on the diagnosis of dementia alone, as there was potential for IWD's competency to consent to change overtime (Fisk, Beattie, & Donnelly, 2007). Currently, there is no standardized assessment tool to test the competency of IWDs to consent to research (Alzheimer's Association, 2004). Therefore, the primary study did not formally assess the capacity of the IWDs to consent. Rather, consent was obtained from a proxy caregiver for the IWDs. Proxy caregivers were encouraged to make the decision for the IWDs to participate in the study based on the wishes and interests of the IWDs (see Appendix D). Ongoing assent from IWDs was obtained prior to each interview. Prior to the initiation of the primary study, ethical approval was obtained from the Ethics Review Board from the University of Western Ontario, the Victorian Order of Nurses Canada, the First Nations Council, and the South West Community Care Access Centre (Forbes et al., 2012; Forbes et al., 2013).

Methodology

This research study was a supplementary secondary analysis of qualitative data, which used Sally Thorne's interpretive descriptive approach (Thorne, Kirkham, MacDonald-Emes, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004b; Thorne, 2008) to develop an understanding of the ways that rural IWDs were currently involved and how they preferred to be involved in their decision-making. This study was a qualitative secondary analysis, as qualitative data from a primary study were used to examine a new research inquiry (Heaton, 2004; Hinds et al., 1997). More specifically, this study was considered to be a supplementary secondary analysis, as it analyzed an aspect of the primary study data that was not originally addressed (Heaton, 2004). The use of Sally Thorne's interpretive description method aligned well with this study, as the results could be used to inform "clinical understanding" on how to involve rural IWDs in their care decisions (Thorne et al., 2004b, p. 3). In addition, through the use of this approach, the researcher was able to use an inductive approach to analysis that was sensitive to the contextual factors that impacted the ways that the IWDs were involved in their decision-making (Thorne, 2008). Sally Thorne's interpretive descriptive approach also enabled the researcher to capture the subjective experience of the IWDs involvement, and preferred involvement in their decision-making (Thorne et al., 1997; Thorne et al., 2004b). Through the use of this approach, a conceptual description of the ways in which IWDs were involved in their decision-making was developed using an inductive analytic process (Thorne et al., 1997). Notably, interpretive description has previously been used by Sally Thorne herself in a secondary analysis of her own work (Thorne, Con, McGuiness, McPherson, & Harris, 2004a).

Sample Selection

Interpretive description can be conducted in samples of "almost any size" (Thorne, 2008, p. 94). However, in participants that are not anticipated to provide in-depth data through interviews, it is recommended to have a higher sample size with multiple interviews in order to maintain credibility and dependability of the data (Beuscher & Grando, 2009). In qualitative data, sample sizes of participants with advanced Alzheimer's disease have ranged from 7 to 28 (Beuscher & Grando, 2009). In this secondary analysis, sorting was used to select a particular subset of data from the primary study that focused on the ways that IWDs, were, and preferred to be involved in their decision-making (Heaton, 2004). There were a total of nine networks in the primary study. However, only five of the nine networks interviewed IWDs. Therefore, for the purposes of this study, interview data and the field notes, from Networks 1, 2, 3, 5, and 9 were used because these five networks included interviews of the IWDs (Table 1.1; Table 1.2). Within these networks, there were a total of 30 interviews and 30 field notes of the IWDs and their ICGs that were selected to be included in this secondary analysis. Of the 30 interviews, 12 interviews were with the IWDs and 18

Table 1.2

Interviews Included in the Secondary Analysis

		Interviews			
Network	Interviewee	Baseline	6 Months	12 Months	Total
Network 1	IWD	√	√	-	2
	ICG	√	√	√	3
Network 2	IWD	√	√	√	3
	ICG	√	√	√	3
Network 3	IWD	-	√	-	1
	ICG	√	√	√	3
Network 5	IWD	√	√	√	3
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
Network 9	IWD	√	√	√	3
	ICG	√	√	√	3
Total	IWD	4	5	3	12
	ICG	6	6	6	18

Note. This table outlines the interviews conducted in Networks 1, 2, 3, 5 and 9 for each individual with dementia (IWD) and their informal caregiver (ICG). The check mark indicates that the interviews were conducted, while the dash indicates that the interviews were not conducted.

interviews were with ICGs (see Table 1.2). All the HCPs interviewed in the primary study were excluded, as the IWDs were the focal point of the research purpose.

Missing data. In Network 1, the interview and field note data were missing at 12 months, as the IWD had been transferred to a long-term care facility. Further, the interviews and field notes of the IWD in Network 3 were not conducted at baseline and 12 months, as the IWD refused to participate in the interviews at these time points (see Table 1.2).

Interview challenges with IWDs. In populations with communication difficulties, such as IWDs, their voices are commonly absent in the literature due to the methodological challenges faced when being interviewed (Carlsson, Paterson, Scott-Findlay, & Ehrenbery, 2007). IWDs have not been thought to be best suited for interviews, as they often do not articulate in-depth experiences well (Morse, 2012). Despite these clear challenges in representing the IWDs' viewpoint, it is important to include them in research and to obtain their perspective (Downs, 2005). In order to increase the credibility and dependability of the findings, the data of the IWDs were triangulated with that of their ICGs (Beuscher & Grando, 2009). Further, inclusion of the ICGs' transcripts was beneficial, as the majority of IWDs were at least "partially reliant" on their ICGs to make their care decisions (Horton-Deutsch et al., 2007, p. 117). In addition, the decisions made by IWDs have been known to occur in a "relational context" (Smebye et al., 2012, p.151). Finally, interpretive description encourages the use of multiple perspectives, in order to develop a "more probable" truth of the participant's experience (Thorne, 2008, p. 78). Therefore, ICGs were an appropriate collateral source (Thorne et al., 1997); and they were included in this study to help enrich the data as "key informants" and helped prevent misinterpretation of the data (Thorne, 2008, p. 135). Field notes were also included to supplement the interview data and helped illuminate the contextual factors that may have influenced the data (Thorne, 2008). The inclusion of field notes also helped prevent data misinterpretation (Thorne, 1998), secondary to a lack of the researcher's presence during the data collection (Heaton, 2004).

Data Analysis

Guided by interpretive description, an inductive process of data analysis was used (Thorne, 2008). Using the "borrowing technique" of interpretive description, the researcher drew "analytic guidance" (Thorne, 2008, p. 153) from the constant comparative method of grounded theory (Corbin & Strauss, 2008). The grounded theory analytic tools were borrowed in this study, as they fit well with the research aims that examined the ways that IWDs were involved in decisions making, within the context of dementia and the rural community setting (Corbin & Strauss, 2008; Thorne, 2008). The grounded theory analytic tools were used within the "context of interpretive description"; and the researcher was not "entirely faithful to the original tradition", as strict adherence to technique can degrade the process of analysis (Thorne, 2008, p.153).

The data analysis involved four phases. Throughout the four phases of data analysis, the researcher engaged in an inductive analytic approach, in which each phase informed the next. An "intensive analytic memo process" was used throughout the analysis (Corbin & Strauss, 2008; Thorne, 2008. p. 154). The researcher had a dedicated notebook to place memos, analytical notes, a list of themes and questions, and patterns that emerged in the data (Thorne, 2008). During each "brainstorming" session, the researcher wrote down key ideas and patterns that emerged through the data (Thorne, 2008, p.153). Methodological notes and an audit trail were used to capture the decisions made throughout the analysis (Thorne, 2008). Throughout the analytic process, the "contextual whole" of the data were preserved (Thorne, 2008, p. 137). Nvivo10 software was used to assist with data analysis and storage (Thorne, 2008). Raw data from the primary study was recoded and entered into Nvivo10 to prevent overlap between the primary study data (Szabo & Strang, 1997).

In the first phase of the data analysis, all the IWDs' interview transcripts and their corresponding field notes were read once in entirety to develop an understanding of the data as a whole from the IWDs' perspective (Corbin & Strauss, 2008; Thorne, 2008). In this phase, each time the data were read, they were read in numeric order, from Networks 1, 2, 3, 5, and 9. Further, in order to inform the researcher of the interview context, each field note was read prior to their corresponding interview transcript. After the *first read* of the IWDs' data, the researcher *re-read* the IWDs' field notes and interview transcripts, after which the researcher proceeded to read the ICGs' field notes and interview transcripts. Lastly, the IWDs' field notes and interview transcripts were read a third time to allow for the richness of the data to be taken full advantage of through multiple readings of the transcripts (Beuscher & Grando, 2009; Thorne, 2008) prior to beginning the coding process (Thorne, 1997, 2008). The IWDs' data were read first, as they were the focus of the research aims, and the ICGs' data were used to inform the IWDs' interviews, as they provided information on the context of the IWDs' ways of decision-making. The ICGs acted as "key informants" and a collateral source (Thorne et al., 1997; Thorne, 2008, p. 135). After reading the ICGs' data the researcher returned to the IWDs' transcripts with questions and insights roused from the ICGs' data. Returning to the IWDs' data helped the researcher keep the research focus on the IWDs' perspective. In this first phase, the researcher used "marginal memos" and highlighted thematically similar text (Thorne, 2008, p. 147). Further, cases that were considered to be particularly meaningful were flagged and placed in a separate file of "quotable quotes" (Thorne, 2008, p. 149). These quotes included a code location and contextual information alongside the data, to prevent them from being read outside of the context of the individuals (Thorne, 2008). During the first phase, a formal coding system was not used. Rather, initial coding began only after lengthy immersion in the data, in order to prevent the "premature coding and sorting" of the data and "bloodless findings" (Thorne et al., 2004b, p. 8).

In the second phase of data analysis, the researcher read the data as networks, and again read the field notes followed by their corresponding transcripts from Networks 1, 2, 3, 5, and 9 in numeric order. For each network, the researcher first read the IWD's field notes and interviews followed by the ICG's data, prior to reading each subsequent network. Again, in this phase, the ICGs' interviews were used to supplement and learn more about the decision-making used and preferred by the IWDs. Open coding began in this phase with the use of "broad-based" and "generic" codes, until the analysis had been well established, and until the researcher was confident in the findings (Thorne, 2008, p. 147). "Meaningless labels" were used to bring together data with similar ideas (Thorne, 2008, p. 148). During open coding, all potential ideas for a block of data were considered prior to applying a conceptual label. Axial coding occurred concurrently with open coding, which facilitated the comparisons of categories and concepts between each other (Corbin & Strauss, 2008).

The third phase used the constant comparative analysis to look for similarities and differences in data between participants (Corbin & Strauss, 2008; Thorne, 2008). Field notes and interview transcripts again were read from Networks 1, 2, 3, 5, and 9 in numeric order, beginning with the IWD's field notes and interview transcripts, followed by their corresponding ICG's field notes and interview transcripts. Each network was analyzed and compared to the previously analyzed networks. In this phase, concepts began to be defined into higher-level concepts (themes) and lower-level concepts (properties) (Corbin & Strauss, 2008). These concepts were labeled in a way that reflected a "common language" (Thorne, 2008, p. 172). The ways of decision-making were further examined by stepping back from the data to think about the larger picture and by examining patterns in the data. Diagraming was used as a tool to "depict relationships between analytic concepts" (Corbin & Strauss, 2008. p. 171). In the conceptualization of the data, negative cases were incorporated; and analysis questions were asked by the researcher to stimulate thoughts about the participant's perspective (Corbin & Strauss, 2008). During the fourth phase, the researcher reread the memos and analytic notes written, and even went back to the literature to examine any concepts that she was unfamiliar with (Corbin & Strauss, 2008; Thorne, 2008).

Common pitfalls. Throughout the analysis of the data, the researcher prevented "premature closure" by continuing the analysis past the first "aha" moment (Thorne, 2008, p. 156). Furthermore, the "over determination of pattern" was prevented by critically reflecting on the patterns noticed in the data and how they related to the research aims (Thorne et al., 2004b, p.8). To prevent the "over-inscription of self", the researcher stepped back from the data occasionally and considered the data from different vantage points (Thorne, 2008, p. 157). Further, the bias of the research was challenged by looking at the data through different 'lenses", and by challenging the current conceptualizations of the data through active questioning (Throne, 2008, p. 158). Other perspectives of the data were also brought into the analysis by "engaging the critic" through actively seeking others' views on the data, and checking "new insights" developed with the current literature (Thorne, 2008, p. 161).

Credibility

While techniques used to establish trustworthiness have been commonly used in research, these techniques may "bolster confidence" in the credibility of the research findings (Thorne, 1997, p. 102). A "more salient approach" would be to consider credibility in relation to the "theoretical strength" of the conducted research (Thorne, 1997, 2008, p. 222). In this secondary analysis, credibility was evaluated using the criteria of interpretive description as follows: epistemological integrity, representative credibility, analytic logic, and interpretive authority (Thorne, 1997, 2008). Epistemological integrity was maintained in this study as: (a) the research aims were answered using an inductive process, and results were "grounded in the data"; (b) the researcher recognized the influence of herself on the data and vice versa; and (c) the researcher believed that the realities were subjectively constructed, were complex, were influenced by context, and must be studied "holistically" (Thorne et al., 2004b, p. 3; Thorne, 2008, p. 224). Representative credibility was established, as claims made by this research were consistent with the limitation of the research.

Furthermore, triangulation of data was used to offer perspectives of the IWDs and their ICGs (Thorne, 2008). Triangulation of methods included the use of field notes and interview data (Thorne, 2008). The inclusion of the field notes from the primary study helped illuminate the context of the interview data (Thorne, 2008) and prevented data misinterpretation (Thorne, 1998), as the researcher was not present during the data collection (Heaton, 2004). An audit trail was used to capture the reasoning process of the inductive analysis (Thorne et al., 2004b; Thorne, 2008). This audit trail served as a record of the decisions made and how analytic conclusions were made (Thorne, 2008). Analytic logic was established by presenting a thick description of the participants' data in the findings (Thorne, 2008). The researcher’s interpretive authority demonstrated that the findings of the data were external to her own bias, through the use of “validity-as-reflexive-accounting” (Thorne, 2008, p. 225). Additionally, validity of the findings was furthered through the application of the “thoughtful clinician test” (Thorne et al., 2004b, p.8). For this test, Dr. Forbes an expert in the field provided her perspective on the research findings (Thorne et al., 2004b). Finally, the researcher used a reflective journal to account for any influences of bias in the data analysis (Thorne et al., 1997).

Researchers in the field of applied science must extend their critique of their research beyond evaluative criteria, and consider the contribution of their research to their discipline using the following criteria: moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness and probable truth (Thorne, 1997, 2008). Moral defensibility is when the researcher can establish that the knowledge that was obtained from the study could be purposefully used. In this study, an understanding of the ways of decision-making used, and preferred by IWDs could be used to provide HCPs with guidance on how to best include IWDs in their care decisions; and may further contribute to greater involvement of IWDs in their care decisions, ultimately contributing to IWDs’ quality of life (Menne et al., 2008). The knowledge gained was relevant to the nursing profession because nurses are involved in the care of IWDs in rural areas, and may use this data to empower IWDs in their decision-making, by collaborating with IWDs and their ICGs in the use of the most appropriate decision-making way.

The pragmatic obligation of the researcher was to recognize that findings may be applied in practice, prior to being proven scientifically, and this recognition was demonstrated in the presentation of the findings (Thorne, 2008). The researcher demonstrated contextual awareness by recognizing that the findings of the study must be considered within the rural context, and the author's disciplinary perspective and own "historical" perspective (Thorne, 2008, p. 228). The researcher bracketed elements of her own "social cultural perspective", and acknowledged that the findings must be considered within the contextual reality that influences the data, as not all assumptions may be evident and bracketed (Thorne, 2008, p. 229). Findings were presented as the "probable truth" as there were no "set of standards" that could be used to ensure the findings were valid (Thorne, 2008, p. 229).

Ethical Considerations

For the purposes of this secondary analysis, ethics approval was obtained from the University of Alberta Research Ethics Board (see Appendix E). Data were stored in a locked filing cabinet in the research office of the primary researcher, and on a password encrypted laptop (Thorne, 2008). A confidentiality agreement was signed by the researcher (Thorne, 2008). Anonymity and confidentially of the population were maintained by ensuring the researcher only had access to data where identifiable information of participants was anonymized and code names were used (Thorne, 1998).

Conclusion

There is an urgent need to address how to best care for IWDs as the population of IWDs, in Canada, is expected to double by 2038 (ASC, 2010). Through an understanding of the ways that IWDs are currently involved and prefer to be involved in their decision-making, HCPs could be provided with informative insight on how to best support IWDs in their care decisions. HCPs could use their understanding of decision-making in dementia to empower IWDs to be more involved in their decisions, and thus may improve their quality of life (Menne et al., 2008). Those dwelling in rural communities face unique challenges and have been found to make different care choices than those in urban centers (Gessart et al., 2006). Currently, it is not known how rural dwelling IWDs are involved in their decision-making. The findings, in this study, could be effectively used to provide strategies to ICGs and HCPs on the best ways to empower rural community dwelling IWDs in the involvement of their decision-making.

Chapter 2: Ways of Decision-Making Used in the Care Decisions of IWDs

Abstract

An understanding of the ways that rural community dwelling individuals with dementia (IWDs) are, and prefer to be, involved in their decision-making could help caregivers maximize IWDs' contribution to their decisions and could thus improve their care. This qualitative secondary analysis used an interpretive descriptive approach to inductively analyze 30 semi-structured interviews, which included 5 IWDs and their 6 informal caregivers (ICGs). Interviews were conducted over a year at the baseline, 6 months, and 12 months. Five ways of decision-making were identified: (a) independent, (b) collaborative, (c) guided, (d) delegated, and (e) directed. Contrary to IWDs' preference for independent decision-making, they most often made guided decisions. Guided decision-making was used when IWDs did not recognize their need to make the specified decision, and when the IWD or their ICG perceived that the IWD needed guidance in their decision. Involvement of IWDs in their decision-making was maximized when their decisions were guided.

Ways of Decision-Making in Dementia

In Canada, the number of individuals with dementia (IWDs) are expected to increase over the next 20 years by 2.5 times; and by 2038 there is expected to be 1.1 million Canadians with dementia (Alzheimer's Society of Canada [ASC], 2010). Dementia is more prevalent as a person ages (Lobo et al., 2000), and the rural population of older adults, in Canada, are aging faster than those of urban areas (Dandy & Bollman, 2008). IWDs, living in rural areas, have reported being excluded from their care decisions, despite their desire for input in their decision-making (Forbes et al., 2011). Ethically, IWDs have the right to be involved in their care decisions (Bartlett & O'Connor, 2010). Importantly, health care providers (HCPs) of IWDs should refrain from the assumption that they are not capable of contributing to their decisions because of their diagnosis alone (O'Connor & Purves, 2009). IWDs' care provided to them better reflected their preference when they were involved in their decisions (Bossen, Specht, & McKenzie, 2009; Van Der Roest et al., 2009). Furthermore, greater involvement of IWDs in their decisions has been significantly related to an increase in their quality of life (Menne, Tucke, Whitlatch, & Feinberg, 2008). An understanding of the ways that rural community dwelling IWDs are, and prefer to be involved in their decision-making could be used to guide informal caregivers (ICGs) and HCPs in the inclusion of IWDs in their decisions.

Capability of IWDs to Contribute to their Decisions

IWDs have demonstrated a capability to articulate and explain reasons for their care decisions (Horton-Deutsch, Twigg, & Evans, 2007; Karel, Moye, Bank, & Azar, 2007; Whitlatch, Feinberg, & Tucke, 2005), and communicate their thoughts regarding their present and future care (de Boer, Dröes, Jonker, Eefsting, & Hertogh., 2012; Dening, Jones,

& Sampson, 2013; Feinberg & Whitlatch, 2001, 2002; Hanmann et al., 2011; Tyrrell, Genin, & Myslinski, 2006; Whitlatch & Feinberg, 2003). Despite IWDs' capability to contribute meaningfully in their decision-making (Hirschman, Joyce, James, Xie, & Karlawish, 2005; Karlawish, Casarett, Propert, James, & Clark, 2002), they are not consistently included in discussions regarding their care (Tyrrell et al., 2006). It is possible that as dementia progresses and IWDs' awareness of their disease decreases, that they may not have an accurate appreciation of their abilities to be involved in their decision-making. For example, Forbes et al., (2012) found that rural IWDs were often in denial about their illness.

There are three common instruments used for measuring decisional capacity of IWDs: the MacArthur Competence Assessment Tool Treatment, the Hope Capacity Assessment Interview, and the Capacity to Consent to Treatment Instrument (Moberg & Rick, 2008). When used to measure overall capacity for treatment decisions in individuals, with mild to moderate dementia, these three instruments had only "fair to good agreement beyond chance" (Gurrera, Karel, Azar, & Moyle, 2007, p.171). It is important for clinicians to keep in mind that the decision-making autonomy of IWDs is a "process", and that IWDs have been found to have different "degrees" of involvement in each part of their treatment decision (Hirschman et al., 2005, p. 386).

Ways of Decision-Making Used by IWDs

To the researcher's knowledge, there has only been one research study that has directly explored the ways that decisions were made by IWDs (Smebye, Kirkevold & Engedal, 2012). Smebye et al. (2012) used a hermeneutics interpretive method to explore IWDs' involvement in their care decisions through interviews with ICGs and HCPs; and through observations of how HCPs facilitated the care decisions of IWDs. Data were collected over a period of one to two days. The sample consisted of 10 IWDs, 10 ICGs, and 10 HCPs, from three municipalities in Norway. IWDs ranged from those who lived independently to those who lived in nursing care homes (Smebye et al., 2012). Five ways of decision-making were identified: autonomous, pseudo-autonomous, shared, delegated, and non-involvement of the IWDs. In this study, IWDs were not asked directly about the ways they were involved in their care decisions. Therefore, further insights may be gathered from exploring decision-making of IWDs through the use of interviews, and the inclusion of the perspectives of IWDs who reside in rural communities.

Rural community dwelling IWDs may provide a different perspective on the ways they are involved in their decisions compared to those in urban centers, as they have a unique set of values and perceptions (Gessart, Elliot, Peden-McAlpine, 2006). Older adults in rural areas are more likely to express a deeply ingrained sense of self-reliance and desire to protect one's dignity (Morgan, Semchuk, Stewart, D'Arcy, 2002; Forbes et al., 2008). Furthermore, in rural areas, the stigma associated with dementia has often impacted how community members and families interacted with IWDs (Morgan et al., 2002). Forbes et al. (2011) found that IWDs, living in rural areas, have reported being excluded from health care decisions, despite their desire to contribute in their decision-making. To the author's knowledge, there are no research articles that directly explore the ways that rural dwelling IWDs are, and prefer to be, involved in their care decisions.

Study Purpose

The purpose of this study was to explore the ways that rural community dwelling IWDs were involved in the decision-making of their care decisions.

Specific Aims

1. To develop a conceptual description of the ways that rural dwelling IWDs were involved in their decision-making.
2. To explore the ways of decision-making that were preferred by rural dwelling IWDs and how these preferences varied between care decisions.
3. To describe the contextual factors that impacted the decision-making of rural dwelling IWDs.

Methodology

A secondary analysis of data from the qualitative study titled "Developing Dementia Care Decisions through Knowledge Exchange in Rural Settings", was conducted using Sally Thorne's (2008) interpretive descriptive approach. The use of Thorne's interpretive description aligned well with this research study as the study examined the ways of decision-making from the perspective of IWDs; and the results could be clinically relevant to HCPs. Further, the research purpose and aims were best answered with the use of an inductive analytic process (Thorne, Kirkham, & O'Flynn-Magee, 2004).

Participants

The participants were recruited for the primary study from: the Alzheimer Society of south western Ontario; First Nation community; South West Community Care Access Centre; and the Victorian Order of Nursing in south western Ontario (Forbes et al., 2012).

Participants included in this study: (a) spoke English, (b) lived in a rural area with a population no greater than 10,000 people, and (c) were diagnosed with dementia by a general practitioner or geriatrician, or were ICGs of the IWDs.

Sample Selection

In the primary study, there were 80 interviews and 80 field notes completed with the included IWDs (n=5), ICGs (n=14), and HCPs (n=14). Data were collected over three points in time: baseline, 6 months, and 12 months post-enrollment (Forbes et al., 2012; see Table 2.1). The interviewer completed field notes after each interview. Sorting was used to select a particular subset of the interviews; and field notes from the primary study were used to illuminate the ways that IWDs were, and preferred to be involved in their decision-making (Heaton, 2004). There were a total of nine networks in the primary study that consisted of IWDs, ICGs, and HCPs. Five of these nine networks, (Networks 1, 2, 3, 5, and 9) were selected to be included in this secondary analysis, as they were the only networks that interviewed IWDs (see Table 2.1). A total of 30 in-depth semi-structured interviews and 30 field notes of IWDs (n=12) and their ICGs (n=18) were included in the secondary analysis (see Table 2.1). The field notes were included to supplement the interview data, which helped prevent data misinterpretation (Thorne, 1998). In addition, field notes illuminated the contextual factors of the interviews (Thorne, 2008) that the researcher would not have otherwise captured, since the researcher was not present during the data collection (Heaton, 2004). The ICGs were used as a collateral source (Thorne, Kirkham, & MacDonald-Emes, 1997), and were included in this study to help enrich the data as “key informants” to prevent misinterpretation of the IWDs interview data (Thorne, 2008, p. 135). All the HCPs interviewed in the primary study were excluded, as the IWDs were the focus of the research.

Table 2.1

Interviews Conducted in the Primary Study

		Interviews			
Network	Interviewee	Baseline	6 Months	12 Months	Total Interviews
Network 1[a]	IWD	√	√	-	2
	ICG	√	√	√	3
	HCP	√	√	-	2
	HCP	√	√	-	2
Network 2[a]	IWD	√	√	√	3
	ICG	√	√	√	3
Network 3[a]	IWD	-	√	-	1
	ICG	√	√	√	3
	HCP	√	-	-	1
Network 4	IWD	-	-	-	0
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
	ICG 3	√	√	√	3
	HCP	√	√	-	2
Network5[a]	IWD	√	√	√	3
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
Network 6	IWD	-	-	-	0
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
	HCP	√	√	-	2
Network 7	IWD	-	-	-	0
	ICG	√	√	√	3
	HCP	√	√	-	2
	HCP	√	√	-	2
Network 8	IWD 1	-	-	-	0
	ICG 1	√	√	√	3
	ICG 2	√	√	√	3
	HCP	√	√	-	2
	HCP	√	-	-	1
Network 9[a]	IWD	√	√	√	3
	ICG	√	√	√	3
	HCP	√	√	-	2
Multiple Networks[b]	HCP 1	√	√	√	3
	HCP 2	√	-	-	1
	HCP 3	√	√	-	2
	HCP 4	√	√	-	2
Sum of Interviews	IWD	4	5	3	12
	ICG	14	14	14	42
	HCP	14	11	1	26
Total Interviews		32	30	18	80

Note. The table outlines the interviews of each individual with dementia (IWD), informal caregiver (ICG), and health care provider (HCP) in the primary study.

[a] Networks that were included in this study [b] HCPs interviewed for multiple network

Data included, in this study, were the anonymized transcribed interviews and field notes of the selected participants. Field notes contained descriptions and information about: (a) the environment including, the people present for the interview and activities that were occurring simultaneously, (b) the informal conversations that occurred with participants, and (c) the nonverbal behaviour of the participants. The length of the interviews ranged from 60 to 90 minutes. Examples of questions asked in the interviews of IWDs and their ICGs that illuminated the ways rural IWDs were, and preferred to be involved in their decision-making included:

1. Who was involved in the decision to initiate this service (support group, day home, respite care)?
2. Under what situations and circumstances would you seek assistance from a family member, or close friend?
3. How do you decide whom to ask for assistance?

Data Analysis

An inductive analytic data process was used and guided by interpretive description (Thorne, 2008). Using the “borrowing technique” of interpretive description, the researcher drew “analytic guidance” (Thorne, 2008, p. 153) from the constant comparative method of grounded theory (Corbin & Strauss, 2008). This grounded theory analytic tool was used within the “context of interpretive description” (Thorne, 2008, p. 153). During each “brainstorming” session, the researcher wrote down the key ideas and thoughts of participants that were seen in the data (Thorne, 2008, p. 153).

The data were analyzed in four phases. In the first phase of the data analysis, all of the IWDs' field notes and interviews were read to develop an understanding of the data as a whole (Corbin & Strauss, 2008; Thorne, 2008). Afterwards, the researcher re-read the IWDs' data, then read the ICGs' data; and finally, for the third time, re-read the IWDs' data (Thorne, 1997, 2008). This process of re-reading was completed in order to take full advantage of the richness of the data through multiple readings of the transcripts (Beuscher & Grando, 2009; Thorne, 2008).

In the second phase of the data analysis, the researcher read the data as networks. In each network, the IWDs' field notes and interviews were read, followed by those of the ICGs'. The included networks, (Networks 1, 2, 3, 5, and 9) were read in numeric order. Open coding began in phase two with the use of "broad-based" and "generic" codes, until the analysis was well established and the researcher was confident in the findings (Thorne, 2008, p. 147). Initial coding began only after a lengthy immersion in the data, in order to prevent "premature coding and sorting" and to prevent "bloodless findings" (Thorne et al., 2004, p. 8).

The third phase was conducted using the constant comparative method to look for similarities and differences in data between participants (Corbin & Strauss, 2008; Thorne, 2008). Again, the five included networks were read consecutively. In each network, the researcher first read the IWDs' field notes and interviews followed by those of their ICGs'. In this phase, concepts began to be defined into both higher-level concepts (themes), and lower-level concepts (properties) (Corbin & Strauss, 2008). These concepts were labeled in a way that reflected "common language" (Thorne, 2008, p. 172). Processes were examined by stepping back from the data to reflect about the larger picture and examine patterns in the data. Diagraming was used as a tool to “depict relationships between analytic concepts” (Corbin & Strauss, 2008, p. 171).

During the fourth phase, the researcher re-read the memos and analytic notes written, and then went back to the literature to examine any concepts that were unfamiliar (Corbin & Strauss, 2008; Thorne, 2008). Nvivo10 software was used to assist with data management and storage (Thorne, 2008). Raw data from the primary study were recoded and entered into Nvivo10 to prevent an overlap with the primary study data (Szabo & Strang, 1997).

Credibility

Credibility was evaluated through the following criteria: epistemological integrity, representative credibility, analytic logic, and interpretive authority (Thorne, 1997, 2008). Epistemological integrity was maintained, in this study, as this research used an inductive process to explore the ways of decision-making by IWDs; and results were presented using examples from the data. In addition, the researcher recognized the influence of herself on the data and vice versa, and recognized that realities were subjectively constructed, complex, influenced by context, and were studied as a whole (Thorne et al., 2004; Thorne, 2008). Representative credibility was established, as claims made by this researcher were consistent with the limitations of the research. Further, the IWDs’ interviews were triangulated with those of the ICGs’ to increase credibility (Beuscher & Grando, 2009), as the use of multiple perspectives provided a “more probable” truth of the participants’ experiences (Thorne, 2008, p. 78). Importantly, having not been present during the data collection, the analysis of field notes helped illuminate the contextual factors of the interview data (Heaton, 2004; Thorne, 2008). Also, an audit trail was used to capture the reasoning process in the inductive analysis (Thorne, 2008). Analytic logic was established by presenting a thick description of the participants' data in the findings (Thorne, 2008). Finally, the researcher used reflective journaling to account for any influences of bias in the data analysis (Thorne et al., 1997).

Ethics Approval

Ethics approval for this secondary analysis was obtained from the Research Ethics Board of the University of Alberta. The researcher signed a confidentiality agreement. Anonymity and confidentially of the participants were maintained by ensuring the researcher of this study only had access to data where the participants' identifiable information was anonymized and code names were used (Thorne, 1998). Pseudonyms were used to anonymize the data.

Results

Participant Characteristics

There were 5 IWDs and 6 ICGs included in this research, and their attributes are presented in Table 2.2. All the IWDs included in this study were diagnosed with Alzheimer's disease. Two of the 5 IWDs were currently employed, while the rest were retired. In three of the five included networks, the ICGs were spouses of the IWDs, while in the other two networks, the ICGs were extended relatives of the IWDs. Two of the 6 ICGs were retired and had significant comorbidities that impacted the care they provided to the IWDs. Further, two of the networks were from a First Nation community. The IWD in Network 1 did not complete the interview at 12 months, as at this time the IWD resided in a long-term care facility. Also, in Network 3, the IWD refused to be interviewed at baseline and at 12 months.

Table 2.2

Social-Demographic Characteristics of Participants

	Participants	
Characteristics	IWDs	ICGs
Age		
Mean (SD)	77.4 (±11.67)	54.5 (± 12.24)
Range	63-95	39-73
Gender (n)		
Female (male)	2 (3)	5 (1)
Marital Status[a]		
Married	3	3
Single	2	3
Highest education level		
Primary or less	2	1
Secondary/trade	2	1
Some post-secondary	-	2
Post-secondary	1	2
Graduate/professional	-	-
Employment status		
Full time	-	4
Part time	-	-
Retired/not employed	5	2
Community population		
<1,000	1	1
1,000-4,999	3	4
5,000-10,000	1	1
>10,000	-	-
Distance from urban centre (km)		
Mean (SD)	26.3 (3.12)	26.75 (3.02)
Range	21.9-29.1	21.9-29.1
Dementia Diagnosis		
Alzheimer's Disease	5	n/a
Other Dementia	-	
Time Since Dementia Diagnosis		
Less than 5 years	4	n/a
Greater than 5 years	1	

Note. Adapted from Forbes et al. (2012, p. 2204)

[a]Married = married or common law; Single= single, widowed, separate, divorced

In reference to the quotes of the included participants, the first number refers to the network (1, 2, 3, 5, or 9). The second letter "A" indicates an IWD's interview, while "B" indicates an ICG's interview. The third number (1, 2, or 3) indicates the time of the interview: baseline, six months, or 12 months respectively. The fourth letter "a" represents the *primary ICG's* interview, while "b" represents the *supporting ICG's* interview.

Decision-Making in Dementia

Five ways of decision-making were identified in the care decisions of IWDs and included: independent decision-making, collaborative decision-making, guided decision-making, delegated decision-making, and directed decision-making. The level of involvement of the IWDs in each of the decision-making ways varied on a continuum from complete independence to complete dependence in their decisions (see Figure 2.1).

Figure 2.1: Ways of Decision-Making

Independent decision-making. In the independent decision-making way, IWDs made their decisions on their own, without guidance. Overall, IWDs preferred to make most of their decisions independently. They preferred this way of decision-making when it was the way they had predominantly used prior to the onset of their dementia. For example, the IWD in Network 5 stated "I always managed my own, done my own work and everything. So when I'm alone, I still do" (5A1, Line 6-7).

IWDs also preferred to make independent decisions when they related their level of independence in their decision-making to their cognitive health. "I don't feel that I have [dementia], because I have common sense or I wouldn't be allowed to work, [because] you have to know what you're doing [to work], and I do" (1A1, Line 752).

The IWDs would often fear that their dementia was going to take away their independence. “He [the IWD] fears [that the dementia] is going to take away his independence” (3B1a, Line 702-706). As a result, they would strive to be as independent as possible. “You know if you do things correctly there isn’t too much to fear. The Alzheimer’s thing is the big thing that would scare me” (1A1, Line 860-861).

This fear would often drive the IWDs to fight for their independence. “Well I got a brother [with dementia] that’s sitting at home waiting to die. I can’t do that. I am gonna fight as long as I can to stay alive” (3A1, Line 1407-1509).

Sometimes the fear impeded the care that they received and the overall involvement in their decision-making, as they would block help from others.

> I’ve heard one person [with dementia say], ‘I think they’re trying to put me in a nursing home, that’s why they come’. So, every time they think about this person, they think they’re going to put them in the asylum or something.…So they’re kind of blocking the help, instead of reaching out and grabbing it. (9A1, Line 1931-1948)

Decisions that the IWDs’ *valued* and decisions that they perceived as having a direct impact on their desired lifestyle were preferred to be made independently. “I like my place tidy…I want [the house cleaned] the way I like it done. That was my job years ago, when I worked, I cleaned houses” (5A2, Line 139-140; Line 317-319).

In addition, independent decision-making was preferred by the IWDs, as it enabled them to *contribute* meaningfully to their lifestyle and relationships. This contribution made the IWDs feel important.

> My son was renovating his bathroom, so he came and got his dad [the IWD], [and] the two of them did it together. There's some stuff [the IWD] can still do, [and] he can pass his knowledge on. It make [him] feel important. (3B3a, Line 1086-1088)

Finally, an independent decision-making way was preferred by IWDs when they *perceived themselves as capable* to make the decision alone. "I've got another nephew, and he stays with me when he can.…which is just as well. 'Cause, I mean, I'm still capable" (9A1, Line 127-133).

Factors facilitating IWD's preference for independent decision-making. Although IWDs often preferred an independent way of decision-making, for decisions regarding their daily activities, driving, finances, medical management, and long-term care, this preference for independence in these decisions did not always correlate with their reality. Decisions that were most often made independently by IWDs were less complex and were around daily activities. They included decisions regarding entertainment, hobbies, and social activities. The use of an independent decision-making way by IWDs was facilitated when: (a) the IWDs were perceived by their ICGs to be capable to make decisions on their own, and (b) when their ICGs encouraged independence of the IWDs in their decisions.

> I think that she's [the IWD] into a routine and she knows what she wants to do and…she'll do her own laundry and she'll even hang them out on a line. So I just feel that no we can't take that away from her, she can do that. Let her do… those little things…I want her to…have her independence as much as possible. (5B2a, Line 381-392)

The IWDs were independent in decisions when they were able to autonomously identify and arrange resources, and had the knowledge and understanding of how to enact the decision on their own. “I bought a new dishwasher, the pump doesn’t work, and we’re having a problem with [the] warranty. So he’s [the IWD] going to take it out and fix it. He’s really handy and if left alone he does it” (3B1a, Line 20-38).

Further, independence was maintained when the IWDs recognized their limitations and safety concerns surrounding a decision. “I don’t get out and walking as much as I’d like to, but I have a bad leg and so I can’t keep up with [my wife]” (2A3, Line 54-56).

The ICGs were willing to support the IWDs to make decisions independently when they *perceived level of risk* associated with the IWDs’ decision to be acceptable. “[In] the summer, she has her garden [and] her legs are a lot stronger. I think that’s good for her. I encourage her to get up and do those kind of things because it makes her stronger” (9B3a, Line 41-58).

The rural setting facilitated the independence of IWDs in their decisions, as the environment increased the ICGs’ comfort with the IWDs’ independence in their decisions.

> Here it’s familiar, and if he wanders too far he can’t get into any difficulty. If we lived in [the city], he would walk in the street, get lost, get hit. There’s a huge advantage to living in the country. He’s familiar here. He can walk outside he can pull the weeds in the garden. He can go down to the creek. He can do all the normal stuff he’s always done. (3B2a, Line 710-716)

The energy to guide the IWDs in their decisions was at times perceived by the ICGs to be more difficult than allowing the IWDs to make an independent decision. Therefore, ICGs, who were burdened, were more likely to compromise their standards and expectations, and allow for the independence of the IWDs in their decision-making.

> So now it’s gotten to the point…when I do laundry, I just put it all in a pile and put it on his dressing table. I don’t put it away because I don’t know where anything is anymore, I gave up on it. (1B2a, Line 570-572)

The ICG would often weigh the risks and benefits of allowing the IWD to have independence in their decision-making. At times, this meant a willingness to accept imperfection in the outcome of a decision made by the IWD, so that the IWD could maintain their independence. “He likes to think he’s contributing. And when he does unload the dishwasher, I spend half the morning trying to find stuff. He’s always putting things down and he can’t remember” (3B3a, Line 336-338).

Collaborative decision-making. Collaborative decision-making was observed solely in IWDs who were in a spousal or common-law relationship with their ICGs. This way of decision-making was used when both the IWDs and the ICGs desired to make the decision collaboratively; and the IWDs were able to engage in the decision in partnership with their ICGs. Interestingly enough, IWDs and ICGs who used a collaborative way of decision-making had incorporated it in their decisions prior to the onset of dementia. Often times, collaborative decision-making was viewed by IWDs as supplemental to their independent decision-making. “I just never really think about asking anybody for extra help, and that kind of thing. Because I’ve always done [things on] my own, or [name: spouse] and I have always worked together” (2A3, Line 369-371).

The IWDs, in the spousal relationships, preferred to engage collaboratively with their ICGs in decisions that were considered to have an important impact on their lifestyles and future plans.

> So if you would have any questions about how the future will look, where would you turn to? Usually we [my wife and I] discuss it, if there's anything that we're not sure of, we talk it over. (2A1, Line 528-550)

Collaborative decision-making was also used when the IWDs were making decisions about a *shared activity* that both the IWD and their ICG valued. Most often, IWDs and their ICGs used this way of decision-making for decisions regarding shared social activities and chores.

> We kind of work together on that, we've got the two mowers, we've got the riding mower and we've got the push mower, and [my wife] quite often she'll take the push mower and do the small parts, where you can't get in with a riding mower. We just work together. (2A1, Line 339-353)

The IWD's capability to engage in decisions collaboratively was impacted by their *ability to contribute* to the decision in a partnership with their ICG. For example, although IWDs preferred to collaborate in decisions regarding finances, this did not always reflect their reality. "We usually talk about [big decisions]…we always did [make big decisions] together…but if it's financial, it's mine [now]" (3B2a, Line 292-303). "He just doesn't understand [the financial decisions]" (3B2a, Line 120).

Collaborative decision-making was initiated by either the IWD or their ICG. When initiated by the ICGs, it reflected their desire to include the IWD in their decision.

> We did have to decide about [the IWD’s] RSP, we had to change it over to a RIF. We went straight to the bank and asked the professionals what we should be doing and what the options were. And you know, based on my experience, we made that decision. Of course, [the IWD] and I talked it over, I wanted him to understand what he could, knowing that maybe a few minutes later or the next day he really wouldn't know. (2B2a, Line 209-217)

Guided decision-making. There were three levels of guided decision-making identified: (a) in level 1 guided decision-making, the IWDs *initiated* the decision and recognized their need for guidance; (b) in level 2 guided decision-making, the ICGs *engaged* the IWDs in their decision-making; and (c) in level 3 guided decision-making, the ICGs *limited* the decision-making choices of the IWDs; however, the IWDs still engaged in making the final decision. In all three levels of guided decision-making, the IWDs made the final decision.

Level 1 initiated guided decision-making. In the level 1 guided way of decision-making, the IWDs *initiated* the request for guidance in their decision. Decisions made with level 1 guidance were those related to: entertainment, community group involvement, work activities, medical management, medication administration, and dementia diagnosis and treatment initiation.

Level 1 initiated guided decision-making was the only way of decision-making in which the decisions made by the IWDs consistently reflected their *awareness of their need for guidance.* The IWDs who used this way of decision-making recognized their limitations in making their decisions and sought guidance.

> She [my wife] goes with me [to the doctors] cuz a lot of times I won't remember this or that,…When she goes with me, she will argue with him…I won't. They could tell me anything and I would believe it cuz they're doctors. (3A1, Line 1170-1178)

The awareness of IWDs about their need for guidance in their decisions did not always coincide with their preference to make their decisions in a guided way. Rather, the recognition of their need for guidance often served as a reminder to the IWDs of their progressive memory loss and associated *loss of knowledge and skill*, which they found frustrating and depressing.

> He becomes frustrated when he sees maybe that he's asking things of me that he wouldn't before [the diagnosis of dementia]…sometimes he does get down, and a big part of my job is encouraging him to always look on the bright side. (2B1a, Line 301-306)

The IWDs who engaged in this way of decision-making had caregivers who were willing to *support* and guide them in their decisions.

> She makes sure I take the right pills. Cuz sometimes I do get a little queasy on what I should take and what I shouldn't take. So she usually knows better than I do, what I should be taking. (2A2, Line 506-532)

Level 2 engaged guided decision-making. Level 2 engaged, guided decision-making was initiated by the ICGs. In this way of decision-making, the ICGs *engaged* and guided the IWDs in making a final decision. The use of level 2 engaged guided decision-making occurred when the IWD either (a) lacked recognition of the need for guidance in their decision, or (b) lacked awareness of the need to make a decision.

The IWDs did not express a preference to make any decisions in a level 2 guided decision-making way, yet they remained willing to engage in this way of decision-making with their ICGs. The IWDs preferred to use an alternative to the level 2 guided decision-making when they perceived themselves as being able to make decisions independently, or alternatively they preferred to make use of a delegated way of decision-making. When making decisions, IWDs and their ICGs most commonly used the level 2 guided decision-making way. “I have to, you know, pretty much guide him with everything” (1B1a, Line 342). The ICGs found their responsibility to guide the IWDs in their decisions to be a challenge. “It’s more responsibility for me to make sure that I’m looking out for both our interests” (2B1a, Line 88-89). “I have to be there more as a caregiver, he’s always been strongly independent, but now…[I have to] remind him, don’t do that…it’s a different relationship” (3B1a, Line 434-445).

The IWDs, who perceived themselves as being able to make their decisions in an independent way, often required guidance when they had a *lack of awareness of their situation and context*. For example, they were often unable to identify the day of the week. Thus, in these situations, the IWDs required guidance in order to continue in the activities that they valued.

> [ICG:] Where you going? [IWD:] Well, [name: work]. [ICG:] It’s Saturday [name: IWD], it’s not open. [IWD:] Oh, it’s not open at all? [ICG:] No, it’s Saturday. [IWD:] Oh, okay. Then I’ll work in the garage. (1B2a, Line 2010-2022)

Further, the IWDs would need level 2 guidance in their decision-making when they did not recognize the need to make a particular decision.

> Like, he forgets to shave, and he used to be really fastidious about doing that every day, [but now he] doesn't do it unless I say to him, 'Hey, you're getting kind of bushy.' And then he'll go shave. But it used to be something that he would do as a routine, but not anymore. (3B3a, Line 350-353)

When the IWDs *lacked a recognition* regarding safety concerns surrounding a decision or had *challenges problem solving independently,* the ICGs would guide the IWDs in their decision-making. "[I] help him get his clothes out the night before [he goes to the day home] so that he's dressed warm enough or cool enough, because he doesn't watch the weather, he doesn't know." (1B1a, Line 257-261)

The ICGs guided the IWDs when they perceived the *level of risk* associated with the decision to be unacceptable.

> There was a little episode about a month ago, and he was out playing around, and he almost cut his toe off with a chainsaw…he just [had a], lapse in judgement, he wasn't supposed to be doing, using it you know…[so] now he wears safety boots and I have to remind him to put them on. (3B1a, Line 199-215)

The resources available to the IWDs and their ICGs helped maximize the involvement of the IWDs in their decision-making. For example, when one of the IWDs was no longer able to continue to safely work independently; instead, of the ICG making a directed decision to terminate the work activities of the IWD, the ICG had friends support the IWD and guide him in his work.

> The good thing, about being in a neighbourhood, is we have some really good friends, and a support network.…We have a house that we have for sale, and he's

> [the IWD's friend, was] doing some work on it, so I called him [and asked him]…'look [name: the IWD] is going to call you, can you help him? So he's [name: the IWD] not alone, so he's working with [a friend who] will use the power tools because [his] common sense or reasoning isn't there'.…I don't want him to chop his fingers off or anything. (3B1a, Line 331-347)

When the IWDs' *lacked of awareness* of their memory loss, as being related to a pathological process, this led to a need for guidance in the decision to see a physician for their dementia diagnosis and treatment.

> Have you ever wondered about some of those changes or asked anybody about why am I having memory problems? No. No, I'm thinking that happens to everybody…so that's what I think. (5A2, Line 362-375)

As a result, the ICGs would engage the IWD in the decision to see a physician to obtain a dementia diagnosis.

> The first year, I noticed that she was forgetful, and she'd tell me, she'd say, 'Oh I'm so…it makes me feel different, I forget a lot'. She says, 'I'd forget a lot', and I said, 'oh, well maybe we should get you to a doctor, I'll make a doctor's appointment and we'll see if he can help us, because if you've got something wrong going on with your memory, then we should find out'. So I made the doctor's appointment. (5B2a, Line 438-443)

The IWDs needed guidance in their decisions as they often *lacked awareness into their care needs* and had *challenges recalling information* required to inform their decision. These challenges led to a need for repeated guidance.

> I noticed, that, just the other day when I was at my grandmother's and looking for other items in her kitchen cabinet and [there were] two packages of medications. One completely unopened, which held a month's worth of medication and another one that was partially opened, but very little taken from it, and she, just coincidentally had an appointment booked yesterday. So, my grandmother doesn't know, [and say asks], 'Why should I take these medications? I feel fine'….I said, 'You're concerned about your memory and one of these medications is there to help with that'. (5B1b, Line 174-181)

The ICGs, who were motivated and *desired to involve the IWDs* in their care decisions, regardless of their lack of recognition of their need for the decision, would make the effort to include them, using a level 2 guided decision-making way. In these situations, the IWDs' involvement rested on the ICGs, as the IWDs either did not see the need to initiate the decision or the need for guidance in their decision. "Well, we talked about [long-term care placement] and he knows, we asked him where he wanted to be and he said he wanted to be close by in [place]." (3B3a, Line 421-424)

Level 3 limited guided decision-making. ICGs and IWDs rarely used a level 3 guided decision-making way. This way of decision-making was used when the IWD had difficulty understanding the need for the decision, but the ICG desired their inclusion in making the decision. In this decision-making way, the ICGs provided the IWDs with the *limited* decision-making option to choose from; and the IWDs were strictly guided in the decision.

> [I] told my mother, I said, ‘Well you know what? It might be getting to a point where you have to come and live with me,’ and she says, ‘Oh no, I don’t want to live over there.’ You know, and I says, ‘Well if we don’t get a home maker, then that’s what’s going to happen, or I’m going to have to come and live with you.’ ‘No I don’t want you living with me.’ (5B3a, Line 743-748)

The limited options available reflected the ICGs *burden* and inability to manage. “I say to my mother [the IWD], ‘Mom, well maybe you don’t think you need one [a home maker], but I do, I need help’” (5B2a, Line 549-551).

Delegated decision-making. The IWDs initiated the use of a delegated decision-making way when (a) they preferred not to be involved in the specified decision, or on occasion (b) when they realized they were unable to manage the decision. In most cases, the IWDs would delegate the decision to their primary ICG. The ICGs would then be responsible for making the final decision on the behalf of the IWD. The use of a delegated decision-making way, by the IWDs, most often reflected their preference not to be involved in making the specified decision. Decisions that IWDs preferred to make in a delegated way were related to: daily activities, financial management, resuscitative end-of-life care, and long-term care placement.

A delegated decision-making way was often used by IWDs and ICGs who were in a spousal relationship, as they had previously delegated decisions to each other prior to the onset of the individual’s dementia. These decisions included things such as cooking, household chores, and financial management. This way of decision-making continued to be preferred, by the IWDs and their ICGs, when the specified decision had been delegated by the IWDs prior to their diagnosis. "[Interviewer:] How about banking? … [ICG:] I do all that too, but I always had, so that's. [IWD:] That's natural" (1A1, Line 564-574).

The preference of IWDs to delegate their decision to their ICGs reflected their *trust* in their ICG to manage the decision on their behalf.

> I think [name: ICG] does most of the bill paying. It doesn't matter, my pension that comes in, her money that comes in, it all goes to the…same pot anyways….We don't worry about who gets what money in that respect. (2A1, Line 375-386)

The preference of the IWDs to use a delegated decision-making way was often related to the *value* they placed on the decision and their view of their *societal gender roles.* For example, IWDs who were male preferred to delegate decisions regarding housekeeping and cooking, whereas female IWDs preferred to delegate outdoor chores, such as shoveling snow and mowing the lawn.

> A lot of the outside work I never used to have to care for, [name: IWD] was always faithful you know in things like taking out the garbage, and mowing the lawn, and you know, all those things that guys do, stereotyping. (2B2a, Line 237-239)

The use of a delegated decision-making way, by the IWDs, required the *resource and willingness* of the ICGs to accept responsibility for their decision. At times, the preference of the IWD to use a delegated decision-making way, was overridden by the ICGs' needs. For example, the *physical limitations* of the ICG prevented the IWD from delegating the task of grocery shopping. "For groceries, I've been taking him [the IWD] with me because I can't manage…the lifting and that" (1B2a, Line 284-288).

ICGs, in a spousal relationship, were confident in making decisions on behalf of the IWDs.

> [ICG:] He doesn't do any shopping. [IWD:] I let [name: ICG] do that. She goes in and gets all the goodies, and things that I shouldn't eat. [Interviewer:] Do you sort of tell her that you'd like her to bring home this and this and this kind of thing? [IWD:] No, no [ICG:] I know what he likes. [Interviewer:] You know what he likes? [IWD:] She's just excellent. (1A1, Line 545-562)

In comparison, to the spousal ICGs, those in more peripheral relationships were reluctant to accept the decision-making responsibility for the IWDs, as they wanted to ensure that the decision made reflected the IWDs' preference. "My mom likes to take her [the IWD] out to go and get her groceries because she wants it to be things that she [the IWD] would eat" (5B2a, Line320-323).

Occasionally, IWDs preferred to engage in an independent decision-making way; however, they would choose to use a delegated decision-making way because of their limitations. When this occurred, the IWDs choice to use a delegated decision-making way reflected an awareness of their limitations and situational context. "[name: ICG] does the lawns most of the time, on the lawn mower. But that's simply because of this leg. She does most of the running around with the mower" (2A3, Line 84-86).

The IWDs had an emotional response to their *loss of independence*. "In, in things outside, like, I've felt bad a little bit at times. She's had to go to the snow, and get stuff that I couldn't go (crying)" (2A2, Line 311-321).

One of the IWDs was a nurse prior to retiring; and she was particularly concerned with the ICG's *limitations and burden,* and as such delegated the decision for long-term care placement to her ICG. "She [name: IWD; says], 'You just tell me when I'm too much. Cause then, I gotta go into a home.'" (9B1, Line 462-472).

Directed decision-making. There were two levels of directed decision-making identified: (a) level 1 informed directed decision-making, and (b) level 2 uninformed directed decision-making. Directed decision-making was initiated by the ICGs, whom would make the final decision on the IWD's behalf.

Level 1 informed directed decision-making. In level 1 informed directed decision-making, the IWDs were aware of the decisions made on their behalf; however, they did not initiate or participate in the decision-making. IWDs either appreciated, or had a lack of appreciation for the decisions made for them by their ICGs. IWDs that *appreciated* the use of a level 1 directed decision-making way by their ICGs were (a) willing to accept direction from their ICGs, and (b) had *insight* into their need for the decision and/or appreciated the outcome of the decision. IWDs' appreciated the use of a level 1 directed decision-making way for the following decisions: household improvements, the purchase of a life-line, informal and formal respite services, and financial management.

Most IWDs who appreciated the decisions made for them, in a level 1 directed way, could have participated further in their decision-making. For example, one of the ICGs ordered a lifeline for the IWD to enable her to have access to emergency services at any location. The IWD appreciated that the ICG made this decision on her behalf, as the device increased her sense of security.

> [Interviewer:] Oh, you have the life-line support? [IWD:] Yeah, even if you hear somebody trying to get in the house, all you have to do is press the button, talk to the lady, tell her what's going on, and she'll send the police right over. That took a lot off my mind of worry. (9A1, Line 139-151)

The ICGs found that IWDs were *willing to accept* a level 1 directed way of decision-making when the IWDs recognized that they had *challenges problem solving*, due to their *loss of knowledge and skill.*

> Like years ago, if we had a problem with the sump pump, he could do it. He could install it. He did install the previous one, but I knew he wouldn't be able to do it this time. So I phoned a plumber, and he was fine with that. He didn't say, you know, 'I can do it.' He was pleased that they came and got to run it. (1B2, Line 1636-1635)

When the decisions of IWDs were perceived by the ICG as not being the best for them, the ICG would override their decision.

> Well, I have a daughter in [place] and…they're really busy. They have a young family, they both work, full time. And it makes it hard, there isn't the time. He did, set [her: the daughter] up as power of attorney, if something happened to me, but I don't think that she could handle it. (1B1a, Line 518-522)

The ICGs used a directed way of decision-making when the IWDs had *challenges understanding* the decision being made.

> Well I tried to talk to him [about long-term care], but you know, on and on he was going on about the [name: LTC setting] and I [told him], 'I have to get three…(and)

> I'm kind of against [name: LTC setting].' Even his sister didn't think he should go there, she didn't think the standards were very good there. (1B1, Line 976-980)

When the IWDs were *unwilling or unable* to recognize the consequence of their decisions, the ICGs would make a directed decision that the IWDs' did not appreciate.

> It's [was] kind of hard to take away all the chainsaws and power tools after he hurt himself. He was really mad about it, but now if he needs something done he'll call our son or he'll call the neighbour, [to] cut the wood or whatever. (3B1a, Line 723-725)

ICGs would intervene and make level 1 informed directed decisions when the IWDs were being taken advantage of financially by others. In this situation, the ICGs made a directed decision to appoint a power of attorney to protect the IWD. "My mom and my uncle have been managing her [the IWD's] finances, because there was some concern around that, where some family members, perhaps, may be taking advantage of that. So they've been managing that for my grandmother." (5B2b, Line 203-207)

Often times, directed decisions were made by the ICGs when they were *burned out*, desperate, and saw no other available options.

> Friday night I had a bus trip…and it was on the calendar for three weeks, four weeks. And he tossed a fit, like he called me and called me and called me. He thinks I'm running around and having a boyfriend….So I've decided, rather than argue with him…the next time I'll get my son, 'Come get your dad and go do something with him. Take him camping, or take him to your house, or whatever.' (3B3a, Line 360-370)

When feeling burdened, the ICGs would make a directed decision to make it easier for themselves, even though they knew the IWD's would have liked to contribute to the decision.

> He helps me with the dishes, but I then I can't find things if I let him put them away, so I have him just kind of leave them out, otherwise I don't know where they are. So, it kind of makes it easier. (1B1a, Line 366-372)

Level 2 uninformed directed decision-making. In level 2 uninformed directed decision-making, the IWDs were unaware of the decisions that the ICGs made on their behalf. The ICGs used this way of decision-making when they perceived there to be no other choice, or when they saw no benefit of including the IWD in their decision. Decisions made in this manner were regarding hobbies (when deemed unsafe), suitable dementia treatments and overall financial decisions. Other decisions were made regarding attending funerals and quitting driving. For example, one of the ICGs decided not to take an IWD to their family member's funeral. It was *perceived* that the IWD would not find the funeral meaningful, since he did not remember that particular family member. Also, the ICG thought the IWD's attendance would make the experience more *stressful.* "So I didn't take him to the funeral. I thought, 'No, I'm not gonna do that, or bother taking him out when he doesn't understand what's going on anyhow.'" (1B2a, Line 118-119)

At times, the ICGs made *assumptions* about the IWDs' preferences, which resulted in the use of a level 2 directed decision-making way. For example, an ICG was reluctant to discuss with the IWD the decision to take over the management of her bills due to *fear of upsetting* her. "I'm really dreading doing this Power of Attorney thing, because she's going to take it like, ‘Okay, I’m one step closer to the grave,’ kind of thing. I think that’s how she’s going to look at it” (9B3a, Line 819-821). Since the ICG preferred not to discuss finances with the IWD, he gradually took over her bills without her awareness. “Like since I’ve moved in with her last year, I’ve been paying her housing loan. I pay for the satellite, the phone. And I pay for about 90% of the food” (9B3a, Line 221-222). On the contrary, if the ICG had discussed the decision with the IWD, he would have realized that the IWD would have been grateful to have help with her finances. “Yeah, so I leave it to them [the ICGs] because they know how much money I have” (9A3, Line 818).

Another, ICG chose to make a level 2 directed decision to have the IWD’s license revoked. The ICG found that the IWD was driving *unsafely* and had a *lack of recognition* about his ability to drive. “I don’t know how much longer he’ll have a driver’s license, because he does some really stupid things. He scares me. He’ll go over the line. But in his mind he’s capable” (3B2a, Line 68-70). The ICG wanted to have the IWD’s license revoked without the IWD’s awareness of her involvement, as the ICG feared the IWD’s abusive behaviours.

> I will go see the family doctor, and she will order an assessment of his driving, because only a police and family doctor can have a license revoked, so it will be a procedure to keep me out of it, because if he thinks I did, it there will be no living with him. (3B2a, Line 624-627)

Adjustment to an Alternative Decision-Making Way

Often times, the IWDs and their ICGs’ first decision-making way attempted was adjusted, by the ICGs, to an alternative way. The decision-making way was adjusted when the first way attempted was not perceived to be the best option by the ICGs. The adjustment of the decision-making way occurred in a fluid manner, while the specified decision was being made. The ICGs often adjusted the decision-making way to one in which the IWDs would have less independence. Nevertheless, when this occurred, the ICGs would often attempt to use the decision-making way that they perceived to be most inclusive of the IWD. The ICGs often would adjust the IWD's decision-making way from an independent or collaborative way, to a guided or directed way.

> "Hygiene…is a constant problem.…I would like the CCAC to assess him and, and see what help that they can offer us.…but they need [name: IWD's] permission to do that…and so far he has not consented to do that. I've tried a couple of times. Now I do have Power of Attorney and I guess maybe that's what I need to do next. I don't, you know, I was kind of hoping, that we'd get his permission each step of the way." (3B3, Line 245-259)

Occasionally, the ICGs would adjust the first attempted decision-making way to one that would allow for greater involvement of the IWD in their decision. This adjustment occurred when the IWDs had used a delegated decision-making way; and the ICGs either needed or preferred the input of the IWDs in the specified decision. For example, although an IWD preferred to use a delegated decision-making way for grocery shopping the ICG included the IWD in the decision, as she needed the help. "I've been taking him [grocery shopping] with me, because I can't manage" (1B1, Line 284).

Overview of the Ways of Decision-Making

Five ways of decision-making were identified: independent, guided, collaborative, delegated, and directed. The level of involvement of the IWDs, in each of the decision-making ways, varied on a continuum from complete independence to complete dependence in their decisions (see Figure 2.1). For most decisions, the IWDs preferred the independent decision-making way. In this way of decision-making, the IWDs engaged in the decision and made the final decision on their own. On the other hand, when the decision was thought of as being shared, those in spousal relationships preferred the collaborative decision-making way. All decisions, made in an independent and collaborative manner, reflected the IWDs' preferred way of decision-making.

There were three levels of guided decision making identified: level 1 initiated, level 2 engaged, and level 3 limited. In the level 1 decision-making way, the IWDs *initiated* the decisions. The preference of the IWD to use a level 1 guided decision-making way, reflected the IWD's insight into their need for guidance. In level 2 and 3, guided decision-making ways, the ICGs initiated the decisions. The initiation of a level 2 or 3 way of decision-making reflected the ICG's desire to involve the IWDs in their decisions. In both level 2 and 3 guided ways of decision-making, the ICGs *engaged* the IWDs in their decision. However, in level 3, the decision-making options that the ICGs provided to the IWDs were *limited*.

Level 1 guided and delegated decision-making ways were initiated by the IWDs, yet the decision to use them did not consistently relate to the IWDs' preferences. Both ways decision-making were used when the IWDs recognized a need for help or guidance with their decision. The main difference between these two decision-making ways was that, in the level 1 guided decision-making way, the IWDs made the final decision. While in the delegated decision-making way, the IWDs allowed the ICGs to make the decision for them.

At times, IWDs found the use of the delegated and level 1 guided decision-making ways upsetting, as it reminded them of their disease process and their loss of independence.

In the directed decision-making ways (level 1 and 2), the ICGs made the final decision on behalf of the IWDs without their involvement. In level 1 directed decision-making, the IWD was aware of the decision made on their behalf. While in level 2 directed decision-making, the IWD was unaware of the decisions made. The ICGs used a level 2 directed decision-making way when they perceived there to be no other choice, or when they saw no benefit of including the IWD in the decision.

Limitations

This research cannot be applied to other situations or contexts as the all the IWDs included in this study were diagnosed with Alzheimer's disease and lived in the rural area of Ontario, Canada (Thorne, 2008). In addition, the findings in this study were based on interview data and field notes from a small sample size. The findings must also be considered from the author's nursing disciplinary lens. Further challenges, as related to this secondary analysis, included an inability to verify findings with the participants and follow up with questions as they emerged from the data (Thorne et al., 2004; Thorne, 2008). Since the researcher drew from a data set that previously existed which was collected for different objectives, there were times where greater detail from more poignant questions may have illuminated further the decision-making ways of IWDs. Field notes were used as supplements; however, the researcher was not involved in the data collection process. As a result, some of the contextual meaning may have been lost. Proactively, the researcher "engaged the critic" through seeking others' views on the data and analyses, and checked "new insights" with the literature (Thorne, 2008, p. 161).

Discussion

The five ways of decision-making identified in this research were: independent, collaborative, guided, delegated, and directed. These decision-making ways related to those identified by Smebye's et al. (2012): autonomous, pseudo-autonomous, shared, delegated, and non-involvement. The independent way of decision-making identified was the same as Smebye's et al. (2012) autonomous decision-making way. Further, a delegated way of decision-making was identified in both studies. The collaborative and the three levels of guided decision-making identified, in this study, related to Smebye's et al. (2012) finding of a shared way of decision-making. This research illuminated further the different ways that decisions were shared by IWDs and their ICGs, adding depth and clarity to the understanding of the decision-making ways in dementia. Pseudo-autonomous decision-making, as found by Smebye et al. (2013), was not found to be present in this thesis research study. Smebye et al. (2012) defined pseudo-autonomous decision-making as implicit and occurring when IWDs made a decision independently, but yet required support to enact the decision. The researcher suspects if the ways that IWDs were supported in their decision had been explored further that it would have illuminated whether the decisions occurred in an independent, collaborative, or guided decision-making way.

Horton-Deutsch et al., (2007) found that the majority of IWDs preferred input from others in their health care decisions. Contrarily, in this study, the rural dwelling IWDs most commonly preferred to make decisions in an independent way. This preference was most common for decisions regarding daily activities; however, at times also encompassed finances and health care decisions. This discrepancy may have been related to the rural individuals' deeply ingrained sense of self-reliance and desire to protect one's dignity (Forbes et al., 2008; Morgan et al., 2002). Despite the preference of rural IWDs for independent decision-making, the most common way of decision-making used was the guided, level 2 engaged way. Level 2 guided decision-making was used when ICGs desired the IWDs input in the decision and when: (a) the ICGs perceived that the IWDs could not make the decision in their preferred way or (b) the IWDs did not recognize the need to make the decision. IWDs often needed guidance to make their decisions, and the guidance received increased their involvement in their valued activities. ICGs and IWDs would often use a guided decision-making way after other more autonomous ways of decision-making were attempted.

Although the capability of the IWDs to make the specified decision was important, this alone did not seem to be the sole determining factor of the decision-making way used by IWDs. The ICG's situation, context, and resources seemed to play an important role in their perception of their decision-making way options. The ICGs in the rural setting expressed that they were more comfortable with allowing independence in the IWDs decision-making as the rural areas were thought to be more supportive and safer than urban centers. Further, many of the IWDs and ICGs in the rural setting had long standing relationships with friends and family who often provided respite to the ICGs and would provide support so that the IWDs could maintain their independence in the activities they valued. This support opened up decision-making options for the IWDs. When decision-making options were available the ICGs often used a guided rather than a directed decision-making way.

As previous research highlighted (Smebye et al., 2012), ICGs often made decisions on behalf of the IWDs when they perceived that there were no other options or choices. The greater the ICG's burden, the more often directed decisions were made (Hirschman, Xie, Feudtner, & Karlawish, 2004; Karlawish et al., 2002). In this study, a directed way of decision-making occurred most often when IWDs had challenges understanding the decision, when the ICGs were burdened or when they had concerns regarding safety that were not recognized by the IWDs. IWDs resented being excluded from making decisions that they valued. However, at times, the IWDs appreciated the directed decisions made for them when they were pleased with the outcome of the decision. In these instances, the level of involvement in their decisions was not as important to the IWDs as achieving a desired outcome.

Conclusion

An understanding of the five ways of decision-making used by rural IWDs could help guide HCPs to maximize the involvement of IWDs in their decisions. Of the five ways of decision-making identified in this secondary analysis, the most commonly used one was the guided, level 2 engaged way of decision-making. Often times, the level 2 guided decision-making way was used when the IWDs did not see the need to make a decision, or did not see the need for guidance in the decision being made. This way of decision-making empowered IWDs to be more optimally involved in their decisions. Overall, the ways of decision-making used by IWDs in their decisions were influenced by: (a) the IWDs' insight into their situational context and care needs, (b) the value that the IWDs' and ICGs' placed on the specified decision, (c) the ICGs' and IWDs' relationship, (d) the ICGs' burden and resources, and ability to support of the IWDs in their decision-making, and (e) the ICGs' ability to live with the risks factors associated with the IWDs decision. Overall, this research added depth and clarity to the ways of decision-making used and preferred by rural community dwelling IWDs.

Future research on the ways of decision-making used and preferred by IWDs and their related factors is needed in broader populations. Research on the factors that affect the various ways of decision-making could provide a greater understanding for HCPs on how to most optimally include IWDs in their decisions. Further, there is a need for research on how the decision-making ways change overtime, and for research on the impact of the time of diagnosis, and type and stage of dementia on the ways of decision-making used.

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Chapter 3: Discussion

The first section of chapter three presents an overview of the research findings as related to the current literature. Subsequently, there is a methodological discussion of the strengths and limitations of this research study, followed by a further discussion of the strengths and limitations related to the secondary analysis approach used in this research. Finally, implications for practice, teaching, and future research is discussed, followed by a thesis conclusion.

Overview of Findings

The purpose of this research was to describe the ways rural dwelling individuals with dementia (IWDs) from Ontario, Canada were involved in their decision-making. To the author's knowledge, there are no other research studies that describe the ways of decision-making used by rural community dwelling IWDs. However, Smebye, Kirkevold, and Engedal (2012) also explored the ways of decision-making used in dementia, but did so within municipalities of Norway. In Smebye et al. (2012), the study data were collected through interviews with informal caregivers (ICGs) and health care providers (HCPs), and through observations of the interactions between HCPs and IWDs. IWDs either resided in their home, a sheltered housing, or nursing home settings, in the municipalities of Norway.

Smebye et al. (2012) identified five ways of decision-making: autonomous, pseudo-autonomous, shared, delegated, and non-involvement. In addition, this thesis research study also identified five ways of decision-making: (a) independent, (b) collaborative, (c) guided, (d) delegated, and (e) directed. The autonomous decision-making way of Smebye et al. (2012) was similar to this research study's independent decision-making way; and the delegated way of decision-making was the same in both. However, pseudo-autonomous decision-making was not found to be present in this thesis research study. Smebye et al. (2012) defined pseudo-autonomous decision-making as decisions that were implicit and in which the IWDs made independently, but required support to carry out. For example, in order to live at home, the IWDs would need support in other decisions such as paying bills. In this secondary analysis, the IWDs at times required support to make a decision, however, the type and how the support was provided differentiated the way of decision-making used. For example, if the IWDs identified and arranged the support they needed, then this was an independent decision. On the other hand, if they needed to ask for guidance on how to make the decision then this was a level 1 guided decision-making way. Shared decision-making was defined broadly by Smebye et al. (2012) and included all decisions made with others. In this thesis research study, shared decision-making encompassed collaborative and guided decision-making. Smebye et al. (2012) identified shared decision-making as the most common. This present research study provided further differentiation between the ways that IWDs made decisions with others and these ways included: collaborative and guided levels 1, 2, and 3. Level 2 guided decision-making was most commonly utilized. Each of these ways of decision-making were clearly delineated in the data and had key differentiating concepts.

Smebye's et al. (2012), non-involvement decision-making way was similar to the directed decision-making way found in this research study. Unlike Smebye et al. (2012), this thesis study differentiated directed decision-making into two levels, 1 and 2. In both levels of directed decision-making, the decisions were made for the IWDs by their ICGs without their involvement. However, in level 1 directed decision-making the IWDs were aware of the decisions made on their behalf, while in level 2 directed decision-making they were unaware. Overall, this thesis research study provided greater depth of understanding of the ways of decision-making used by IWDs from the perspective of those residing in rural Canada. Further, this research, unlike Smebye et al. (2012), explored the ways IWDs preferred to be involved in their decision-making.

Samsi and Manthorpe (2013) reported that overtime the decision-making of IWDs and their ICGs changed from mutually made decisions to caregiver directed decisions. Samsi and Manthorpe (2013) did not describe the different ways that decisions were made, but rather described how decision-making changed overtime. Although, this thesis research study collected data overtime, it was not analyzed for changes overtime. However, it did find that the level of involvement of the IWDs in each way of decision-making varied on a continuum from complete independence to complete dependence and occurred respectively as follows: independent decision-making, collaborative decision-making, guided decision-making, delegated decision-making, and directed decision-making. Unlike Samsi and Mantorpe (2013), the ways of decision-making used varied with the decisions and circumstances unique to each situation. Moreover, there was further evidence that ICGs often adjusted the first decision-making way used to a more appropriate alternative when they perceived that the IWDs were not able to make the decision in the first way attempted. The caregiver continued to make adjustments to the decision-making way being used until they found the way that was best suited for the decision. These adjustments were not time related, but occurred fluidly during the decision-making. However, future research is needed to examine how the decision-making ways used change overtime. Overall, the ways of decision-making used by IWDs in their decisions were influenced by: (a) the IWDs' insight into their situational context and care needs, (b) the value that the IWDs' and ICGs' placed on the specified decision, (c) the ICGs' and IWDs' relationship, (d) the ICGs' burden and resources, and ability to support the IWDs in their decision-making, and (e) the ICGs' ability to live with the risks factors associated with the IWDs decision.

Methodological Considerations

Research Strengths and Limitations

A common criticism of a qualitative secondary analysis is that the researcher analysing and completing the study was not present during data collection, resulting in interpretive challenges (Heaton, 2004). Although the researcher of this study was involved in the data analysis of the primary study as a research student, she was not involved in the data collection. As such, this led to challenges in the interpretation of the data. In order to ensure the most accurate interpretation of the data, the primary study investigator (Dr. Forbes) clarified and verified interpretations throughout the research analysis. Further, the researcher analysed the primary field study notes to help illuminate some of the contextual factors important for capturing a clearer understanding of the participants' data. The interpretive description approach recommends that researchers verify data through concurrent data collection and analysis to allow for new questions to emerge during the data analysis (Thorne, Kirkham, & O'Flynn-Magee, 2004b, Thorne, 2008). However, the researcher was unable to adhere to this strategy because of the nature of a secondary analysis. Throughout the analysis, there were questions that ignited a desire for further exploration, and may have illuminated even further the ways that IWDs were involved in their decisions.

A strength of this study is that throughout the research process, the researcher followed interpretive descriptions' criteria for credibility, epistemological integrity, representative credibility, analytic logic, and interpretive authority (Thorne, 2008). *Epistemological integrity* was upheld as the research aims were answered using an inductive process and results were "grounded in the data" (Thorne et al., 2004b, p. 3; Thorne, 2008); and study results, presented in chapter 2, used key quotes to support the findings.

Representative credibility is the application of the research findings to other contextual settings. The results of this study cannot be applied to other settings as the research results were influenced by the context of those being studied, the collected data, and the researcher's experience (Thorne et al., 2004b; Thorne, 2008). To increase the credibility of the findings, the researcher explored multiple perspectives of the data by analyzing data of both the IWDs and their ICGs. In addition, the methods were triangulated through the inclusion of field notes and interview data in the analysis (Thorne, 2008). An audit trail was used to capture the reasoning of each step in the inductive analysis (Thorne, 2008), and acted as a record of the decisions and analytic conclusions that were made throughout the analysis (Thorne, 2008).

Analytic logic was established by presenting a description of the participants' data in the findings (Thorne, 2008). The researcher's *interpretive authority was* demonstrated as the researcher used "validity-as-reflexive-accounting" (Thorne, 2008, p. 225), and repeatedly returned to the data to ensure that evolving findings were not influenced by the researcher's bias and fit with the data. Additionally, validity of the findings was furthered through the application of the "thoughtful clinician test" (Thorne et al., 2004b, p. 8). Importantly, Dr. Forbes, the thesis supervisor and an expert in rural dementia research, was consulted for her perspective on the research findings (Thorne et al., 2004b). Finally, the researcher used a reflective journal to account for influences of bias in the data analysis (Thorne, Kirkham, & MacDonald-Emes, 1997).

The critique of this research study extended beyond the critique of the methods used to maintain credibility and included: moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness, and probable truth (Thorne, 1997, 2008). This study is *morally defensible* as the findings could provide HCPs with guidance on how to include IWDs in their care decisions; and it may contribute to an increased appropriate involvement of IWDs in their care decisions, and ultimately contribute to the IWDs' quality of life (Menne et al., 2008). The knowledge gained is relevant to the nursing profession as nurses are involved in the care of IWDs in rural areas, and could use these findings to empower IWDs by collaborating with them and their ICGs in the use of the most appropriate way of decision-making. The researcher recognizes that the findings may be applied to practice prior to being scientifically 'proven.' As a *pragmatic obligation* and demonstrated *contextual awareness,* the researcher recognizes and recommends that the findings be considered within the context of the participants. Further, the researcher suggests that findings be considered from the author's nursing disciplinary lens and historical experience as a registered nurse (Thorne, 2008). The researcher bracketed elements of her own "social cultural perspective". When analyzing the data she also considered the contextual realities that had influenced the data (Thorne, 2008, p. 229), including the setting of the participants, their type of dementia diagnosis, and the IWDs' relationships and resources. Findings were presented as the *"probable truth"* as there were no "set of standards" that could be used to ensure they were valid (Thorne, 2008, p. 229).

Methodological Considerations Related to a Secondary Analysis

The benefit of the use of a secondary analysis was that it allowed the researcher to access a large comprehensive data set, and enabled the researcher to answer her question in a feasible, cost effective and timely manner (Szabo & Strang, 1997; Thorne, 1998), while maximizing the use of the data in the primary study (Thorne, 1998).

An important consideration in this secondary analysis of qualitative data was that the approach used aligned with the qualitative approach of the primary study (Heaton, 2004). In this case, the primary study used a grounded theory approach, from which Thorne's et al. (2004b) interpretive description borrows greatly**.** The data from the primary study examined the subjective experiences of participants using interviews, which were an appropriate data source for this approach. A common critique of interpretive description is that it method slurs, because it allows for variation in data collection and analysis (Thorne et al., 2004b). Interpretive description does not provide a prescription of how a study is to be conducted, rather it is represented as a "design logic model" and serves as a "methodological framework" which allows for the use of a variety of techniques for data collection and analysis (Thorne, 2008, p. 73). In the case of this secondary analysis, this weakness was considered a strength as it allowed for flexibility of the analytic approach within the limits of the secondary analysis. Further, interpretive description studies require detailed information on the context and background of the individual participants (Thorne, 2008). The context and background of the participants were illuminated in the results. In the primary study, the researcher had limited access to identifiable information about the participants; this was a requirement from the ethics research board.

In order to determine the re-usability of the primary data for this secondary analysis, it was important to examine the degree of fit of the primary and secondary research purpose

(Heaton, 2004; Thorne, 1998). One of the primary study's objectives was to develop a theory to explain the process where knowledge was exchanged between rural IWDs, ICGs, and HCPs about their care decisions (Forbes et al., 2012; Forbes et al., 2013). The primary study data fit well with the proposed secondary analysis research aims, as the primary data were collected in a rural setting, and one the study's aims was to explore the decision-making of the IWDs in their knowledge exchange process (see Appendix B; Appendix C). The researcher of this study also noted, during the data analysis of the primary study data, that interviews of the IWDs included information about the decision-making preferences of the IWDs. For example, questions regarding the regular day of the IWDs, and questions about the involvement of the IWDs in planning their home care services resulted in responses that provided insight into the ways they were, and preferred to be involved in their decisions. As a result, the primary study provided the data required to describe the ways in which rural IWDs were and preferred to be involved in their care decisions.

The quality of this study was also affected by the re-usability of the primary data set (Heaton, 2004; Thorne, 1998). The primary data being used for this secondary analysis was of high quality as all: participants were asked questions as per the pre-established guided interview questions, audio tapes were compared to transcribed interviews, and the primary study was well designed and executed (Hinds, Vogel, & Clarke-Steffen, 1997). The primary study used a grounded theory approach and analysis where multiple methods were employed to maintain trustworthiness (Heaton, 2004; Hinds et al., 1997). Trustworthiness was established through: member checking, peer debriefing, data triangulation, diagramming, monthly team meetings to discuss data analysis, an audit trail, and a thick description of the findings and context (Forbes et al., 2012; Forbes et al., 2013; Streubert & Carpenter, 2011).

Implications for Professional Practice and Teaching

Promoting Involvement of IWDs in their Decisions

Decision-making ways. Dementia is a disease process that impacts the decisions and health of all those involved. HCPs can be advocates for the appropriate involvement of IWDs in their care decisions. This research study found that IWDs often required guidance to maintain autonomy and to safely engage in activities that they perceived as important to their quality of life. Further, IWDs generally required guidance in their health care decisions, as they were often unaware of their need to make a specified decision or their need for guidance in their decision-making. Therefore, HCPs may be able to more optimally involve IWDs in their decisions through the use of a guided decision-making way. The guidance of IWDs, by HCPs, in their decisions could help HCPs better understand the care preferences of IWDs and could potentially result in a provision of care that better reflects their needs. However, in certain circumstances, IWDs were able to make independent decisions regarding their daily activities regarding their hobbies and their entertainment. In these situations, involvement of IWDs in their daily activities could be maximized by HCPs when they provide IWDs with opportunities to engage in independent decisions.

Through this research, it is evident that a trial and error approach was used by ICGs to find the way to most optimally include the IWDs in their decisions. Often, the ICGs allowed for the independence of IWDs in their decisions, unless they thought that guidance was needed. The ICGs would often adjust the decision-making way first used, to an alternative and more appropriate way. When this occurred, the ICGs often strove to use the decision-making way that allowed for the greatest amount of independence of the IWD. As such, HCPs should be mindful that IWDs may be vulnerable in willing to include them in their decisions. Thus, appropriate use, by HCPs, of the ways of decision-making could enhance IWDs' involvement in their decisions.

The values of IWDs and their preferred decision-making way. The values of the IWDs impacted how involved they preferred to be in their decisions. For example, IWDs who preferred not to cook would delegate the decision-making regarding meals to their ICGs. Interestingly enough, HCPs could determine IWDs preference for involvement in their decisions by simply asking them about their values and their decision-making preferences for each specified decision. HCPs could use this strategy to improve the involvement and understanding of the ways IWDs preferred to make each of their decisions.

ICGs' burden and the decision-making involvement of IWDs. ICGs who reported higher levels of caregiving burden were more likely to report making decisions in a directed way (Hirschman, Xie, Feudtner, & Karlawish, 2004; Karlawish, Casarett, Propert, James, & Clark, 2002). The impact of care burden on the decision-making involvement of IWDs was also noted in this research. Aligned with previous research, this study found that ICGs who reported burden were less supportive of IWDs in their decision-making (Van Der Roest et al., 2009). HCPs could advocate for the resources to help decrease the burden of ICGs, which may result in greater involvement of IWDs in their decision-making.

Home Care System's Culture and Decision-Making in Dementia

It has been reported that the home care system has promoted processes that have repressed the voice of the IWDs and excluded them from their decision-making; in fact, a "paternalistic" pattern was reinforced (St. Amant et al., 2012, p. 431). This approach has limited the choices and the involvement of the IWDs and ICGs in care decisions (St. Amant et al., 2012). It is, therefore, not surprising that many IWDs felt that they were not listened to amply when making decisions, and felt they had limited freedom to participate in and express their opinions regarding their care decisions (Tyrrell, Genin, & Mylinski, 2006). In this research, there were times when the ICGs used a directed way of decision-making primarily for their ease without considering the IWD's ability to be involved in the decision. IWDs resented when they were excluded from their decision-making. They wanted to maintain involvement in their decision-making as long as they were capable, and appreciated strategies that aided in their involvement (Fetherstonhaugh, Tarzia, & Nay, 2013). HCPs should reflect on their reasons for making decisions in a specified way and be careful not to exclude IWDs for their decision-making ease. In order to empower IWDs in their decision-making, HCPs need to recognize these practices and proactively collaborate with IWDs in their decision-making (St. Amant et al., 2012).

Teaching

As the population of IWDs, in Canada, increases (Alzheimer's Society of Canada [ASC], 2010), nurses will likely be more often involved in the care of IWDs. In the education of nurses, it is important to teach ways of decision-making used by IWDs and their ICGs to make decisions. Knowledge of the decision-making ways used in dementia may help nurses to consider and develop strategies that could optimize the involvement of IWDs in their decisions.

Implications for Future Research

There were relatively few studies that have researched the ways of decision-making used by IWDs, and those that have been conducted used a qualitative approach (Smebye et al., 2012) or a cross-sectional design (Karlawish et al., 2002). Research has also been done on the ways that decision-making involvement changed overtime (Hirschamen et al., 2004; Samsi & Mantorpe, 2013), the factors related to changes overtime (Horton-Deutsch, Twigg, & Evans, 2007; Menne & Whitlatch, 2007), and the essence of decision-making (Fetherstonhough Tarzia, & Nay, 2013). Several studies have examined IWDs' preferences and their ability to communicate what they preferred (de Boer, Dröes, Jonker, Eefsting, & Hertogh., 2012; Dening, Jones, & Sampson, 2013; Feinberg & Whitlatch, 2001, 2002; Hanmann et al., 2011; Karel, Moye, Bank, & Azar, 2007; Lee, Lam, & Tang, 2006; Mozley et al., 1999; Tyrrell et al., 2006; Whitlatch & Feinberg, 2003). However, this is the first study, to this researcher's knowledge, that examined the ways of decision-making used and preferred by rural dwelling IWDs that used qualitative semi-structured interviews of IWDs. This research adds to the depth of our understanding of the ways of decision-making used and preferred by rural community dwelling IWDs, including the factors associated with these ways of decision-making. Further research of these decision-making ways, in a broader population, could help clarify the relevance of the findings in a broader context, and could illuminate further factors influencing the decision-making ways used by IWDs and their ICGs. As well, future research could examine multiple perspectives of the ways of decision-making used by IWDs and their ICGs by including HCPs of IWDs. Further, research is needed to examine how the decision-making ways used change overtime. Although this research identified some of the decisions that IWDs preferred to make in each way, it was not exhaustive. In this study, the decisions that the IWDs and their ICGs made seemed to be related to those decisions that were of significant value or frustration for the IWDs or their ICGs.

The findings from this research suggest that capacity alone is not the main factor that impacts the way of decision-making used for a specified decision. Although capacity and competency are important for some decisions, such as driving where the impact of poor judgement is high, they were often not as pertinent in day-to-day life decisions. Factors that influenced the IWDs' preferences and context were also important. Through a greater understanding of the factors that impact the ways of decision-making used, a tool that extends beyond capacity and competency could be developed to provide HCPs with guidance on the factors that need to be in place to make decisions in each way. This tool may take the emphasis off capacity and competency alone, which seems to be only one of the factors influencing decision-making involvement of IWDs.

Finally, there is a need for further research on the relationship between the ways decisions are made and the influence of the time of diagnosis, and the stage and type of dementia on the IWDs' decision-making ways. This research could provide HCPs with an understanding of the influence of these factors on the decision-making ways used.

Conclusion

An understanding of the ways of decision-making used and preferred to be used by IWDs and ICGs in their decision-making could guide HCPs on how to best involve IWDs in their care decisions. Although the independent decision-making way was most commonly *preferred* by IWDs, engaged guided level 2 decision-making was most commonly *used*. IWDs often needed guidance to make their preferred decision. This guidance, although at times was not seen by IWDs as necessary, helped increase the involvement of IWDs in their valued activities. Although independence in decision-making was important to IWDs, the focus on independence should not be the determent of the IWDs' safety. This research illustrated that IWDs and their ICGs would adjust the decision-making way used to an alternative way when the ICGs perceived that the way of decision-making being used was not the best. The adjustment occurred in a fluid manner, while the decision was being made. Further research is required to study the ways of decision-making in more diverse populations of IWDs, to further examine the factors related to each way of decision-making. HCPs knowledge on how to optimally involve IWDs in their care decisions will increase as our understanding of ways of decision-making used by IWDs grows.

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Appendix A

Search Strategy Key Words

Medline Key Words

The following is the search strategy used to search Medline:

- (alzheimer* or dement* or "lewy bod*") AND ("decision mak*", patient*+"or"choice behavior" or "patient* preference*" or "patient participant*" or "personal autonomy" or "advance directive" or "living will" or "care decision*" or "care preference")

CINHAL Key Words

The following is the search strategy used to search CINHAL:

- (alzheimer* or dement* or "lewy bod*) AND ("decision mak*, patient*" or preference* or "advance* directive" or "care decision*" or "personal autonomy" or "patient participant*" or "living will" or "care preference")

Social Abstracts in Gerontology

The following is the search strategy use for to search Social Abstracts in Gerontology:

- (alzheimer* or dement* or "lewy bod*") AND ("decision*n3patient*" or "advance directive" or "livign will*" or "personal directive*" or "patient* preference" or "patient participant*" or "personal autonomy" or "care preference")

Proquest

The following is the search strategy used for to search Proquest:

- all((dement* OR alzheimer* OR "lewy bod*) AND all(decision*w/3 patient* or "advance directive*" or "livign will*" or "personal directive*" or "patient preference" or "patient participation" or "decision mak*" or "care preference" or "care decision" or "personal autonomy")

Appendix B

Primary Study Interview Guiding Questions for Individuals with Dementia

Opening of the Interview

Thank you for participating in this interview. I would like to understand as much as possible about your experience with living with memory problems, how your family members, friends and neighbours support you, the availability of services and information that are needed by you, and how your home care case manager, nurse, and/or personal support worker(s) assist you and in providing access to needed services and information.

Guiding Questions

Tell me about yourself. I am interested in

- how do you spend a usual day;
- what are some more enjoyable times and more challenging times; and
- how has your memory loss affected you?

Tell me about your family members who may or may not live with you. Think about your spouse, children, children-in-law, brothers and sisters.

Probes. Do you have any of these family members? If so,

- what relation are they to you;
- are they male or female;
- where do they live, how far from you;
- under what situations/circumstances would you seek their assistance;
- how do you decide whom to ask for assistance;
- what have they done to assist you (e.g. personal care, meals, shopping, driving, banking, housework, yard maintenance, information, emotional support);
- what kinds of information have they shared with you;
- what kinds of information do you need from them but have not received;
- how did you use and apply the knowledge you received from your family members;
- what was the result/outcome of using this knowledge;
- how often in the past month have they provided assistance, support, and/or information;
- has this increased, stayed the same or decreased? Why?; and
- how satisfied are you with the support that you have received? Why?

Tell me about your close friends. By close friends, I mean people who are not your relatives but with whom you feel at ease with or can talk to about what is on your mind, and with whom you talk with on a regular basis.

Probes. Do you have any close friends? If so,

- are they male or female;
- where do they live, how far from you;
- under what situations/circumstances would you seek their assistance;
- how do you decide whom to ask for assistance;
- what have they done to assist you (e.g. personal care, meals, shopping, driving, banking, housework, yard maintenance, information, emotional support);
- what kinds of information have they shared with you;
- what kinds of information do you need from them but have not received;
- how did you use and apply the knowledge you received from your close friends;
- what was the result/outcome of using this knowledge;
- how often in the past month have they provided assistance, support, and/or information;
- has this increased, stayed the same or decreased? Why?; and
- how satisfied are you with the support that you have received? Why?

Tell me about your home care case manager, nurse, personal support worker, and/or community-based health care provider.

Probes. Do they visit on a regular basis? If so,

- how did you learn about home care;
- what prompted the need for home care services;
- who was involved in making the decision to request home care services;
- did you participate in the home care assessment;
- were you involved in planning the home care services;
- how many home care workers visit;
- how often in the past month have the home care providers visited;
- has this support increased, stayed the same or decreased? Why?;
- how do you feel about them visiting;
- are they male or female;

- what do they do when they visit (e.g. assist with personal care, meals, housework, emotional support);
- what kinds of information have the home care providers shared with you;
- what kinds of information do you need but have not received;
- how did you use and apply the knowledge you received from the home care providers;
- what was the result/outcome of using this knowledge;
- what do you know now that you didn't know prior to receiving the information that you described; and
- how would you describe the relationship you have with …. (home care provider).

Look for descriptors that reflect mutuality, partnerships, inclusion of caregiver expertise, support for emotional/affective aspects of caregiving or absence of these.

- what is it about this relationship that makes it easier or more difficult to share and receive needed information and services?
- how satisfied are you with the support that you have received? Why?
- is there anything about home care that you would like changed; and
- in an ideal world, what home care supports and information would assist you ?

Tell me about other support community services (e.g. Alzheimer Support Group, Day Away Centre, Respite Care) you have used.

Probes. Are these services used on a regular basis? If so,

- how did you learn about this service;
- what prompted the need for this service;
- who was involved in making the decision to initiate this service;
- how do you feel about using these services;
- are the people who provide these services male or female;
- how do they assist you;
- what kinds of information have they shared with you;
- what kinds of information do you need from them but have not received;
- how did you use and apply the knowledge you received from them;
- what was the result/outcome of using this knowledge;
- how often in the past month have you used this service;

- have you used this service more often, the same or less? Why?
- how satisfied are you with the support that you have received from using this service? Why?; and
- is there anything about these services that you would like changed?

Further probing questions include

- others have told me…Has this been your experience?; and
- is there anything else that you would like to add?

Appendix C

Primary Study Interview Guiding Questions for Informal Caregivers

Opening of the Interview

Thank you for participating in this interview. I would like to understand as much as possible about your experience caring for … (name of family member with dementia): how your family members, friends and neighbours support you, the availability of services and information that are needed by you, and how your home care case manager, nurse, personal support worker(s) and/or community-based health care provider assist you in caring for …(name of family member with dementia), and in providing access to needed services and information.

Tell me about …(name of family member with dementia).

Probes. I am interested in

- how does…...(name of family member with dementia) spend a usual day;
- what are some more enjoyable times and more challenging times; and
- how has ….(name of family member with dementia) memory loss affected him/her and you?

Tell me how you spend a usual day?

Probes: I am interested in

- what do you do for...(name of family member with dementia);
- why did you do this for …(name of family member with dementia);
- how often in the past month have you done this for …(name of family member with dementia); and
- what impact has this had on you, on …(name of family member with dementia)?

Tell me about your family members who may or may not live with you.

Probes. Think about your spouse, children, step-children, children-in-law, brothers and sisters, and parents if they are still living. Do you have any of these family members? If so,

- what relation are they to you;
- are they male or female;
- where do they live, how far from you;
- under what situations/circumstances would you seek their assistance;
- how do you decide whom to ask for assistance;

- what have they done to assist you in looking after …(name of family member with dementia) (e.g. meals, shopping, driving, banking, housework, yard maintenance, information, emotional support);
- what kinds of information have they shared with you;
- what kinds of information do you need from them but have not received;
- how did you use and apply the knowledge you received from your family members,
- what was the result/outcome of using this knowledge;
- how often in the past month have they provided assistance, support, and/or information;
- has this increased, stayed the same or decreased? Why?; and
- how satisfied are you with the support that you have received? Why?

Tell me about your close friends. By close friends, I mean people who are not your relatives but with whom you feel at ease with or can talk to about what is on your mind, and with whom you talk with on a regular basis.

Probes. Do you have any close friends? If so,

- are they male or female;
- where do they live, how far from you;
- under what situations/circumstances would you seek their assistance,
- how do you decide whom to ask for assistance;
- what have they done to assist you in looking after …(name of family member with dementia) (e.g. meals, shopping, driving, banking, housework, yard maintenance, information, emotional support);
- what kinds of information have they shared with you;
- what kinds of information do you need from them but have not received;
- how did you use and apply the knowledge you received from your close friends;
- what was the result/outcome of using this knowledge;
- how often in the past month have they provided assistance, support, and/or information;
- has this increased, stayed the same or decreased? Why?; and
- how satisfied are you with the support that you have received? Why?

Tell me about your home care case manager, nurse, personal support worker and/or community-based health care provider.

Probes. Do they visit on a regular basis? If so,

- how did you learn about home care;
- what prompted the need for home care services;
- who was involved in making the decision to request home care services;
- were you involved in the home care assessment;
- were you involved in planning the home care services;
- how many home care workers visit …(name of family member with dementia);
- how does ….(name of family member with dementia) feel about them visiting;
- are they male or female;
- what do they do when they visit (e.g. assist with personal care, meals, housework, emotional support);
- what kinds of information have the home care providers shared with you;
- what kinds of information do you need but have not received;
- how did you use and apply the knowledge you received from the home care providers;
- what was the result/outcome of using this knowledge;
- what do you know now that you didn't know prior to caring for …(name of family member with dementia) and prior to receiving the information that you described;
- how often in the past month have the home care providers visited;
- has this support increased, stayed the same or decreased? Why?; and
- how would you describe the relationship you have with …. (home care provider).

Look for descriptors that reflect mutuality, partnerships, inclusion of caregiver expertise, support for emotional/affective aspects of caregiving etc, or absence of these. Further probing questions include:

- what is it about this relationship that makes it easier or more difficult to share and receive needed information and services?;
- how satisfied are you with the support that you have received? Why?;
- are there services and/or information that you need but not received;
- is there anything about home care that you would like changed; and

- in an ideal world, what home care supports and information would assist you in caring for …(name of family member with dementia).

Tell me about other support community services (e.g. Alzheimer Support Group, Day Away Centre, Respite Care) you or …(name of family member with dementia) have used.

Probes. Are these services used on a regular basis? If so,

- how did you learn about this service;
- what prompted the need for this service;
- who was involved in making the decision to initiate this service;
- how does ….(name of family member with dementia) feel about using these services;
- are the people who provide these services male or female;
- how do they assist you;
- what kinds of information have they shared with you;
- what kinds of information do you need from them but have not received;
- how did you use and apply the knowledge you received from your close friends;
- what was the result/outcome of using this knowledge;
- how often in the past month have you used this service;
- have you used this service more often, the same or less? Why?;
- how satisfied are you with the support that you have received from using this service? Why?; and
- is there anything about these services that you would like changed?

Further probing questions include:

- Others have told me…Has this been your experience?; and
- Is there anything else that you would like to add?

Appendix D

Primary Study Consent Forms

Information Letter

Person with Memory Problems and Caregiver

Because you are experiencing memory problems or support/care for a family member, relative or friend with memory problems you are invited to participate in a research project titled *Developing Dementia Care Decisions through Knowledge Exchange in Rural Settings.*

Sponsors: Alzheimer Society of Canada, Canadian Nurses Foundation, CIHR Institute of Aging

Researcher

Dr. Dorothy Forbes, Principal Investigator, Arthur Labatt Family School of Nursing, The University of Western Ontario

Objectives and Procedure

The specific objectives of this research are three-fold:

(i) to better understand what knowledge is needed by rural persons with memory problems, their caregivers, and their community-based nurses and health care assistants;

(ii) to describe how they make dementia care decisions that contribute to sustaining their care work and improving their quality of life; and

(iii) to develop best practice guidelines that will improve the quality of care provided to persons with memory problems and their caregivers residing in rural areas.

You are invited to participate in three interviews over the year to share your perspectives on these objectives. A copy of the guiding questions is attached to this letter. The interviews will be held in your home (or another location if preferred) and are expected to last 1 to 1.5 hours.

Potential Risks

There are no known risks to participating in the study. However, if the sharing of your experiences is upsetting to you, a referral to an appropriate health care professional (e.g. counsellor, home care provider) can be made with your permission.

Potential Benefits

The findings from this research may not directly impact you. However, understanding what information you and your caregiver need and how community-based nurses and their assistants can best support you will assist policy makers and decision makers in ensuring that the most appropriate services are available to you. An honorarium of $25.00 per interview will be paid to you to help defray any costs to you and as a token of our appreciation.

Storage of Data

The data collected during the interviews will be stored in a locked filing cabinet in Dr. Forbes' research office for a minimum of seven years. The contact information sheets will be stored in a separate locked filing cabinet and will be destroyed at the end of the data collection period.

Confidentiality

Although the findings from this study will be published and presented at conferences, the data will be reported in aggregate form and quotations used from the interviews will have all identifying information removed, so that it will not be possible to identify individuals. All of the information that you provide will be kept confidential.

Right to Withdraw. *You may withdraw from the study for any reason, at any time, without penalty of any sort (and without loss of access to relevant services, etc.) and you may refuse to answer any question. If you withdraw from the study at any time, any data that you have contributed during an interview will be destroyed.*

Questions. If you have any questions concerning the study, please feel free to contact the researchers at the numbers provided above. This study has been approved on ethical grounds by the University of Western Ontario Research Ethics Board on (insert date). If you have any questions about your rights as a research participant or the conduct of the study you may contact the Director of the Office of Research Ethics at (519) 661-3036 or email ethics@uwo.ca.

A researcher will be calling you within the next few days to discuss the study in more detail and to discuss your willingness to participate. Thank you in advance for considering to participate in our research study.

Western

Consent to be Contacted Form

Developing Dementia Care Decisions through Knowledge Exchange in Rural Settings

Principal Investigator:

Dr. Dorothy Forbes, Arthur Labatt Family School of Nursing, The University of Western Ontario

I agree to provide my name and phone number to Ms. Susan Scott (or other research staff member) who will contact me to further explain the project and discuss my participation.

__________________________________ Name of potential participant (Print) (Person with memory problems)	____________________ Phone number
__________________________________ Signature of potential participant	____________________ Date
__________________________________ Name of Caregiver or legally authorized representative (Print)	____________________ Phone number
__________________________________ Signature of Caregivers or legally authorized representative	____________________ Date
__________________________________ Name of person obtaining consent (Print)	
__________________________________ Signature of person obtaining consent	____________________ Date

Consent Form

Person with Memory Problems and their Caregiver

Developing Dementia Care Decisions through Knowledge Exchange in Rural Settings.

Sponsors: Alzheimer Society of Canada, Canadian Nurses Foundation, CIHR Institute of Aging

Researcher

Dr. Dorothy Forbes, Principal Investigator, Arthur Labatt Family School of Nursing, The University of Western Ontario

I have read the Letter of Information, have had the nature of the study explained to me and I have agreed to participate. All questions have been answered to my satisfaction.

Name of Person Obtaining Consent (Print)	
Signature of Person Obtaining Consent	Date
Name of Participant with Memory Problems (Print)	
Signature of Participant	Date

____
Name of Caregiver or legally authorized
representative (Print)

________________________________ ____________________
Signature of Caregivers or legally authorized representative Date

Are you interested in participating in a KE and Consensus Workshop to be held towards the end of the project (fall, 2011) during which best practice guidelines will be developed based on the findings of the study?

Yes _______

E-mail address ___________________________

Mailing address ____

____

No_________

Do you wish to be forwarded a summary of the results of the study?

Yes _______

E-mail address ___________________________

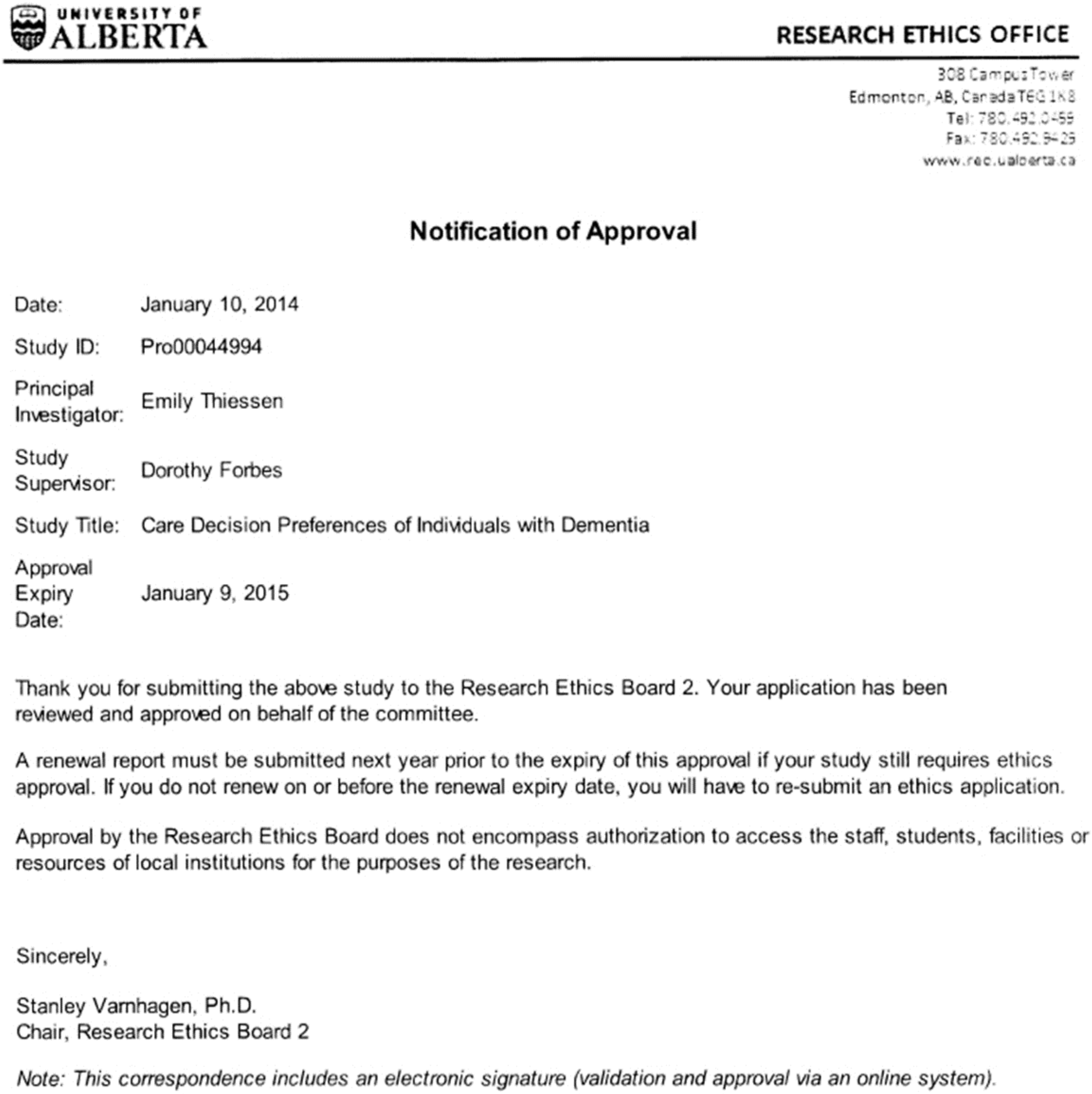
Mailing address ____

____

No ________

Appendix E

Research Ethics Approval



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Notification of Approval

Date:	January 10, 2014
Study ID:	Pro00044994
Principal Investigator:	Emily Thiessen
Study Supervisor:	Dorothy Forbes
Study Title:	Care Decision Preferences of Individuals with Dementia
Approval Expiry Date:	January 9, 2015

Thank you for submitting the above study to the Research Ethics Board 2. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Stanley Varnhagen, Ph.D.
Chair, Research Ethics Board 2

Note: This correspondence includes an electronic signature (validation and approval via an online system).