

EVALUATING A QUESTIONNAIRE ASSESSING HEALTHCARE PROVIDER  
PERCEPTIONS OF RURAL DEMENTIA CARE

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In Partial Fulfilment of the Requirements for the Degree of Master of Nursing  
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By

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## ABSTRACT

Dementia touches the lives of many people in Canada and, when it occurs, it affects all aspects of the day-to-day lives of individuals and families. Individuals with dementia living in the community may face barriers to accessing care and resources, which is further compounded for those living in rural and remote areas. How healthcare providers in rural settings meet the needs of those living with dementia in the community is not well documented. Understanding the challenges of rural healthcare providers is essential for improving services along the continuum of care for dementia. A questionnaire was developed by the Rural Dementia Action Research (RaDAR) team to assess current strengths and gaps in dementia care along the continuum from assessment through management in rural primary healthcare settings. The questionnaire was based upon the RaDAR program framework and a scoping literature review conducted by Aminzadeh et al. (2012). The purpose of this study was to pretest the questionnaire to determine whether it was feasible and acceptable to participants, and if there was adequate evidence for validity of the instrument. The pretest study was conducted with twelve participants from four healthcare provider categories (i.e., family physicians, nurse practitioners, homecare registered nurses, and occupational therapists). Semi-structured telephone interviews were conducted to assess feasibility, acceptability, and evidence for validity of the questionnaire. The design was an iterative, sequential evaluation process, which allowed modification to the questionnaire throughout the data collection period. Data sources included the transcribed interviews, participant feedback, graduate student researcher notations, and RaDAR team notations. The pretest showed that the questionnaire was feasible based on the length of the interview and the format for administration. The questionnaire was shown to be acceptable to participants based on the wording, flow, and level of understandability of the content. Multiple sources of evidence for validity were identified, including item content and response process. Consensus was reached by the RaDAR team and graduate student that the questionnaire was ready for use in a larger study.

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## **LIST OF ABBREVIATIONS**

RaDAR: Rural Dementia Action Research

CSHA: Canadian Study of Health and Ageing

CAD: Canadian dollars

FP: Family Physician

NP: Nurse Practitioner

RN: Registered Nurse

OT: Occupational Therapist

MRI: Magnetic Resonance Imaging

CT scan: Computerized Tomography scan

EMR: Electronic Medical Record

PHC: Primary Healthcare Team

## **1 CHAPTER ONE - INTRODUCTION**

Dementia represents a variety of brain disorders characterised by a progressive decline in intellectual abilities, which affect daily functioning and cannot be explained by other etiology (American Psychiatric Association, 2013; Alzheimer's Association, 2016). Worldwide, dementia affects 46.8 million people (Alzheimer's Disease International, 2015). As the overall population continues to age, the number of individuals living with dementia is expected to double every twenty years (Alzheimer's Disease International, 2015).

Using best practice is the ultimate goal of care for all patients. Best practice is referred to as interventions or strategies that optimize outcomes, are adaptable to different situations and environments, and are based on high quality evidence (Public Health Agency of Canada, n.d.). This concept is integral to quality care for individuals with dementia, in both the community and institutional setting. Best practice in dementia care covers all facets of the illness and moves across health disciplines. Best practice guidelines exist from several different organizations for persons with dementia throughout the continuum of care (Registered Nurses Association of Ontario, 2016; Government of British Columbia, 2014; Alzheimer Society of Canada, 2011), however straightforward application of these guidelines to every setting is not possible. Best practice for individuals with early dementia is different than those in an advanced state, it varies for those in institutional settings versus community settings, and may differ for those living in rural areas versus urban centres. Availability of resources also has an additional effect on the application of best practices and all of these factors can potentially lead to gaps in care.

### **1.1 Statement of Research Problem**

Access to quality healthcare is an expectation of every Canadian; however, barriers exist for individuals and families who live in rural and remote areas of Canada. In rural and remote areas, lack of geographic proximity to quality healthcare services can limit ease of accessibility to healthcare (Crooks & Andrews, 2009). Primary healthcare principles advocate using a diverse team of healthcare providers to deliver comprehensive, relevant, and affordable care to the community, with primary healthcare teams forming the basis for care services (Smith, Jacobson & Yiu, 2008). Primary healthcare teams are essential to rural and remote areas because equal access and opportunity to rural residents is limited due to the distance between communities and urban centres (Crooks & Schuurman, 2012). The province of Saskatchewan serves a large sparsely populated geographical area, making access to the few urban centres and tertiary

services difficult. Rural and remote healthcare services need to adapt to the geographical challenges and continue to provide services which meet the community's needs, while being conscientious of fiscal challenges.

Providing quality healthcare services to persons living with dementia and their families can be difficult in any healthcare setting. The characteristics of rural and remote areas, such as long distances to services and sparse populations, pose challenges regarding the best methods to use resources to serve the community. Aminzadeh et al. (2012) note current issues that exist in Canada related to the lack of qualified specialists in dementia care, which is further compounded in rural and remote areas. Knowledge of the resources and services in rural and remote areas for persons with dementia and their families is a key component to understanding how care is provided and what challenges exist. Identification of strengths and gaps in current healthcare services provided in rural and remote areas will help to improve appropriate care and resources for persons with dementia and their families.

## **1.2 Aim & Objectives**

The aim of this study was to pretest a single questionnaire that was administered to primary healthcare professionals from different disciplines to assess strengths and gaps along the continuum of care for individuals with dementia living in rural community settings. The objectives of the pretest were to: (1) examine the construction of the questionnaire in relation to feasibility and acceptability, (2) provide evidence to support validity of the questionnaire, and (3) using an iterative process, provide recommendations for refinement of the questionnaire to be used in a larger study.

## **1.3 Purpose and Rationale**

The study pretested a newly developed questionnaire prior to its use in an interview format in a larger study conducted by the Rural Dementia Action Research (RaDAR) team (Principal Investigator: Dr. Debra Morgan). The pretest was conducted in different health regions from the larger study and the questionnaire was refined based on pretest results.

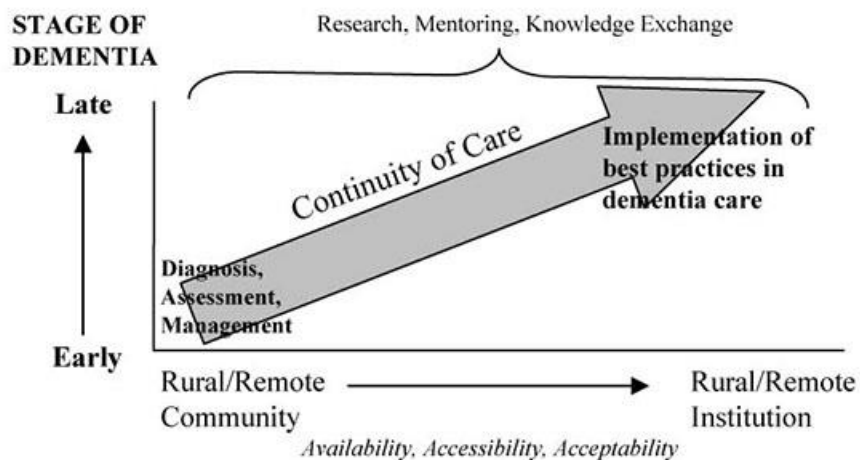
The larger study conducted by RaDAR (using the refined questionnaire from the pretest), aimed to explore current strengths and gaps in primary healthcare for individuals with dementia and examined the perspectives of primary healthcare professionals in a rural Saskatchewan health region. Data for this larger study was used to prepare for phase two of the study, in which interventions were developed in partnership with primary healthcare teams to improve the

quality of services for persons with dementia across the continuum of care. Thus, it was important to pretest the questionnaire prior to implementing it with a larger number of participants to ensure the questionnaire would obtain the data needed to implement new strategies and interventions.

### 1.4 Conceptual Framework

The study is guided by the conceptual framework developed for the RaDAR team’s overall research program (Morgan et al., 2009) and a scoping review completed by Aminzadeh et al. (2012). The overarching goals for the RaDAR program are research, mentoring, and knowledge exchange (Morgan et al., 2005). As shown in Figure 1, this multidisciplinary research program focuses on early to late stage dementia care in rural and remote settings (Morgan et al., 2005). The framework focuses on the continuity of care from community to institutional care and the assessment, diagnosis and management of dementia (Morgan et al., 2005). The goal of the framework is to provide the best possible dementia care grounded in best practices (Morgan et al., 2005). This conceptual framework provides a basis for the format of the questionnaire, with questions organized along the continuum of care starting with assessment, progressing through to diagnosis and finishing with questions regarding management. This will aid in the identification of current practices and provide a basis for comparison to best practices.

**Figure 1 – RaDAR Program Framework**



The second component of the theoretical framework is based upon a review completed by Aminzadeh et al. (2012). The authors utilized an interpretive scoping review methodology to identify Canadian and Western literature regarding diagnosis and management of dementia by primary care providers (Aminzadeh et al., 2012). Due to the chronic nature of dementia, primary

care providers are often the first line of interaction for persons with dementia and their families (Aminzadeh et al., 2012). These primary providers may be the essential link for families and individuals to access other resources; therefore, the goal of Aminzadeh et al. (2012) review was to identify the barriers and enablers for optimal care for persons with dementia in primary care settings. The focus of the review was on diagnosis and management of individuals in the community setting, which fits along the continuum of care as identified in Figure 1. Examining the literature, the authors were able to identify the main barriers in primary dementia care in Canada to be: (a) the complex nature of dementia; (b) gaps in knowledge, skills, and resources among persons with dementia their families, and healthcare workers; and (c) broader system challenges (Aminzadeh et al., 2012). The authors were also able to identify enablers or key strategies for comprehensive, integrated primary healthcare associated with better outcomes for patients and caregivers: (a) use of multidisciplinary teams, (b) ongoing care management, (c) formal training for primary care physicians and staff, (d) standardized protocols and guidelines, (e) access to technology resources, (f) education and support for persons with dementia and caregivers in collaboration with community agencies, and (g) regular patient follow-ups (Aminzadeh et al., 2012).

The seven key strategies identified by Aminzadeh et al. (2012) provide the second component of the theoretical framework for the study and questionnaire. In addition to the questionnaire being structured along the continuum of care, the questions are also formulated to address the seven key strategies outlined by Aminzadeh et al. (2012). The literature identifies these strategies as being integral to comprehensive primary care and the aim of the questionnaire is to determine current strengths and gaps in rural dementia care. The seven key strategies formed the analytic framework for data comparison to determine evidence for validity of the questionnaire.

## 2 CHAPTER TWO – LITERATURE REVIEW

### 2.1 Review of Literature

The literature review will begin with a current examination of dementia epidemiology worldwide, in Canada, and in Saskatchewan; followed by the current state of dementia in primary healthcare and in rural and remote settings. Afterward, the current literature regarding healthcare provider perceptions' on dementia care will be presented. The literature review will end with an examination of evidence for validity in instrument design.

**2.1.1 Dementia epidemiology.** Geographically, dementia has no limitations to its reach across the globe. Prevalence varies by region and globally ranges between 4.6% and 8.7% for those age 60 or older (Alzheimer's Disease International, 2015). Worldwide in 2015, it was estimated there are 46.8 million people living with dementia (Alzheimer's Disease International, 2015). This number is expected to double every twenty years, with much of this increase occurring in low to middle income countries (Alzheimer's Disease International, 2015). Globally, the incidence rate is estimated to be 9.9 million new cases every year (Alzheimer's Disease International, 2015), or 17.3 per 1000 persons age 60 or older.

Dementia continues to touch the lives of many Canadians. The first epidemiological study of dementia in Canada was the Canadian Study of Health and Aging (CSHA), which sought to obtain an accurate assessment of prevalence and incidence of dementia in Canada (Canadian Study of Health and Aging Working Group, 1994; 2000). The CSHA was completed in 1991 and updated in 1996 and 2001 (Lindsay et al., 2004). In Canada, the prevalence of dementia was estimated to be 8% for adults older than 65 years (Canadian Study of Health and Aging Working Group, 1994). The incidence was found to be 21.8 (women) and 19.1 (men) per 1000 persons per year (Canadian Study of Health and Aging Working Group, 2000). Using projections from the CSHA data, as of 2016, there were an estimated 564, 000 Canadians living with dementia (Alzheimer Society of Canada, 2016b). The direct cost to the healthcare system is estimated to be over \$10 billion Canadian (CAD) per year, and does not include the indirect cost patients and families must bear (Alzheimer Society of Canada, 2016b).

The province of Saskatchewan, similar to the rest of Canada, serves a diverse, aging population over a wide geographic area. In a report conducted by the RaDAR team, which extracted data from provincial health databases, the incidence rate was estimated to be 7.28 per 1000 persons age 45 or older (Kosteniuk, et al., 2015). The prevalence of dementia in

Saskatchewan was found to be 13,012 reported cases in the province, or 2.82% of persons over age 45, with 4,394 of these occurring in rural areas of Saskatchewan (Kosteniuk et al., 2015). The values reported in the report from Kosteniuk et al. (2015) are likely an underrepresentation of the true number of individuals with dementia in Saskatchewan, as the results are based on reported diagnoses of dementia in a health database and this has been found to be generally underreported.

**2.1.2 Dementia in primary healthcare.** Currently in Canada there is no comprehensive national plan available to provide guidance and implementation strategies to assist persons with dementia, their families, and healthcare workers. The Alzheimer Society of Canada released a comprehensive document titled, *Rising Tide: The Impact of Dementia on Canadian Society*, which provided estimates of dementia epidemiology, an overview of dementia care in Canada, and projected future economic and societal impacts (Dudgeon, 2010). The report aimed to provide an accurate description of dementia in Canada using research evidence, and included explicit recommendations for the development of a national dementia strategy with the hope provincial and federal governments could build upon the report's work to develop a national strategy (Dudgeon, 2010). In 2014, the Canadian government pledged to collaborate with provincial and territorial governments to develop a national strategy (Alzheimer Society of Canada, 2014) and in February 2016 a private members bill was introduced at the federal level for the creation and implementation of a national strategy (Alzheimer Society of Canada, 2016a). In June 2017, bill C-233 was officially passed and work will now begin on the creation of a national dementia strategy for Canada (Alzheimer Society of Canada, 2017). Several countries, including the United States, France, and England, have developed national strategies with specific goals and priorities in order to provide quality care to persons with dementia (Alzheimer's Disease International, n.d.). However, these national strategies are unique to the individual countries' needs and Canada cannot simply adopt these strategies for use in the healthcare system. As well, national strategies generally examine interventions and barriers within the system as a whole and may not focus specifically on a particular area of healthcare management, such as primary healthcare.

Without a national strategy, individual jurisdictions within Canada must develop evidence-based strategies to support quality dementia care, leading to varying dementia care across the country. The Provincial Advisory Committee of Older Persons (2004) in

Saskatchewan released a strategy outlining the best possible care for persons with Alzheimer's disease and dementia, with explicit recommendations for action. This strategy remains in place; however its long-term outcomes and evaluative effects are not clear as to their success.

**2.1.3 Rural dementia care.** Providing care for persons with dementia in rural settings presents similar challenges as in urban settings, but often with increased geographic distance between care centers and patients, and fewer human resources in rural settings. Morgan, Innes, and Kosteniuk (2011) conducted a systematic review to evaluate the current state of formal dementia care services in rural areas. Throughout the literature, common themes emerged regarding formal care practices in rural settings including the need for increased training of local practitioners, access and use of technology and integration of care services (Morgan et al., 2011).

A perspective on formal care services only offers one side of the current reality, as often families and friends provide the bulk of supportive care to persons living with dementia in rural settings. A systematic review by Innes, Morgan, and Kosteniuk (2011) focused on informal care providers (i.e., family caregivers) and services for persons with dementia in rural areas. Although literature in this area was identified, the findings of most of the studies pertained to difficulties accessing services rather than the perspective of informal caregiving (Innes et al., 2011). Culture emerged as a re-occurring theme throughout the literature, but the perspective of the rural setting was ill-defined or not the main focus of several of the studies, making the systematic review challenging (Innes et al., 2011). The literature evaluated in the above two review articles demonstrates an identifiable gap in the current published literature, with a need for more comprehensive studies in rural dementia care to better understand the current reality.

**2.1.4 Healthcare professionals' perspectives on dementia care.** There is currently a dearth of published literature regarding healthcare professionals' perspectives about strengths and gaps in community-based dementia care. Pratt, Clare, and Kirchner (2006) utilized semi-structured telephone interviews with healthcare practitioners to determine the adequacy of current dementia care services within an urban area of London, England. The participants were drawn from the same geographical area and included equal representation from family physicians, psychiatrists, speech language pathologists, and community nurses (Pratt et al., 2006). The interview focused on eliciting perspectives regarding the needs of persons with dementia, how these needs were addressed in the community, and current barriers to services (Pratt et al., 2006). The study found that participants believed persons with dementia have



complex needs which were inadequately met in the service area and this was further compounded in persons with dementia from a minority group (Pratt et al., 2006). The study findings highlight the need for dementia services to consider individual needs during program development, but also to examine the wider social context (Pratt et al., 2006).

Manthorpe and Alaszewski (2002) sought to determine the perspectives of nurses and managers regarding current dementia services in the community and in residential care in order to identify current gaps in dementia care. The study used telephone interviews and questionnaires to elicit data within a geographical area which included both urban centers and a rural population (Manthorpe & Alaszewski, 2002). The study found there was a lack of specialist care, a lack of appropriate respite and day care services, and a need for more comprehensive education for staff caring for individuals with dementia, as perceived by the participants (Manthorpe & Alaszewski, 2002). The study highlights that although eliciting perceptions of care services from the users (persons with dementia and their informal caregivers) is vital and important to service development, the input from the dementia workforce is equally valuable, as their first-hand knowledge and experience can provide a unique perspective.

Bokberg et al. (2014) investigated best practices along the continuum of care as perceived by healthcare professionals in Sweden. The study used focus groups to elicit views on conditions needed for optimal best practice for persons with dementia (Bokberg, et al., 2014). The participants were primarily registered nurses with a few occupational therapists and social workers participating (Bokberg, et al., 2014). The qualitative study used an interview guide during the focus groups and identified five key components for best practice throughout the continuum of dementia care: necessity for diagnosis, routines, competent staff, availability of day care facilities, and participation of next of kin (Bokberg, et al., 2014). Bokberg et al. (2014) highlighted the need for best practice in the early stages of dementia but as evidenced by the participants, is difficult to attain even into the late stage of the illness.

The above literature highlights the gaps in services that exist regarding community-based dementia care. Research on gaps in services tends to use methods such as questionnaires, interviews and focus groups. Quality of these methods is equally important to ensure the most accurate and relevant information is collected.

## **2.2 Questionnaire Development**

The measurement tool selected by the RaDAR team for this study is a questionnaire. Questionnaires are one of the best ways to collect large amounts of data in a standardized manner, while optimizing resources (Sheatsley, 1983). The questionnaire is a measurement tool frequently utilized in research and is a standardized method for gathering data and information (Rattray & Jones, 2007). They are used to collect a wide variety of data, from knowledge and attitudes, to intention and behaviour (Rattray & Jones, 2007). The range and versatility of a questionnaire can be well suited to many different topics and areas of research. Questionnaires are traditionally used as a self-report tool and allow the participant to answer the questions at their own pace and on their own time (Loiselle & Profetto-McGrath, 2011). There are noted disadvantages to using questionnaires, such as different interpretations by participants or forcing participants to choose one response to a question (Sheatsley, 1983), which may not fit his or her reality.

Development of a good quality questionnaire is important, as a poorly designed questionnaire will inevitably provide poor data and findings (Gillham, 2000). Sheatsley (1983) recommends three points to consider when developing a questionnaire: the questionnaire should “(a) meet the objectives of the research; (b) obtain the most complete and accurate information possible; and (c) do this within the limits of available time and resources” (p. 201). The steps for developing a questionnaire generally begin with identifying the purpose and scope of the topic to be studied, examining the literature for relevant information, pretesting the questionnaire with similar test subjects, and modifying the questionnaire to ensure its feasibility and validity (Grove, 2017).

A wide range of questionnaire structure is possible when developing an instrument; from unstructured, where a participant’s comments on a topic are analyzed; to structured, where a participant is given a finite choice (e.g. yes, no) for their response (Gillham, 2000). A structured questionnaire may provide ease with data analysis, but the participant is limited in their ability to express the meaning behind their answer; whereas, open questioning results in large amounts of data and the potential for irrelevant information (Krosnick & Presser, 2010). An intermediate option is a mix of both closed-ended and open-ended questions, which is commonly referred to as a semi-structured questionnaire (Gillham, 2000). The use of a semi-structured questionnaire allows for a variety of different types of questions to be used and Gillham (2000) suggests this is

beneficial as it allows for the collection of different types of data as well as maintaining the interest throughout the questionnaire by the participant.

Questionnaires can be delivered in a variety of ways, including via mail, online, or as an interview, either via telephone or face-to-face with the participant (Sheatsley, 1983). Each method has its own advantages and disadvantages, and selection of the appropriate medium is dependent on the type of research being conducted (Oppenheim, 1992). A questionnaire delivered in an interview format (either via telephone or face-to-face) takes on characteristics of a structured interview, as it allows the interviewer to control the sequence of questioning and provide the questions in an identical manner to all participants (Waltz, Strickland, & Lenz, 2010). Structured interviews may allow for small deviation from the line of questioning or may be precise in their administration (Grove, 2017). Administering the questionnaire in an interview format is advantageous, particularly in a pretest, as it provides opportunities for immediate clarification of questions (Waltz et al., 2010). Additional advantages include the relative low cost to administer and the speed with turn-around time versus administering face-to-face (Oppenheim, 1992).

### **2.3 Pretest**

Pretesting a questionnaire is considered a vital step in designing a high quality questionnaire (Krosnick & Presser, 2010). Conducting a pretest or a “trial run” (Waltz et al., 2010, p. 145) of a measure is beneficial as it identifies potential issues with the questionnaire, such as confusing or poorly worded questions, irrelevant questions, formatting issues, and logistical challenges (Oremus, Cosby, & Wolfson, 2005). Although a pretest of a questionnaire will result in added expense and time, the goal in the end is to save time and money during the actual research phase by streamlining the process and instrument (Oppenheim, 1992). It is recommended to pretest questionnaires and interview guides by having similar participants to those required in the main study with an opportunity for participants to provide feedback on the questions and format, including clarity, ease of understanding, time required to complete and method for administration (Burns & Grove, 2005). Sheatsley (1983) suggests twelve to twenty-five participants in a pretest are often sufficient to discover major problems or issues with a questionnaire. A pretest will show if a questionnaire works as intended (Oppenheim, 1992).

When a questionnaire is delivered as a structured interview, conducting a pretest is beneficial. A well-designed pretest will result in changes and revisions to the questionnaire to

improve its quality (Singleton & Straits, 2002). It is necessary and important to pretest every aspect of the questionnaire, including the introduction, wording and order of questions, and delivery (Oppenheim, 1992). During the pretest, the researcher examines the process for delivering the questionnaire and identifies questions that are problematic for participants (Singleton & Straits, 2002). It is common after a pretest to debrief with the research team to discuss how it went (Singleton & Straits, 2002).

Systematic strategies exist for identifying what revisions may be required to improve a questionnaire administered via interview. One method is behaviour coding which involves systematic coding of questions which elicited unexpected results, such as incorrect wording by the interviewer, respondents asking for clarification, or a need for more probing (Singleton & Straits, 2002). Although behaviour coding is a useful systematic tool that can be used by multiple researchers for the same instrument, it does not reveal the reasons behind problematic questions (Singleton & Straits, 2002). To get at the root of problematic questions, another strategy is the ‘think-aloud’ strategy, where participants are asked to describe the thought process and reasoning behind their answers (Bowling, 2009).

The benefits to pretesting, as stated above, are obvious when implementing a new questionnaire. However, there has been very little research conducted to show pretesting definitively identifies problems within questionnaires or that it improves questionnaires (Presser et al., 2004). Methodological guidelines do not exist for pretesting and rarely is the process and results of pretesting documented (Presser et al., 2004). The scant research available does demonstrate using systematic methods during pretesting are effective to identify problems within a questionnaire; however it is not always clear what the solution is to those problems or if revisions result in better data (Presser et al., 2004).

Although this paradox exists when conducting a pretest, it is still beneficial for evaluating the research process being proposed for the study. If a new instrument is intended to be used in a research study, it remains important to evaluate the construction and effectiveness of the instrument. When evaluating a new instrument, it is often up to the users to determine what parameters will determine if it is satisfactory (Feinstein, 1987).

**2.3.1 Feasibility and acceptability.** The term feasibility is often used in the literature in the context of a feasibility study. Examining feasibility is done to determine if the study or research in question can in fact be done and what parameters are required to conduct a larger,

successful study (National Institute for Health Research, 2016; Oregon State University, n.d.). The term ‘pilot study’ is occasionally used interchangeably with feasibility; however, the aims of each are different. A feasibility study is meant to determine if a research question warrants further testing and the data collected in the feasibility study is not a focus of the purpose; whereas a pilot study is often a scaled-down version of a larger study where analysis of the data is often conducted as it would be in the larger study (Bowen et al., 2009; Eldridge et al., 2016). Ideally, feasibility is examined at an early stage in the research process and should examine the practical aspects for conducting the study, including logistics and clinical relevance (National Institute for Health Research, n.d.). Feasibility encompasses many factors, such as estimating sample size, determining outcome measures, response rates to questionnaires, time to complete (Eldridge et al., 2016), research design (Oppenheim, 1992), and implementation (Bowen et al., 2009).

Acceptability is another factor to consider during the pretest phase of a new instrument. Acceptability is how participants react to or receive an intervention during a research study (Ayala & Elder, 2011; Bowen et al., 2009) and further includes the acceptability of the intervention to those who are conducting the research (Campbell, Braspenning, Hutchinson, & Marshall, 2002). It is common to assess acceptability of an intervention with interviews or focus groups with the target population to help inform the urgency, importance and changeability of the proposed strategy (Ayala & Elder, 2011).

Examining the acceptability of a new instrument encompasses many concepts, which may vary depending on the research being conducted. For example, it may include (a) relevancy, (b) applicability, (c) flow, (d) sensibility, and (e) understandability. Oppenheim (1992) states every question in the questionnaire should be there with a purpose, and should not have items included for ‘interest’s sake’ or that will have no bearing on the final data analysis. This is commonly referred to as relevancy (Oppenheim, 1992). Including relevant questions assists with increasing motivation of a participant to both participate in the questionnaire and to provide sincere answers to the questions (Gillham, 2000). Pretesting a questionnaire can often distinguish whether there are questions or sections that are irrelevant to participants (Sheatsley, 1983). Instruments are commonly developed with a specific target population in mind, and the contents must be applicable to all participants who will use it and demonstrate applicability (Feinstein, 1987). This is important when an instrument will be used with specific professions

and a potential threat to applicability is if the instrument is not significant to a profession (Burns & Grove, 2005). Acceptability also includes how well the instrument flows. The instrument should move smoothly and maintain the participant's train of thought throughout (Sheatsley, 1983). Bowling (2009) states a confusing order to the questionnaire can impact the responses by participants. Sensibility refers to the 'common sense' attributes of an instrument (Feinstein, 1987). Feinstein (1987) states it can be difficult to define sensibility in practical settings as it covers areas in the clinical world that are often overlooked. Often the simpler and clearest wording of a question can improve sensibility (Sheatsley, 1983). Understandability simply refers to whether participants understand or comprehend the information within the instrument (Bowling, 2009).

**2.3.2 Evidence for validity.** Validity is a central component in the assessment of quality in research. The term validity is used to refer to different aspects of the research process but generally refers to the 'soundness' or 'truth' of the design, instruments, or findings (Loiselle & Profetto-McGrath, 2011). Validity is not a characteristic that can be achieved in some absolute manner, but rather is a relative term which needs evidence to establish this soundness in a specific research context. For present purposes, the focus will be on measurement validity related to the development of a research instrument such as a questionnaire in an interview format. Traditionally, the definition of measurement validity has been whether a research instrument measures what it was intended to measure (Loiselle & Profetto-McGrath, 2011), and procedures have been developed for different types of validity assessment (content, criterion-related, and construct) in the development of research instruments.

Validity has witnessed a metamorphosis over the decades, moving from an absolute, where an instrument was either valid or it was not; to a dynamic entity changing based on the research and subject (Goodwin & Leech, 2003). Traditionally, validity was classified into three types: content, criterion-related, and construct. Content validity of an instrument was based on how accurately an instrument reflected the subject at hand and was often based on expert opinion (Bowling, 2009). Face validity was considered very similar to content validity, however it was generally deemed more superficial (Bowling, 2009). Criterion validity was how well an instrument correlated to an existing, comparable instrument (Bowling, 2009). Construct validity answers the question of whether the instrument measures what it was intended to measure (Burns & Grove, 2005).

The American Educational Research Association [AERA], American Psychological Association [APA] and the National Council on Measurement in Education [NCME] (1999) critique this traditional view and suggest that interpretation of the results is more important than the validity of the individual items. Cook and Beckman (2006) sum it up eloquently by stating “Validity is not a property of the instrument, but of the instrument’s scores and their interpretations” (p. 166e8). Thus, validity must be established each time an interpretation is made in a different context.

As validity is not an absolute, evidence must be gathered to support the argument of construct validity and this evidence can be gathered from five sources: test content evidence, response process, internal structure, relation to other variables, and consequences (AERA & NCME, 1999). Content evidence refers to how well the content of the instrument represents what is being sought and is similar to content validity (Goodwin & Leech, 2003). Response process is when the actions or responses provided by the participant are then reviewed with the participant to determine whether their intent with the response fits with the content (Cook & Beckman, 2006). The third source of evidence is internal structure and is most closely related to reliability in quantitative research as it refers to consistency of responses between participants (Cook & Beckman, 2006). If an item is expected to yield a certain result, then strong internal structure would yield consistent results between participants (Cook & Beckman, 2006). Relation to other variables refers to consistency between similar instruments measuring the same construct (AERA & NCME, 1999). The final source of evidence, consequences, examines the intended and unintended results of an assessment and is generally considered the least reported source of evidence when evaluating tools as few guidelines for its use are available (Goodwin & Leech, 2003). Obtaining evidence using a combination or all of these concepts can help to support an instrument or research findings claim of validity.

Validity is a concept associated with quantitative research; however, assessing data quality is also an essential component of qualitative research. Quality in research is the ability to produce believable results and is known as trustworthiness (Lincoln & Guba, 1985). Trustworthiness focuses on the consistency of methods, creating confidence in the truth of the research results, and minimizing bias (Lincoln & Guba, 1985). In qualitative research, demonstration of confirmability, dependability, credibility, and transferability of research findings are used to establish trustworthiness. Establishing confirmability is related to objectivity

and neutrality of methods and findings (Lincoln & Guba, 1985). Dependability is the consistency and replicability of the research methods (Lincoln & Guba, 1985). The inherent truth with the results is referred to as credibility and transferability is the applicability or generalizability of the methods and results to other contexts or populations (Lincoln & Guba, 1985).

Comparing validity in quantitative research with trustworthiness in qualitative research is not a straight-forward process. A series of standards or strategies for assessing quality in qualitative research have been outlined to assist with navigating the variability between research approaches (Miles, Huberman and Saldana, 2014). These strategies assist with determining if qualitative research demonstrates confirmability (objectivity), dependability (reliability), credibility (internal validity), and transferability (external validity) (Miles et al., 2014). Despite the dichotomous view to these two types of research, establishing validity or trustworthiness is central to maintaining rigour in the research process.

## **2.4 Research Questions**

The purpose of the pretest was to examine the construction of the questionnaire (i.e., determine the feasibility and acceptability of the questionnaire) and to determine if there was evidence for validity of findings in relation to the key strategies outlined by Aminzadeh et al. (2012) along the continuum of care. The aim of this study was to pretest a single questionnaire that would be administered to primary healthcare professionals to assess strengths and gaps in the continuum of care for individuals with dementia in rural settings. The data obtained from the questionnaire in this pretest was not the focus of the study; the content was important in relation to whether the questions asked would provide the necessary information for the larger study.

The following three questions were formulated for the pretest:

- What is the overall feasibility of the questionnaire?
- Is the questionnaire acceptable to participants?
- What evidence is there for validity of the questionnaire?

The first two questions are specific to the questionnaire's construction. Based on data obtained for each of these questions, suggestions for modification of the questionnaire were provided to the RaDAR team.



### **3 CHAPTER THREE – METHOD**

The method chapter will begin with an overview of the planned, larger study to be completed by the RaDAR team, followed by an examination of the research design for this study. This will be followed with the participants for the study, ethics approval, recruitment strategy, operational definitions used, and inclusion of guiding questions in the questionnaire. The method section will end with an overview of the data collection procedure and the data analysis strategy used in the study.

#### **3.1 The RaDAR Study**

The questionnaire development was based on the (1) the conceptual framework proposed by Morgan et al. (2005) in Figure 1; and (2) the scoping interpretive literature review conducted by Aminzadeh et al. (2012), which identified key strategies for comprehensive, dementia care guidelines based on evidence obtained in the literature. The questionnaire followed the continuum of care from assessment, through diagnosis and management. Gaps and strengths in care, which will be the focus of subsequent studies, are inherent throughout the questionnaire through wording and selection of the questions.

The data collected from the questionnaire must adequately point to strengths and gaps in services provided to persons with dementia and their families in order to meet the intents of the larger research study. As the questionnaire was structured along the continuum of care and incorporated the key strategies from Aminzadeh et al. (2012), questions were focused specifically on identifying strengths and gaps in care. Thus, the pretest was conducted to ensure that the questionnaire was feasible, acceptable, and provided support for evidence of validity. By showing evidence for validity, the questionnaire would capture the data needed for the larger study.

#### **3.2 The Pretest Research Design**

The pretest informed the RaDAR team about the overall feasibility of using the questionnaire and the acceptability to potential participants, as well as providing evidence for validity of the questionnaire. Therefore, the research design was integral to the success of the pretest. In order for the pretest study to achieve the objectives outlined, the study must be able to answer the research questions and mimic as closely as possible the larger RaDAR study. Therefore, the sample of participants and data collection strategies closely resembled the eventual larger study.

The research design followed an iterative and dynamic process. The end goal of the pretest was to provide evidence that the questionnaire was feasible and acceptable to participants with its current construction so it could be used in the larger research study to obtain data on current dementia care in rural Saskatchewan. This was done by providing recommendations for refinement of the questionnaire throughout the interview process. By following an iterative process with the pretest design, changes were made to the questionnaire throughout the interview process and troublesome or confusing questions were identified immediately and revisions made to ensure construction issues were modified for subsequent interviews. By following an iterative revision process after each interview, the end product was a feasible and acceptable questionnaire.

### **3.3 Participants for the Pretest**

The pretest study was conducted with multidisciplinary primary healthcare team members from rural communities outside of the Saskatchewan health region used for the larger study to ensure potential participants in the larger study were not exposed to the questionnaire. A purposive sample of twelve rural primary healthcare team members was sought for the pretest with three participants in each of four provider categories: family physicians (FP), nurse practitioners (NP), home care registered nurses (RN), and occupational therapists (OT). Advisory Council members for the RaDAR team recommended these four categories of healthcare providers be targeted for the larger study, as they have the most interaction with individuals with dementia and their families.

Inclusion criteria for the study were clinicians: (1) working in one of the four target provider categories, (2) who were currently employed in a rural setting in the Saskatoon Health Region or Kelsey Trail Health Region, (3) whose current area of practice was predominantly primary healthcare, and (4) whose scope of practice included diagnosis, assessment, or management of individuals with dementia. The participants were asked to dedicate a one hour time period to complete the questionnaire and required access to a telephone for the interview.

The purposive sampling method yielded a total of twelve participants: two family physicians, three nurse practitioners, four home care registered nurses, and three occupational therapists. Due to difficulties with recruitment, only two family physicians agreed to participate over the ten month data collection period. In order to ensure twelve participants were recruited, study invitations were provided to more than twelve candidates and this resulted in an additional

home care registered nurse participating in the study, as scheduling of interviews overlapped with other participants who had already agreed to participate. The RaDAR team agreed this sampling was satisfactory for the pretest.

### **3.4 Ethics Approval**

Although the study design posed a minimal risk to participants, all potential risks were considered. Ethics approval was obtained from the University of Saskatchewan Behavioural Research Ethics Board (REB 14-474), Saskatoon Health Region, and Kelsey Trail Health Region. Operational approval was also obtained from Saskatoon Health Region. A consent form (see Appendix A) was provided to all participants in the study outlining potential risks and that they may withdraw at any time without penalty. The consent form was provided via email at first contact with the participant when an interview time was also arranged. Oral consent was then confirmed via telephone at the start of each of the participants' interviews.

A potential area of discomfort or stress for participants identified prior to the pretest was if a participant felt their current practice was unsatisfactory or lacking in relation to dementia care. Strategies to avoid this stress from occurring included reiterating the goal of obtaining data in order to understand current care practices for persons living with dementia or their families and asking questions in an objective manner. Emphasis was placed on the participant setting the pace for the interview and directly inquiring about the participant's comfort in answering the questions. The above strategies helped to minimize risk during the study. It was also decided before initiating the pretest that if at any point a participant sounded stressed or uncomfortable to the graduate student or the participant voiced a desire to stop the interview, the participant would be asked whether they would like to continue and if not, would be withdrawn from the study. At no time did this occur during the interview process.

Potential benefits also existed for participants in the study. The overall goal for the larger study was to develop interventions and strategies to improve dementia care in rural settings. The pretest was meant to guide refinement of the questionnaire for the larger study; therefore participants may have felt satisfaction knowing participation in the pretest may be beneficial for rural dementia care in the province.

### **3.5 Recruitment Strategy**

The graduate student worked in partnership with three contacts to identify potential participants for the study. They included the director of primary health and chronic disease

management in the Saskatoon Health Region, a nurse practitioner in Kelsey Trail Health Region, and a research assistant with the RaDAR team. The contacts were responsible for identifying potential participants and distributing recruitment information within their respective health regions and contacts to those that fit the inclusion criteria. Utilizing these contacts was beneficial for this process as he/she was aware of current staff in rural primary care, had access to contact the individuals, and could facilitate access to potential participants. The graduate student provided recruitment material to the contacts in the form of an outline and description of the proposed study (see Appendix B) which was then distributed throughout the respective health regions and networks. Each participant was offered a \$100 honorarium in the form of a Visa gift card upon completion of the interview, which all but one family physician participant accepted. As potential participants came forward to the contacts citing their interest to participate, their information was provided to the graduate student and the graduate student then directly contacted potential participants via email.

### **3.6 Operational Definitions**

The first two research questions were concerned with the overall construction of the questionnaire. The first question was *What is the overall feasibility of the questionnaire?* The operational definition of feasibility for the purposes of this study included the time required to complete the questionnaire, the selected format for administering the questionnaire, and whether or not the participant received the questionnaire in advance of the interview. The questionnaire was administered via telephone interview and feasibility was concerned with whether the amount of time to complete the questionnaire was realistic and practical for participants, as well as whether the format of telephone interview was reasonable to obtain the data being sought. Furthermore, comparisons were made between those participants who received the questionnaire and those participants who did not to address feasibility.

The second research question for the research study was *Is the questionnaire acceptable to participants?* For this study, the term acceptability encompassed several concepts, including: how relevant and applicable the questionnaire was to the participant's practice, the order of questions and how they flowed together, if the questions made sense and were logical, and how easily the participant was able to understand the questions.

The third research question was *What evidence is there for validity of the questionnaire?* Validity is concerned with whether the proposed instrument measures what it is intended to

measure (Loiselle & Profetto-McGrath, 2011). Evidence for validity was sought through multiple sources and individual items in the questionnaire were analyzed to demonstrate they obtained the information sought.

### **3.7 Guiding Questions**

Additional guiding questions (see Appendix C) were added to the questionnaire for the pretest which will not appear in the larger study. The guiding questions were added to obtain additional information from participants regarding the overall questionnaire. These questions acted as a prompt to remind participants of the aim of the study, as well as to potentially gain more data. The guiding questions were intended to remain open-ended and neutral to allow the participant to speak freely on the questionnaire and direct the conversation. The questions focused primarily on gaining information on the acceptability of the questionnaire, and participants were not asked directly about feasibility. Some participants did provide insight on the feasibility of the questionnaire given the open nature of the questions. Guiding questions were inserted at the end of the following questionnaire sections: Assessment, Diagnosis, Management, and Additional Questions. The intent of placing guiding questions throughout the questionnaire versus only at the end was to aid with recall. The guiding questions also followed the iterative process and were changed through the interview process (see Appendix C).

### **3.8 Data Collection Procedure**

Data were collected by telephone interview using the questionnaire (see Appendix D). All interviews were audio recorded and transcribed verbatim by a third party and transcripts were cleaned by the graduate student. The sources of data for the study were the notes made by the graduate student and RaDAR team during and after the interview, and the transcribed text.

The first source of data collected from the interviews were the notes made by the graduate student during each interview. Examples of the types of notations included when participants (a) asked for further clarification of a question, (b) needed further clarification as evidenced by their response to the question, (c) made general comments through the interview, and (d) provided responses to the guiding questions. A further notation was made regarding whether the participant had received the questionnaire in advance of the interview.

After each interview, the graduate student would summarize the notations and analysis and provide them electronically to the RaDAR team leader and a content expert from the RaDAR team (both thesis committee members). The RaDAR team members would then listen to

the recorded interview and provide further analysis regarding the feasibility and acceptability of the interview. All of the notations/analysis from each interview were summarized and recorded. Based on these notes, modifications were made to the questionnaire, if necessary. These sets of notations formed the first component of the data collected.

The second source of data collected was the transcribed interviews. Interviews were transcribed verbatim by a third-party. These services were provided by the Social Sciences Research Laboratory at the University of Saskatchewan and were paid by the RaDAR team through a research grant. The transcripts were cleaned by the graduate student to ensure preciseness.

### **3.9 Data Analysis**

The analysis focused on two key components: the construction of the questionnaire and the content obtained from the questionnaire. An analysis of the construction aspects of the questionnaire focused on answering the first two research questions: (1) *What is the overall feasibility of the questionnaire?* And (2) *Is the questionnaire acceptable to participants?* Further content analysis (Krippendorff, 2004) was used to guide the data analysis of the transcripts in order to answer research question (3) *What evidence is there for validity of the questionnaire?*

**3.9.1 Feasibility and acceptability.** To determine if the questionnaire was feasible and acceptable, three sources of data were used: notations and analysis (i.e., interpretations) conducted by the graduate student during and after the interviews, analysis provided by the RaDAR team, and comments made by the participants with respect to the guiding questions. All of the notations and analyses were summarized for each interview, including the modifications made to the questionnaire based on the notations/analyses. Each of the notations was categorized based on whether the notation/modification reflected a feasibility or acceptability issue.

**3.9.2 Evidence for validity.** The data used to determine whether there was evidence for validity of the questionnaire came from the transcribed interviews. The questionnaire was structured along the continuum of care and was designed to elicit information on strengths and gaps in rural dementia care. In order to provide support for evidence of validity of the questionnaire, responses from participants should fit within the original aim of the question.

The first step in the analysis process was to determine the aim of each individual question. Each question within the questionnaire was mapped to Aminzadeh et al. (2012) seven key strategies: (a) use of multidisciplinary teams, (b) ongoing care management, (c) formal

training for primary care physicians and staff, (d) standardized protocols and guidelines, (e) access to technology resources, (f) education and support for persons with dementia and caregivers in collaboration with community agencies, and (g) regular patient follow-ups. These seven strategies formed the categories for mapping. For example, if a question was included to elicit information on the primary healthcare team, it would be mapped to the strategy/category 'Multidisciplinary teams'. The mapped questionnaire was then sent to the questionnaire content expert for review and feedback. The content expert made suggestions and consensus was reached for the mapping of questions to Aminzadeh et al. (2012) key strategies. The content expert also suggested the addition of an eighth additional category for mapping for questions that did not fit within the seven key strategies: Dementia Care Continuum. The RaDAR team utilized several other sources during development of the questionnaire to ensure all information was collected on strengths and gaps, including Glasser and Miller (1998), BC Guidelines (2014), Moore et al. (2014), Murphy et al. (2014), Ngo and Holroyd-Leduc (2014), and Parmer et al. (2014) (see Kosteniuk, Morgan, O'Connell, Kirk, & Stewart, 2016). Additional questions were added to the questionnaire which were not directed by the seven key strategies but were integral to covering the entire continuum of care and these questions fell within the final category of Dementia Care Continuum. With mapping complete, a foundation for the aim of each question was established.

The next step in the analysis of evidence for validity was to divide all of the questions into two groups: open-ended questions and closed-ended questions. Open-ended questions were defined as those questions with no limitations on the participant's potential responses (Loiselle & Profetto-McGrath, 2011). Closed-ended questions were defined as questions with a definitive answer, such as a scaled response or those questions with a singular word response (yes, no, sometimes, etc) (Loiselle & Profetto-McGrath, 2011). Each question was then itemized, as some questions contained additional bulleted questions within and analysis of responses to these questions is necessary (See numbering within { } in Appendix D for itemization).

Following this organization of the questionnaire, content analysis was conducted on each open-ended item to extract data from the individual questions for ease of comparison. Content analysis is a research technique used in qualitative research to make inferences from text in a replicable and reliable process (Krippendorff, 2004). The goal of content analysis is to gain meaning from the text, beyond counting words (Hsieh & Shannon, 2005). The process begins with summarizing meaning units or sections of text down into a few words known as a

condensed meaning unit and using the condensed meaning unit, a code can emerge (Graneheim & Lundman, 2004). This strategy was used for each open-ended item in the questionnaire, whereby the question and participant response were condensed into a short statement and then assigned a one or two word code based on its meaning. The information was organized in tables using Microsoft Excel. This was replicated with each transcript interview, compared across the interviews, and resulted in all of the responses for each question being coded. Thereby, all responses to each item in the questionnaire were then summarized by a few codes or words. Closed-ended items used a different approach, as the responses were suggested to participants, either via a scale or wording of a 'yes' or 'no' question. Each of the responses to the closed-ended items were also organized and summarized in tables using Microsoft Excel for ease of comparison. To ensure rigour in the analysis and support confirmability, one of the graduate student's co-supervisors independently analyzed three transcripts and coded them. These codes were then compared to the graduate student's coding and consensus was reached. Once coding was complete, participant responses could then be compared to the original aim of the question to determine if participants were answering as suggested or related to the mapped categories. A response of unsure to a question was considered a valid response as this still provided information on knowledge within the team. A *rule of thumb* of ten out of twelve respondents answering as suggested or within the aim of the question supported evidence for validity of that item. Based on the results of the analysis, recommendations were provided to the RaDAR team for further potential changes to the questionnaire, particularly when items demonstrated variability in responses from participants, as measured by three or more participants answering outside the suggested response or aim of the question.

**3.9.3 Trustworthiness.** Trustworthiness of the data was supported by using principles of triangulation, where possible in the pretest, and this in turn supported the evidence for validity of the questionnaire. Using multiple sources of data (i.e., triangulation) is beneficial when pretesting a new instrument and reflects a desire to gain a deeper understanding of the phenomena being studied (Denzin & Lincoln, 2011). Different types of triangulation exist, including data, investigator, theory, methodological, and multidisciplinary (Marcus & Liehr, 1998). This study sought to utilize data, investigator and methodological triangulation to support the rigour and trustworthiness behind the findings. Several sources of data were combined (e.g., perspectives on teams from four types of healthcare providers) to help strengthen and



corroborate the results of the study, and are particularly useful when both quantitative and qualitative data sources are used in the study design (Creswell & Plano-Clark, 2011). Investigator triangulation, with input from two experts along with the graduate student investigator, was used in the data analysis phase in the determination of evidence for validity. Both qualitative and quantitative approaches were used in the questionnaire design and for assessing the feasibility, acceptability and evidence for validity, demonstrating methodological triangulation.

## 4 CHAPTER FOUR – RESULTS

Twelve interviews were conducted in the pretest over a period of ten months, from March 2015 to January 2016. The first eleven interviews occurred over a three month period (March 2015 – May 2015) and due to difficulties with recruitment of a family physician, the final interview occurred seven months later (January 2016). The first two participants were recruited from Saskatoon Health Region and the remaining participants were recruited from Kelsey Trail Health Region.

Demographic data of participants is available in Table 1. Ten participants identified as female and two identified as male. The average age of participants was 45.5 years and they were, on average, a member of their primary healthcare team for seven years. Two participants had completed a medical degree, one an advanced certificate, one a diploma and the remaining participants had completed a bachelor's degree. All participants stated they regularly interacted with other multidisciplinary team members.

### 4.1 Construction

Changes were made to the questionnaire collaboratively throughout the interview process based on participant feedback, combined with graduate student and RaDAR team notations and analysis. All changes made to the questionnaire, including question additions/deletions, wording changes and organization changes are summarized in bold font throughout Appendix D. There were a total of ten iterations of the questionnaire throughout the interview process, with two interviews resulting in no changes to the questionnaire.

Respondents varied in the amount of feedback they provided regarding the questionnaire. The majority of feedback was a result of the guiding questions, although some respondents provided feedback throughout the questionnaire. Following the second interview, the guiding questions were changed to attempt to elicit additional feedback from respondents and after interview #3 a statement was added to the guiding questions to improve clarity (See Appendix C and Appendix D). All respondent feedback was discussed by the graduate student and RaDAR team and taken into consideration with team analyses when deciding to make improvements to the questionnaire.

The first two research questions for the present study were specific to the overall construction of the questionnaire. The first research question focused on the feasibility of the

**Table 1 – Demographic Data**

Interview #	Professional Background (Participant ID)	Level of Education	Year Education Completed	Role on Team	Years on Team	Work Setting	Interact with multi-disciplines?	Age	Gender
1	NP(a)	Bachelor's degree	*	NP	12	*	*	45	Male
2	RN(b)	Diploma	1984	Homecare RN	4	Homecare	Yes	51	Female
3	RN(c)	Bachelor's degree	1991	Case manager	2.5	Health center	Yes	45	Female
4	NP(d)	Bachelor's degree	2004	NP	9	Primary care clinic	Yes	59	Female
5	OT(e)	Bachelor's degree	2004	OT	11	Outpatient clinic	Yes	35	Female
6	RN/NP(f)	Bachelor's degree	1992	RN	6	Homecare	Yes	45	Female
7	NP(g)	Advanced certificate	2013	NP	1.5	Primary care clinic	Yes	42	Female
8	RN(h)	Bachelor's degree	2000	Case manager	0.5	Homecare	Yes	37	Female
9	OT(i)	Bachelor's degree	2003	OT	7	Outpatient clinic	Yes	37	Female
10	FP(j)	Medical degree	2003	FP	~	Primary care clinic	Yes	38	Male
11	OT(k)	Bachelor's degree	1993	OT	10	Homecare	Yes	45	Male
12	FP(l)	Medical degree	1978	FP	15	Primary care clinic	Yes	67	Male

**Legend**

NP: Nurse Practitioner

RN: Registered Nurse

OT: Occupational Therapist

FP: Family Physician

\*Question added after Interview #1

~ Information not obtained

questionnaire for obtaining information and the second research question examined the acceptability of the questionnaire for participants.

**4.1.1 Feasibility.** Feasibility was concerned with the time required to complete the questionnaire, the format for administering the questionnaire and whether participants received the questionnaire in advance of the interview. The range of time for completion of interviews was from 32 minutes, 20 seconds, to 51 minutes, 25 seconds to complete. The average time needed to complete the questionnaire being 40 minutes, 6 seconds. All participants were able to complete the questionnaire during a single phone call. A few respondents chose to comment on the length of the questionnaire. One respondent (RNc) commented “I was feeling like I was losing focus a little towards the end. So maybe it’s a little bit long” however she was unable to offer any suggestions to shorten the questionnaire. Another respondent (RNh) when asked directly to comment on the length of the entire questionnaire during the last set of guiding questions commented “I think it was fine”. Other respondent comments included “the length wasn’t horrible” (OTi), and “I can’t think of any way that you could shorten it” (OTk). Based on this data, the RaDAR team concluded that the time required to complete the questionnaire was feasible.

Examination of feasibility of the questionnaire also included whether the method for administering the questionnaire via telephone interview was appropriate to obtain the data being sought. All respondents were able to obtain access to a telephone for the interview and access to a telephone did not appear to be a deterrent in recruitment of participants. No serious technical issues were noted throughout the telephone interviews. Minor connection problems were noted, as evidenced by the comments of one respondent (OTk): “The only reason I asked you to repeat it was your voice was kicking in and out. So either your phone or my phone it crackled a bit”. None of these minor occurrences impeded the interview process. One respondent (FPI) chose to comment specifically on the format of telephone interview: “As you saw I was struggling with the choices, so there has to be a way I know my choices better. . . When doing it on paper or online, it’s easy, you just see them but when you’re doing it through voice it’s hard for you to tell me sometimes”. Taken together, all participants were able to understand the questions and provide answers to the questions with little to no issues. Therefore, we concluded that administration of the questionnaire via telephone interview was feasible.

The final component of feasibility of the questionnaire was whether participants received the questionnaire in advance of the interview. The RaDAR team was interested in knowing whether participants having the questionnaire in front of them during the interview would improve understandability and participant responses. The graduate student was also interested to know if participants having the questionnaire would improve feedback on the questionnaire as it would be easier to make note of potentially confusing questions.

The first five participants received the questionnaire and guiding questions via email one day in advance of the interview. The participants were asked to not read the questionnaire until the time of the interview. This did not always happen as demonstrated by one respondent (an RNb) who went over the questionnaire in advance and shared it with colleagues to gather answers to all of the questions: “I kind of went over this questionnaire. So just a little bit prepared. I kind of actually got some feedback from other people that I work with; kind of discussed the questionnaire and got any concerns and stuff they have”. This is potentially problematic as the answers this respondent gave may not have been wholly her perspective, but based on the input of her colleagues. Another respondent (an NPd) also looked through the questionnaire prior to the interview and felt it positively impacted the interview: “In fact it was quite nice to be able to go through it this morning when you had sent it. If there is a very positive thing that would be what I would say, to be able to have it in front of you at any case would be very good”. From those who received the questionnaire in advance there were further positive comments including this from an OTe: “I really like that I have the questionnaire in front of me while you are reading it out, because otherwise there’s a lot of words”.

The last seven participants did not receive the questionnaire in advance and only received a list of the guiding questions via email one day prior to the interview. The decision to stop sending the questionnaire in advance was chosen at Interview #6 as it was the anticipated half-way point of the interview process. Guiding questions were provided to further reiterate to participants the intent of the interview to determine the feasibility and acceptability of the questionnaire and encourage feedback. Based on previous comments made by respondents, it was anticipated there may be difficulties for respondents to complete the questionnaire without it in front of them. However, time to complete the interview did not increase and respondents were still able to answer all questions adequately compared to the participants who did receive it. There did not appear to be any difficulties completing the questionnaire without it in front of the

respondent. One respondent (an RNh) when asked if having the questionnaire in front of her would make the questionnaire easier, responded “No, I don’t think so”. Despite the comments from those respondents who did receive the questionnaire, it was feasible to conduct the interview without the participants receiving it in advance and a participant having the questionnaire or not did not impact the outcome of the interview.

Overall, feasibility of the questionnaire was supported based on team notations/analyses and participant responses. Time to complete the questionnaire was consistent across interviews, the format of telephone interview to administer the questionnaire was well received, and participants were able to complete the questionnaire through verbal cuing without a physical copy in front of them.

**4.1.2 Acceptability.** Acceptability of the questionnaire was examined using the following concepts: relevancy, applicability, flow, sensibility, and understandability. The first concept considered how relevant the questions were to practitioners working on a primary healthcare team and dementia care. An issue that arose repeatedly related to relevancy was how participants identified with the wording of *primary healthcare team*, which is used repeatedly throughout the questionnaire. Recruitment of participants aimed to select practitioners working on primary healthcare teams, however several participants in the study stated they did not feel like they were on a formal primary healthcare team. Comments from respondents regarding this included “I think the only thing for me is that I’m not necessarily on the primary healthcare team, and that wording keeps coming up” (an OTi) and “So far is it’s kind of leading me on a path that’s saying our primary healthcare team. We don’t actually have a formal team where we sit together and discuss individual patient care. . . we work together as a team, but we don’t actually sit and discuss like in grand rounds kind of format” (an NP). It is unclear however if these comments are reflective of the respondent not being part of a primary healthcare team or is merely their perception of their work environment lacking a team atmosphere. Based on the comments of one respondent (an RNf), the inability to identify as a team is more related to lack of access: “I do find we’re a little disjointed sometimes as a primary healthcare team. So I don’t necessarily know what’s happened over at the medical clinic or somewhere else”.

The graduate student and RaDAR team attempted to mediate the concerns expressed by these comments throughout the interview process by including further description in the preamble as to the focus of the questionnaire (see Appendix D). The graduate student and

RaDAR team also discussed whether a further definition of primary healthcare team should be included in the preamble to highlight both formal and informal team environments, but due to the preamble length, it was not included. These comments by respondents point to a potential issue with the relevancy of the questionnaire as it relates to a formal primary healthcare team, but respondents were still able to provide answers to most questions and no variability was identified between those respondents who had issue with the wording of primary healthcare team and those that did not. Based on this information, we concluded the questionnaire is relevant to participants.

Another component of acceptability of the questionnaire was how applicable the questionnaire was to participants, both as a whole and within individual professions. There was an expectation prior to commencing the study that certain professions (i.e., RNs or OTs) would have more difficulty completing all sections of the questionnaire as certain aspects, such as diagnosis, are traditionally not part of their role. The goal was to determine if this caused a hindrance to any participants completing the questionnaire. Furthermore, a guiding question was included to ascertain if applicability of the questions was a problem for participants. As expected, some respondents did comment on applicability of some of the questions to their practice: “Some of the questions I felt didn’t really pertain to me, but you can’t really get away from that because it’s all members of the team. Like a physician would find them more appropriate” (an RNb) and “It’s just not very – that part is not very applicable to my role [section on diagnosis]” (an OTi). One respondent (an RNh) also commented on specific questions when asked to do so at the guiding questions: “There were a few. Just sometimes with the bloodwork and MRI, CT-scan, we aren’t in a position to order those. So it wouldn’t be applicable to many of us out in the community”. Conversely, RNf respondent commented favourably when a section was more applicable to their role: “That was my favorite part [section on management]. Those were ones that I actually felt I had answers to”. The NPs and FPs did not comment on the applicability of questions to their practice or express difficulty with certain questions, which was expected.

The graduate student and RaDAR team noted the potential issue of applicability of the entire questionnaire to some professions and made the decision after the third interview to include in the preamble a statement addressing this: *This questionnaire is being used with all members of the PHC [Primary Healthcare Team] team. . . Therefore, to include all team*

*members' areas of practice, there are questions on all aspects of care and some specific treatments or managements may not be a regular part of your practice. It is OK if you do not know all of the answers to all of the questions. We are interested in the whole continuum of care and your feedback is valuable to us.* This statement had the effect of increasing the respondents to answer "I don't know" to certain questions and this was viewed as acceptable. This not only allowed for the RaDAR to team to understand what team members know about the continuum of care for persons with dementia, but also potentially prevented respondents from guessing as a means to provide a response. The inclusion of this statement also did not prevent respondents from answering the questions. All RNs and OTs were still able to complete the majority of the questionnaire and no pattern appeared as to potentially problematic questions for certain professions. Therefore, we found that the questionnaire was likely applicable to all participants.

Acceptability also focused on the flow of the questionnaire, including the progression of questioning along the continuum of care and the delivery of the questions. Respondents overall had favourable comments regarding the flow of the questionnaire, including this from NPD: "I think they [the questions] flow fairly well" and this from an RNh: "I think it seemed to flow quite well and you were very good at asking the questions". The organization was obvious to participants and was viewed positively, as evidenced by these comments from RNh: "I think you've organized it quite nicely from diagnosis, assessment, management. You know it flows very nice. I think you've touched on everything".

In regards to the delivery of the questionnaire, this was sporadically problematic. During data analysis, it was noted some questions were inconsistently asked between participants and wording of questions was occasionally changed by the graduate student. This generally did not change the overall responses to the questionnaire but did lead to variability of responses for certain questions. This appeared to be an error of the graduate student at the time of the interview, as the mistakes were not consistent across the interviews and is likely related to inexperience, but is something to note if different individuals will be administering the questionnaire in future. Overall the flow of the questionnaire was viewed favourably by respondents and we concluded it increased acceptability of the questionnaire.

Sensibility of the questionnaire examined the wording, symmetry and the potential for confusing questions. Participants provided feedback on this point most prominently as it related to confusing wording. This specific feedback from participants often resulted in changes made to



the questionnaire. One example from OTe was “On number 42 [item 130] I would maybe change the word of informal caregivers, or explain it a little more. . . or even take out the word informal and just have caregivers, because it is already specific to people in the community”. This feedback resulted in the removal of the word *informal* from item 130. Respondents were also specifically asked during the guiding questions if there were any questions that did not make sense and this resulted in respondents generally stating “no”. The only negative feedback regarding sensibility came from FPI who felt there was a “feeling of repetitiveness” throughout the questionnaire. Several of the questions use identical wording, however change their focus between assessment, diagnosis, and management and this is the repetitiveness FPI was likely identifying, and yet these questions are asking for different information. Therefore the repetitive use of wording for certain questions may be potentially confusing.

Most changes to the questionnaire based on sensibility were based on the notations and analysis of the graduate student and the RaDAR team. This resulted in subtle word changes throughout the questionnaire and is summarized throughout Appendix D. Examples of this include changing the word *validated* to *standardized* in item 27, changing the word *patients* to *caregivers* in item 101, and adding the statement *outside of the primary healthcare team* to item 110. These changes, and others like it, were an attempt to make the questionnaire more coherent and sensible to the participant. Sometimes these changes were made simply from listening to the interviews and noting how the questions sounded from a third-person perspective or were based on how respondents were answering the questions. All of these changes were in an attempt to improve sensibility of the questionnaire and acceptability to the participant.

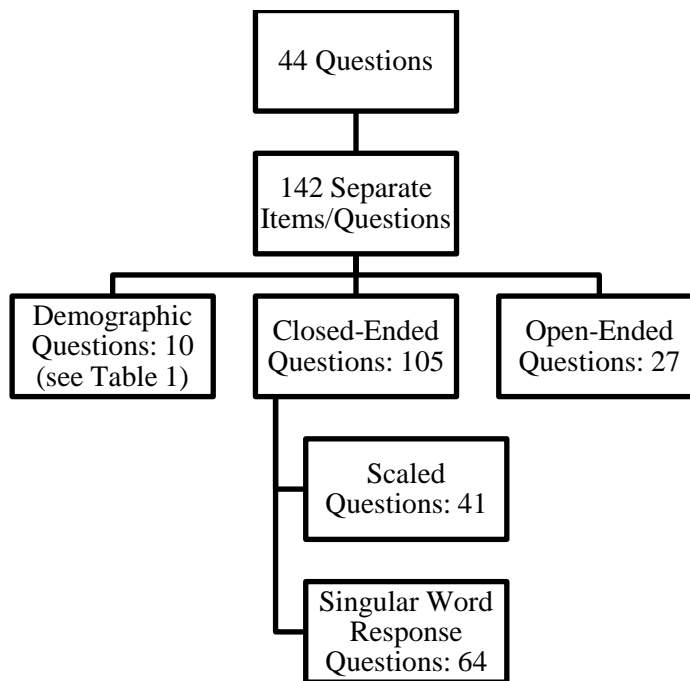
The final component examined for acceptability of the questionnaire was understandability. This component focused on how easily understandable the questions were and if participants answered the questions within the response options provided or within the aim of the question based on the mapping to Aminzadeh et al. (2012). Comments from participants were positive in relation to the questionnaire understandability including this from FPI: “I think it went well and I understood each question”, and this from RNh: “It was very clear and easy to understand”. Notations and analysis of the interviews resulted in a few changes to the questionnaire based on how participants were answering questions. For example, participant NPa answered item 110 with a singular focus on behavioural issues. As this is only one component of interest for this question, an introductory sentence was added to ensure participants thought of all

aspects: *Thinking about all aspects of care for patients with dementia (medication, behavioural, social, etc)*. Overall, there were no understandability issues noted by participants and only a few noted by the RaDAR team and graduate student, which were altered to improve understandability.

#### 4.2 Evidence for Validity

The final version of the questionnaire has a total of 44 numbered questions. Including bulleted sub-questions throughout, the questionnaire has a total of 142 items (See Appendix D). Figure 2 outlines the breakdown of format for individual items within the questionnaire. Appendix E lists which items provided support for evidence of validity, which included content and response process evidence (AERA & NCME, 1999). Unintended consequences were also examined.

**Figure 2 – Formatting of Items within the Questionnaire**



Each item in the questionnaire was mapped to the seven key strategies outlined by Aminzadeh et al. (2012) in their scoping review: (a) use of multidisciplinary teams, (b) ongoing care management, (c) formal training for primary care physicians and staff, (d) standardized protocols and guidelines, (e) access to technology resources, (f) education and support for persons with dementia and caregivers in collaboration with community agencies, and (g) regular patient follow-ups. The purpose of this mapping was to help determine the aim of each question

and was used to demonstrate if participant’s responses fell within that aim and provide support for evidence of validity of that item. Additional questions were included in the questionnaire by the RaDAR team which did not fall within Aminzadeh et al. (2012) key strategies. The RaDAR team framework (see Figure 1) is the other component to provide structure to the questionnaire and adding questions was deemed important for gathering information about the care continuum. For mapping purposes, this eighth category was known as ‘Dementia Care Continuum’. Table 2 outlines which items fell within each category. Certain categories had higher representation throughout the questionnaire. This was a reflection of what was deemed to be best to gather information on strengths and gaps in care along the dementia care continuum.

**Table 2 – Items Mapped to Aminzadeh et al. (2012) Key Strategies**

<b>Category</b>	<b>Item</b>
Multidisciplinary Team	11, 23, 58, 61, 65, 66, 68, 72, 91, 112,113, 119, 133, 134, 139
Ongoing Care Management	12, 69, 114, 131, 135, 136
Formal Dementia Training	13-15, 120-126, 140-142
Use of Standard Tools/Protocols/Guidelines	16, 24-56, 73-90, 93-94, 96-99, 101, 102, 104-109, 115, 132
Access to Information Technology	17, 18, 116
Education/Support for Patients/Caregivers	20, 21, 130
Regular Patient Follow-up	19, 137, 138
Dementia Care Continuum ( <b>Additional category; not an Aminzadeh et al. (2012) strategy</b> )	22, 57, 59, 60, 62-64, 67, 70, 71, 92, 95, 100, 103, 110, 111, 117, 118, 127-129

Content analysis (Krippendorff, 2004) was conducted on all items in the questionnaire, excluding the ten demographic items. As the responses for the closed-ended items were structured according to the categories of the scale for each item, formulation of codes was generally straight-forward. Codes for open-ended items were extracted based on their content. For each item, the responses or codes from each participant were compared back to the mapped category as outlined by Aminzadeh et al. (2012) to determine fit of the response. If a response did not fit within the category and aim of the question, this was noted. The responses were also compared between participants to determine the amount of variability with answers. An item with several participants responding outside the aim of the question was considered as a potential issue with the question.

**4.2.1 Closed-ended questions.** Closed-ended questions/items were defined as those questions with a response along a scale or as a singular word response (yes, no, sometimes, etc) (Loiselle & Profetto-McGrath, 2011). Of the 105 closed-ended items in the questionnaire, 41 items had a suggested response along a Likert scale which was provided to the participants and 64 items had a suggested response of a singular word response.

**4.2.1.1 Scaled questions.** Evidence for validity of scaled questions was supported if the respondents answered the question along the scale provided to them, in the form of a Likert scale. Responses for each item were organized in Microsoft Excel spreadsheets for ease of comparison and responses were compared to the scaled options provided. Table 3 shows an example of an analysis for a scaled question, item 61. All participants answered the question along the scale provided, supporting evidence for validity of this item.

**Table 3 – Content Analysis for Item 61**

Question 16 [Item 61] Thinking specifically about the assessment phase, as a whole, my primary healthcare team effectively assesses patients with suspected dementia? On a scale of strongly agree, agree, neutral, disagree, and strongly disagree		
Interview #	Response:	Code
1	Neutral	Neutral
2	Disagree	Disagree
3	Agree	Agree
4	Neutral	Neutral
5	Agree	Agree
6	Agree	Agree
7	Agree	Agree
8	Agree	Agree
9	Agree	Agree
10	Agree	Agree
11	Agree	Agree
12	Agree	Agree

There was evidence for validity of 21 of the 41 scaled questions, as all twelve respondents were able to answer the question along the scale (See Table 3). Four items (13, 17, 64, and 67) had some respondents answering ‘Unsure’ as opposed to the scaled response as the question did not pertain to their role on the team. This is still considered a valid response and as

the remainder of respondents answered the question along the scale, support for evidence of validity of that item is provided.

**Table 4 – Evidence for Validity of 41 Scaled Questions**

Underline items: those items with support for evidence of validity

Items with responses along the provided scale <i>n</i> =25	Items with multiple selections <i>n</i> =5	Items with responses related to a scaled item <i>n</i> =7	Items with varied responses <i>n</i> =4
<u>11-15</u> , <u>17</u> , <u>19</u> , <u>61</u> , <u>64</u> , <u>67</u> , <u>68</u> , <u>74-83</u> , <u>85</u> , <u>88</u> , <u>119</u> , and <u>126</u>	<u>20</u> , <u>21</u> , <u>72</u> , <u>84</u> , and <u>91</u>	<u>86</u> , <u>87</u> , <u>89</u> , <u>114</u> , <u>120</u> , <u>122</u> , and <u>124</u>	<u>16</u> , <u>62</u> , <u>69</u> , and <u>115</u>

Five of the scaled items resulted in respondents making multiple selections along the scale (See Table 3), suggesting respondents were unable to choose one response along the scale (e.g.,- *strongly agree*, *agree*, *neutral*, *disagree*, *strongly disagree*). These participants felt one choice did not adequately meet their response to the question or felt their answer fell between two choices. In item 20, one respondent (OTk) wanted a choice between *strongly agree* and *agree*. In item 21, one respondent (RNf) wanted a choice between *agree* and *neutral*. In item 72, one respondent (NPa) wanted a choice between *neutral* and *agree*. In item 84, one respondent (NPd) wanted a choice between *often* and *occasionally*. In item 91, one respondent (OTe) wanted to select both choice A and C. As all of these items represented only one respondent out of twelve having difficulty choosing a response and the respondents varied across disciplines, no inherent issue is perceived with these questions. Therefore, evidence for validity of these items was supported based on participant responses.

Seven of the scaled items resulted in an answer from respondents that did not fall along the provided scale but was still related to a scale item (See Table 3). In item 86, one respondent (RNc) was unsure and did not provide a response and one respondent (RNh) answered ‘yes’ as opposed to choosing along the scale of *strongly agree* to *strongly disagree*. This response likely coincides with a response of *strongly agree* or *somewhat agree* and the interviewer failed to prompt the respondent to choose along the scale, which may have negated a response not along the scale. Item 87 resulted in responses such as “it does” (RNf), “yes” (NPg), and “I’m not sure it gives me more information that the Functional Activities Questionnaire” (FPI), which may be

linked to the scale but a definitive choice was not made. In item 89, one respondent (RNf) responded 'It does' as opposed to selecting along the scale of strongly agree to strongly disagree.

In item 114, one respondent (OTi) was unsure if case discussion meetings are held for each patient and two respondents (RNh, FPI) responded with "not each" and "case by case" respectively, versus selecting along the scale. It is noted for both of these respondents, the question was not asked as written and the choices were not provided to the respondents representing an error by the interviewer. In item 120, one respondent (NPg) responded "occasionally" which is not a provided response on the scale. This could be because the respondent felt the options provided did not fit with their answer or could have been confusion as it relates to the choices available or the respondent may have thought "occasionally" was an option. The interviewer did not correct the respondent's choice and therefore it is unknown the reason "occasionally" was stated. In item 122, three of four respondents (NPd, NPg, FPj) stated 'no' instead of selecting a response along the scale. This wording could be interpreted as a response of *never*, which is a choice along the scale but this was not confirmed by the interviewer. Item 124 had the same issue with two of four respondents (NPg, FPj) stating "no" versus selecting *never* on the scale.

In the case of items 86, 89, and 120, the majority of participants were still able to answer the question along the scale; therefore providing support for evidence of validity of these items. Items 87 and 114 did not meet the rule of thumb of ten participants answering as suggested. Responses to items 122 and 124 do represent a majority of participants having difficulty answering along the scale, (although only a small number of respondents participated in these items). However, as the answers from the respondents can be linked clearly to one of the responses and the interviewer failed to confirm their choice along the scale, there is no suggestion of a lack of evidence for validity.

The remaining scaled items had varying responses from participants which were not related to the given scale. In item 16, one respondent (OTe) was unable to answer the question from the team perspective as they were only aware of their personal practice and one respondent (NPg) was unable to answer the question as she felt the wording of *guidelines* was too ambiguous and was unsure if this referred to team specific guidelines or national guidelines. This item meets the rule of thumb of ten participants answering as suggested and supports evidence for validity of this item. In item 62, one respondent (OTe) chose two answers along the scale

(*frequently to always*), suggesting she felt the scaled options were inadequate for their answer. The main concerns with item 62 presented themselves when compared with the answers of item 63. Only eight of twelve respondents were able to select an answer along the scale, which also coordinated with their answer in item 63. Two respondents (RNf, RNh) chose patients were “frequently” informed of their diagnosis, but when asked in item 63 to comment on the circumstances when patients are not informed, the respondents were unable to provide an example. Two respondents (NPd, NPg) stated patients were “always” informed of their diagnosis, but were able to offer examples of when patients were not informed. If looking simply at the responses of item 62, the question does provide evidence for validity with only one respondent not answering along the scale. However, when taken as a pairing with item 63, there appears to be issues with this item.

In item 69, eight respondents were able to provide an answer along the scale. One respondent (RNh) was unsure and did not respond. Two respondents (RNb, OTe) selected a choice along the scale but included with their response that they actually were unsure. One respondent (RNf) made a choice along the scale, but when prompted for more information, revealed she was actually unsure. A response of unsure is considered a valid response to the scale, so therefore this item does provide support for evidence of validity. However, the fact the respondents still arbitrarily chose a response along the scale shows there may be some level of guessing with responses. Item 115 demonstrated several issues with respondent’s answers, with only four respondents able to answer along the scale and two respondents unsure. Four respondents answered the question with a *yes/no* (NPa, RNf, RNh, FPj), one respondent chose two answers (RNC), and one respondent answered “Not that I know of” (OTe). The issues with responses to this item were identified prior to data analysis and following interview twelve, the scale was eliminated from the question and replaced with a straightforward *yes/no*.

One issue noted during data analysis was the variability of wording of the scales throughout the questionnaire. The most frequently worded opinion scale throughout the questionnaire is the 5-point opinion scale of *Strongly Agree, Agree, Neutral, Disagree, or Strongly Disagree*, which is used in several question (e.g. item 11, 61, 119). However, question 28 uses a different 4-point opinion scale of *Disagree, Somewhat Disagree, Somewhat Agree or Agree*. This discrepancy was pointed out by the graduate student to the RaDAR team following interview #6, however the decision was made to remain with the language already created.

Further variability was noted with the wording of frequency scales throughout the questionnaire. These questions aimed to determine how frequently different practices occurred. Items in questions 13 and 30 use a 4-point scale of *Always*, *Occasionally*, *Rarely* or *Never*; item 62 uses a 5-point scale of *Always*, *Frequently*, *Sometimes*, *Rarely*, or *Never*; question 28 uses a 4-point scale of *Never*, *Rarely*, *Occasionally*, or *Often*; item 114 uses a 5-point scale of *Never*, *Rarely*, *Occasionally*, *Generally*, or *Often*; and question 38 uses a 4-point scale of *Never*, *Sometimes*, *Often*, or *Always*. This variability in wording may be a factor in consistency of participant responses.

**4.2.1.2 Singular word response questions.** Evidence for validity of closed-ended items with a singular word response was provided if the participant’s answer fit within the suggested response of the question and was often characterized by a response of *yes* or *no*. *Unsure* is also categorized as a valid response to these items if the question did not fit within the role of the healthcare provider. Responses for each item were organized in Microsoft Excel spreadsheets for ease of comparison and responses were compared to the suggested response provided. Table 5 shows an example of an analysis for a singular word response question, item 134. Eleven participants answered the question as suggested with a response of *yes* or *no*. OTk answered the question with an open-ended response. As the rule of thumb was met with eleven participants answering as suggested, support for evidence of validity of this item was provided.

**Table 5 – Content Analysis for Item 134**

Question 42 [Item 134] I will read a list of functions with respect to dementia care. As I read this list, please tell me if you consider these functions to be part of your role: Diagnosis		
Interview #	Response: ‘Diagnosis is part of my role’:	Code
1	Yes	Yes
2	No	No
3	No	No
4	Yes	Yes
5	No	No
6	No	No
7	Yes	Yes
8	No	No
9	No	No
10	Yes	Yes
11	Informally yes	Open-ended response
12	Yes	Yes



Sixty-four of the items were classified in this category during data analysis. Twelve of these items showed evidence for validity based on participant responses (See Table 6).

**Table 6 – Evidence for Validity of 64 Singular Word Response Questions**

Underline items: those items with support for evidence of validity

Items with responses as suggested <i>n</i> =12	Items with format changes after interview #11 <i>n</i> =46	Items with interviewer error <i>n</i> =2	Items with varied responses <i>n</i> =4
<u>90</u> , <u>121</u> , <u>123</u> , <u>125</u> , <u>130</u> , <u>131</u> , <u>133</u> , <u>134</u> , <u>137</u> , <u>138</u> , <u>140</u> , and <u>142</u>	24-27, 30, 33-48, 50-56, and 92-109	18 and 116	73, 132, 135, and 136

Questions 13 and 30 initially constituted a large majority of questions with a singular word response as suggested answers (See Table 4). However, after interview #11, these questions were changed to elicit a response along a scale of *always*, *occasionally*, *rarely*, or *never*. This change was made in the hope it would elicit more information from participants and was not based on the results of an individual interview, but rather the collective. As only one respondent (FPI) completed the questionnaire along this scale, conclusions cannot be drawn as to whether this change caused an improvement in consistency of responses. Content analysis of all items was conducted; however, given the change in the response structure near the end of pretest, it is inconclusive whether there is evidence for validity of these items. The majority of these items had few issues with respondent answers. Items 47, 50, 104, and 105 demonstrated repeated issues with the interviewer not asking these items. This potentially could be related to the layout of the questionnaire.

Within questions 13 and 30, notable issues were noted with items 33-42, 48, 102, and 108. Items 33-42 deal with referring patients for bloodwork. The question as originally worded asks if patients are *referred for comprehensive bloodwork* and then goes on to list several individual blood tests. This caused confusion with respondents of whether they were to answer the original root question and/or the corresponding list. These items had variability with how they were asked as well by the interviewer, with not all blood tests being listed. Respondents had difficulty with item 48 as only specialists are able to refer patients for MRI or CT scan and resulted in various responses. In item 102 and 108, the majority of respondents were able to answer the question, however several respondents added “only if the services are available”. As

the major issues with all of the above items is related to wording of the items, re-wording these items may be required for better understanding.

Two singular word response items were unable to show evidence for validity due to insufficient responses and how they were asked. Item 18 was added after interview #11, but due to interviewer error, the question was not answered. Item 116 was only applicable to three respondents. One respondent was able to answer as suggested (NPg), one respondent was unsure (OTk), and one respondent answered with an explanation of where the flow sheets were located with no linkage to the root question of the electronic medical record (EMR) (RNb). As this question was applicable to so few respondents, it is difficult to draw conclusions about the evidence of validity of this item. Also of note, this item is linked to the response of item 115, which was changed after interview #12 due to inconsistencies with responses.

Two singular word responses items had varying responses. Eleven of twelve respondents answered item 134 as suggested with a *yes* or *no*. One respondent (OTk) stated “not diagnosis per se, but informally yes” implying yes, they have a role in diagnosis, but not formally. This may imply the wording of *Diagnosis* is ambiguous, however this respondent was the only one who answered this way. Item 137 had two of twelve respondents not answer with a *yes* or *no* but instead answering with “regular by not necessarily pro-active” (NPg) and “not always” (FPj). This suggests NPg had difficulty with the wording of *Pro-active* and FPj wanted a choice between yes and no. As the majority of respondents to these items were able to answer the questions as suggested, there is support for evidence of validity of these items.

Four singular word response items demonstrated considerable variability of responses, suggesting potential issues with the questions. In item 73, seven of twelve respondents answered the question with *yes* or *no*. The remaining respondents (NPa, RNb, RNC, RNh, OTk, FPI) gave varying responses. The wording of the question appears to be problematic. The question asks if respondents are *aware of clinical practice guidelines....* Respondents would state they are in fact aware of guidelines but did not know of any specific guidelines. Examining the original aim of the question, being awareness, then eleven of twelve respondents were able to answer the question. However, when coupled with respondent’s further remarks, they were unsure of what these guidelines consisted of or where to find them. This implies the wording of this item is problematic. Seven of twelve respondents were able to answer item 132 with a “yes” or “no” response. The remaining five respondents (NPa, NPd, RNC, RNf, OTk) all had difficulty with the

wording of the question *Case finding and screening* as they were unsure what case finding implied or stated they would only screen patients. Nine of twelve respondents answered item 135 with a *yes* or *no* as suggested. Two respondents (RNc, OTi) answered with “somewhat” and one respondent (NPd) answered with “to some degree”, suggesting these respondents needed a choice other than “yes” and “no”. Four respondents also had difficulty with item 136 with one respondent stating they only manage the care plan and do not implement (NPg) and three respondents (NPd, OTi, FPj) answering between *yes* and *no*, suggesting a further option is needed for this item or different wording of the item. These three items represent potential areas for improvement within the questionnaire.

**4.2.2 Open-ended questions.** Open-ended questions were defined as those items with limitless potential responses from participants (Loiselle & Profetto-McGrath, 2011). A response of “unsure” was considered a valid response if it related to the participant’s practice and not to the wording or structure of the question. Twenty-seven items within the questionnaire were categorized as open-ended questions.

Content analysis was used to extract data from the individual items. Responses from each participant were inserted within the Excel spreadsheet and key words and phrases (i.e., meaning units) were extracted from the responses. These meaning units were broken into two to three word codes to represent their meaning for the participant’s response. Each item had previously been mapped to one of eight categories to determine what the aim of the question was, for example if it was attempting to elicit information on ‘Multidisciplinary team’. The codes were then compared back to the original aim of the question based on the category to determine their fit. If the code fit within the original aim of the question, support for evidence of validity of that individual item was provided. Table 7 represents an example of content analysis conducted for an open-ended question, item 117. This item was mapped to the category ‘Dementia Care Continuum’ and aimed to gather information on challenges in the management phase of the continuum. Fit was determined if the participant responded with a challenge related to management of dementia. All participant response’s codes fit within the aim and mapped category for the question, providing support for evidence of validity of this item.

**Table 7 – Content Analysis for Item 117**

<p>Question 36 [Item 117] Thinking about the management phase, what are the top 2-3 challenges faced by your PHC team?</p>
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Interview #	Response: 'Top challenges are':	Code
1	Access to resources and not using flow sheets or consistent practice guidelines	Access to resources Use of clinical practice guidelines (CPGs)
2	Lack of consistency within the team and not communicating	Inconsistent practice Communication
3	Incorporating clinical practice guidelines	Use of CPGs
4	Patient denial, distance to specialists, lack of drugs for the condition, dealing with behavioural problems, keeping people in their homes	Patient denial Access to specialists Lack of treatment options Patient safety
5	Inconsistent access to information, rural area, and access to services	Access to resources Proximity
6	Access to patient and family support, such as respite	Access to resources
7	Lack of community resources and inconsistent approach to care	Access to resources Inconsistent practice
8	Patient resistance to care/confusion, and speed of referrals for Aricept coverage	Patient denial Speed of referral
9	Keeping patient safe in their home	Patient safety
10	Patients coming in for follow-up appointment	Proximity
11	Transitioning declining patients	Patient safety
12	Other staff availability, distance and stigma	Access to specialists Proximity Stigma

Fourteen items provided support for evidence of validity as all respondents were able to provide a response within the aim of the question (See Table 8). As noted above, when looking at the response of item 63 alone, all respondents were able to provide evidence of why patients are not informed about their diagnosis based on the codes extracted from content analysis (i.e., *disease progression, family request, or is always conveyed*) but when coupled with responses in

item 62, the responses do not fit together. This represents a potential issue with item 62; however data for item 63 provides support for evidence of validity.

**Table 8 – Evidence for Validity of 27 Open-Ended Questions**

Underline items: those items with support for evidence of validity

Items with responses within question aim <i>n</i> =14	Items with interviewer error <i>n</i> =7	Items with varied responses <i>n</i> =6
<u>22</u> , <u>28</u> , <u>49</u> , <u>58-60</u> , <u>63</u> , <u>65</u> , <u>70</u> , <u>71</u> , <u>110</u> , <u>112</u> , <u>113</u> , and <u>117</u>	29, 31, 32, 57, 111, <u>128</u> , and 129	<u>23</u> , <u>66</u> , <u>118</u> , <u>127</u> , 139, and 141

Seven items had issues with the question not being asked due to interviewer error. Item 29 was not asked of three respondents (RNb, RNC, RNh), item 31 was not asked of three respondents (NPg, OTi, FPI), item 32 was not asked of five respondents (RNb, RNf, NPd, NPg, OTi), item 57 was not asked of four respondents (RNf, RNh, OTi, FPj), item 111 was not asked of four respondents (RNh, OTi, FPj, FPI), item 128 was not asked of two respondents (NPa, FPI), and item 129 was not asked of three respondents (RNb, NPg, OTi). Items 29, 31 and 32 are all sub-questions of a root question and may not have been asked due to the layout of the questionnaire. Item 57 and 111 also may not have been asked due to the layout of the questionnaire. Items 128 and 129 are both related to driving and may not have been asked based on the response the participants gave to the question preceding, where the participants stated they did not ask about driving. However, items 128 and 129 are not dependent on the response of the proceeding question and were an error on the part of the interviewer. This appears to have misled the interviewer and resulted in the questions not being asked. All other respondents for the above items were able to answer the questions as suggested. Item 128 maintained the rule of thumb of ten participants answering within the mapped category, maintaining support for evidence of validity of that item. The remaining items did not meet the rule of thumb, but as the issues were due to interviewer error, it is not conclusive the above items provide support for evidence of validity due to incomplete results. From the remaining responses it appears there are no issues with these items.

In item 23, eleven of twelve respondents were able to provide evidence of how they communicated patient changes in cognition with the rest of the team (electronically, meetings, referral, or privately). One respondent (FPj) provided a response which did not fit within the aim

of the question: “Clinic visit and also coming along to the visit with patient”. In item 66, eleven of twelve respondents were able to provide evidence of how patients diagnoses’ were communicated with the rest of the team (unsure, electronically, verbally, or a letter). One respondent’s answer (RNh) did not fit the aim of the question. In item 118, eleven of twelve respondents were able to provided evidence of team strengths during the management phase. One respondent (OTe) was unable to answer the question with a strength and instead answered with more challenges in the management phase. In item 127, nine of ten respondents were able to provide evidence of the circumstances they ask patients about driving. One respondent’s answer (NPa) did not fit the aim of the question. As the majority of respondents for these items were able to answer the question as suggested, there is support for evidence of validity of these items.

Item 139 was added after interview #10 and was therefore only asked of two respondents. Although both respondents were able to answer the question within the mapped category, two respondents is an insufficient number to provide support of evidence for validity of this item and further testing is required. In item 141, eight of ten respondents were able to provide evidence of the type of dementia education they have received, however only five of the respondents were able to provide evidence of the timing of this education. Due to the inability of many respondents unable to answer this question, there is a lack of evidence for validity item 141. Modifying this item to a scaled response may improve respondent answers. Overall, respondents had very few issues answering open-ended questions in the questionnaire and were able to consistently show support for evidence of validity of these items.

## 5 CHAPTER FIVE – DISCUSSION

This project sought to determine the feasibility and acceptability of a questionnaire assessing healthcare provider's perceptions of dementia care in rural settings and to determine whether there is adequate evidence for validity of the questionnaire for future use. The questionnaire's aim is to identify strengths and gaps in primary dementia care in rural settings and is structured to reflect the seven key strategies outlined by Aminzadeh et al. (2012) for comprehensive, integrated primary healthcare and the RaDAR program framework for continuity of care for persons with dementia and their families. A pretest was conducted and it showed that the questionnaire was feasible, acceptable, and had adequate evidence for validity. Based on the changes made throughout the interview process, the RaDAR team concluded the questionnaire was ready for use as a structured interview in the larger study.

The following will be a discussion of the construction of the questionnaire, including feasibility and acceptability. Sources of evidence for validity will follow, focusing on instrument content, response process, and consequences. After this, a discussion of limitations will be provided and finish with a conclusion.

### 5.1 Construction of the Questionnaire

An important component of the pretest was to determine if the questionnaire's form and content (i.e., construction) was feasible and acceptable to participants. At the outset of the study, all of the questions included in the questionnaire were viewed as purposeful and necessary by the RaDAR team to accurately provide a picture of current dementia care in rural settings. This resulted in a lengthy questionnaire and there was concern of whether this would be feasible to administer and acceptable to participants. Data for supporting feasibility and acceptability of the questionnaire were collected by means of participant feedback, notations and analyses by the research team and graduate student, and the time required to complete the questionnaire. Based on the results obtained through ten iterations of the questionnaire, consensus was reached the questionnaire was most likely feasible and acceptable in its final form (see Appendix D).

**5.1.1 Feasibility.** Parameters to determine feasibility of the questionnaire included the time required to complete the questionnaire, the format for administering the questionnaire and whether participants received the questionnaire in advance of the interview. Providing the questionnaire in advance to select participants was a specific feature of the pretest study design and was not intended for the full study.

The length of the questionnaire was a concern prior to beginning the interviews, as the RaDAR team worried the amount of questions in the questionnaire may take too long to complete in an interview format and participants would fatigue prior to completing. Chin et al. (2014) identified length as a challenge during a pilot test of a new questionnaire. Determining length of the questionnaire is important prior to implementing as it helps to determine what resources are required and the amount of data to be collected (Sheatsely, 1983). Gillham (2000) states that four to six pages of questions is usually the maximum length most participants are able to work with (depending on layout). The questionnaire hovered around ten pages in length throughout the interview process and therefore length remains a concern. A few respondents did comment the questionnaire was 'long' but all interviews were completed in one interview and no one asked to stop the interview due to length.

The matter of whether the questionnaire remains too long is still a topic for discussion. A longer questionnaire requires more resources and time required to complete and may be a deterrent to participation by respondents. Sheatsley (1983) noted that a lengthy questionnaire is acceptable as long as all the content within is useful and serves a purpose in data analysis. Deleting erroneous questions is one method to shorten the length and this did happen through the interview process (See Appendix D, questions 39 and 43); but it could be looked at in more detail following the pretest. If in subsequent studies using the questionnaire resources become a limiting factor, the length of the questionnaire may need to be re-examined. For the purposes of this pretest and the subsequent larger study to follow, the length was supported to be feasible.

The format chosen to administer the questionnaire for the pretest was via telephone interview. The RaDAR team also considered face-to-face interview formats as a potential option. Face-to-face interviewing is generally more appropriate for long, complex questionnaires, such as the one being tested, but telephone interviews are more resource-friendly and easier to administer, particularly to rural and remote participants (Singleton & Straits, 2002). Bradburn and Sudman (1979) examined multiple forms of administering questionnaires, including face-to-face, telephone, and self-administered and found telephone interviews generally have better completion rates than face-to-face interviewing, potentially due to accessibility. Da Silva et al. (2014) in a randomized-control trial comparing face-to-face interviewing and telephone interviewing found no difference in outcomes or results between the two methods and concluded both were satisfactory for collecting data. Face-to-face interviews present logistical and resource



challenges not faced by telephone interviews, such as travel time to the determined meeting place and selecting a suitable location. Delivering questionnaires over the telephone also has the added advantage of interviewer uniformity between participants and reduced interviewer effects (Shuy, 2002). This is a potential benefit with this questionnaire if a less-experienced interviewer is administering the interview. A drawback in comparison is participant responses are generally improved with face-to-face interviews as research has shown participants provide more information to open-ended questions and give more thoughtful responses in-person (Shuy, 2002). Although this remains a concern with the questionnaire, the majority (105/142 items) were closed-ended questions and therefore the chosen route of administration will have less of an effect.

Another option for administration is via mail or email. One participant (FPI) suggested providing the questionnaire via mail or internet, as he suggested it would be easier to complete, especially with the amount of scaled questions. Internet surveys are considered more resource-friendly than other methods and are useful for displaying and organizing complex material (Couper & Bosnjak, 2010). The potential drawback with this method is mailed or internet surveys have decreased response rates as compared to the questionnaire being administered as an interview (Oppenheim, 1992) and internet surveys have been shown to have even lower response rates than mailed surveys (Couper & Bosnjak, 2010). In mail and internet surveys, it is not possible to understand a non-response from a participant and it can be difficult to obtain a representative sample (Couper & Bosnjak, 2010). Administering the questionnaire via interview also gives the advantage of explaining fully the intention of the questionnaire, which is not possible via mail or internet (Oppenheim, 1992). The inclusion of qualitative based questions in the survey was purposeful to gather rich data which otherwise cannot be collected from a scaled question. Administration of these open-ended questions in a self-administered format may not yield the same depth of information which can be obtained through an interview. Based on the literature and the results of the study, the chosen method of administration via telephone interview was the most feasible choice.

The final point of interest in the study related to feasibility was whether participants received the questionnaire in advance of the interview or not. The literature is scant in terms of outcomes on questionnaire results if the participant has the questionnaire in front of them during an interview. Due to the dearth of literature, the outcome measure for the study became

differences in time needed to complete the interview between those who received the questionnaire and those who did not and participant comments. There was no marked difference between length of the interview between those who received the questionnaire and those who did not, and participants did not exhibit increased difficulty with completing the questionnaire when it was not provided to them. This crude analysis, coupled with the logistics of providing the questionnaire ahead of time, was sufficient indication to the research team that providing the questionnaire in advance was not necessary. It is important to note as well that participants were not asked directly about the feasibility of the questionnaire and it was only through their personal comments their feedback on feasibility was ascertained. Information regarding support for feasibility was largely gathered from the graduate student and RaDAR team notations and analysis.

**5.1.2 Acceptability.** Acceptability of the questionnaire was defined by the concepts of relevancy, applicability, flow, sensibility, and understandability. Determining support for acceptability of a questionnaire is best conducted during a pretest. Chin et al. (2014) tested similar concepts during a pilot study of a new questionnaire to ensure readiness in future studies.

Relevancy and applicability shared common characteristics and were considered to determine if the questionnaire content was relevant to those working on a primary healthcare team and were applicable to individual professions. A concern prior to beginning the pretest was whether there should be different questionnaires for the different professions of the primary healthcare team. It was expected some members would have difficulty with questions that do not pertain to their role. For example, diagnosis of dementia is not in the scope of practice for registered nurses and occupational therapists, therefore these participants may have issues with questions pertaining to diagnosis. Conversely, all professions provided assessments which contribute to a diagnosis, and therefore relevance and applicability are not absolute concepts between professions. For simplicity, the RaDAR team decided to use only one questionnaire for all participants. The choice to use one questionnaire versus using different questionnaires for each profession was not a focus of this pretest but remains a potential point of discussion and consideration for future studies. The decision to use different questionnaires would rest on determining if richer data would be gathered from this approach and it remains to be seen if this would be the case. There is value from knowing what knowledge each profession has on the continuum of care for planning interventions to improve care and even a participant having a

lack of knowledge in a particular area is still useful information. It would, however, be possible to gain more in-depth data on each profession if different questionnaires were used and it may improve the applicability of questions.

Ensuring flow of the questionnaire was important during the pretest to gain the most accurate data and increase the acceptability of the questionnaire for participants. Structuring the questionnaire along the continuum of care was a useful strategy to ensure flow of the questionnaire, as it provided a framework for grouping questions. Identifying a thoughtful ordering of questions is beneficial and it has been found participants respond better when questions are grouped appropriately (Sheatsley, 1983). Deleting onerous questions is another strategy to improve flow and was utilized throughout the interview process based on notations by the RaDAR team. This was important as each question in the questionnaire should be there with a purpose, and if it is determined a question no longer has meaning or use for the research study, it is important they are eliminated (Oppenheim, 1992).

Generally, there were few issues with the sensibility and understandability of the questions during the pretest. Issues were identified by the RaDAR team and some word changes and structuring of questions was altered. It is suggested questions should have less than twenty-five words to increase understandability and short questions produce better data than long questions, especially when delivered in an interview format (Sheatsley, 1983). This is simply related to a person's ability to remember a question and keeping participant's attention (Sheatsley, 1983). Most of the items in the questionnaire have succinct wording and intention, but there are some questions with lengthy explanations (i.e., question 28 in Appendix D) and participants did comment on the difficulty with remembering, however the quality of data from these questions did not seem to be affected.

Data analysis revealed a potential problem with wording of the scaled questions. Wording of questions is incredibly important, as the meaning of a word is different to each person and can impact a participant's response (Bradburn & Sudman, 1979). The largest majority of questions which showed variability with responses were the scaled items, with 16 of 41 items resulting in varied responses away from the suggested response of the question by participants. Bradburn and Sudman (1979) found using different descriptive words in front of scaled response questions results in changing the outcome of the participant's response. The

effect remained small, but was still significant (Bradburn & Sudman, 1979) and points to the importance of wording in a scaled question.

The amount of variability in wording of scales could potentially lead to confusion among participants and may partly explain why participants had difficulties with some questions, such as items 16, 62, and 69. Five-point scales are the most common choice for questionnaires, as participants generally respond better and have less trouble with five choices, and is easier for researchers when conducting sub-group analyses (Sheatsley, 1983). Also, going beyond five choices is difficult to organize appropriate descriptors and participants generally do not respond well to more than five choices (Sheatsley, 1983). Research has been conducted to determine what categories and wording are most effective for scaled responses. For opinion questions, *strongly-agree* to *strongly-disagree* is considered a highly useful and well understood scale (Sheatsley, 1983). For frequency scales, Sheatsley (1983) recommends either *Regularly, Often, Seldom, or Never* and *Always, Most of the Time, Some of the Time, Rarely, or Never*. Based on this, the wording of the frequency scales throughout the questionnaire is appropriate, but the variation between using both terminologies throughout the questionnaire may be confusing to participants and selecting one scale throughout may be a beneficial revision to the questionnaire. The pretest uncovered the variability in wording of scales and this may explain why participants struggled to answer scaled questions as expected (i.e., along the scale).

Overall, the construction of the questionnaire was viewed favorably by participants and no major issues were identified during the pretest. Issues that were identified were remedied during the iterative process. Therefore, the questionnaire was able to show support for feasibility and acceptability during the pretest.

## **5.2 Evidence for Validity**

Data analysis was conducted on a total of 132 items in the questionnaire, based on the final iteration of the questionnaire after interview #12. Of the 132 items, 56 provided support for evidence of validity, as respondents were able to answer based on the scale provided or answered within the aim of the question. There were 46 items that changed from a singular-word response to a scaled response after interview #11 and therefore insufficient data were available to determine if this change was beneficial for improving evidence for validity. The remaining 30 items had various issues discovered through data analysis, with recommendations for change provided.

The questionnaire was structured to reflect the seven key strategies outlined by Aminzadeh et al. (2012) for optimal primary dementia care and the RaDAR program framework for continuity of care. This structure was selected to elicit strengths and gaps in rural primary dementia care and formed the basis for identifying evidence for validity of the questionnaire items. Each item in the questionnaire was mapped to the seven key strategies of Aminzadeh et al. (2012) and an eighth additional category to reflect the questions representative of the RaDAR program framework. Responses to individual items were meant to meet the aim of these eight categories and evidence for validity was supported if the participant responses reflected the category represented in the item. The addition of expert input during the interview process provided further corroboration of the findings.

Each item in the questionnaire was independently analyzed to determine if there was sufficient evidence for validity of the questionnaire. The AERA and NCME (1999) outline a framework of five sources of evidence available to support validity of an instrument's inferences: (a) test content, (b) response process, (c) internal structure, (d) relations to other variables, and (e) consequences. The AERA and NCME (1999) stress professional judgement is the best guide for selecting which forms of evidence are used to support validity and a small amount of strong evidence is better than a lot of poor quality evidence. As this study did not employ factor analysis or reliability measurements, internal structure is not applicable as a source of evidence. Also, there is no comparative instrument to the questionnaire and relations to other variables as a source of evidence is not applicable. Therefore, the remaining three sources of evidence (i.e., test content, response process and consequences) are the focus for the pretest to support the instrument's design.

**5.2.1 Instrument content.** The content of an instrument should reflect the construct it is purported to measure and evidence of this is referred to as test content or instrument content (AERA & NCME, 1999). Content evidence is one source of evidence to support an instrument's validity. Issues to consider when determining evidence of instrument content include wording, format of questions, and guidelines for delivering the instrument (AERA & NCME, 1999). A method for evaluating evidence for instrument content is utilizing experts in the field to determine the instrument reflects the construct of interest (AERA & NCME, 1999). The questionnaire was developed by the RaDAR team members who are experts in the field. Evaluation of instrument content should involve a logical and empirical analysis of the

relationship between the content of the instrument and the subject area (AERA & NCME, 1999). This was conducted by mapping questions to Aminzadeh et al. (2012) seven key strategies for comprehensive care for persons with dementia living in a community setting. The responses from questions were then compared to the original strategy and aim of the question for fit. By this strategy, evidence for validity of individual items was supported.

**5.2.1.1 Wording.** Wording of the introduction, instructions, and questions was an important focus of the pretest to ensure dementia care in the community was the focus of the instrument. To provide evidence for validity of an instrument, the wording in the instrument should reflect the construct being tested (AERA & NCME, 1999). In this case it was important wording reflected the perspectives of the participants providing rural dementia care.

One way this was done was by providing a clear introduction of the questionnaire to participants to ensure their focus on the topic content. Changes were made to the wording of the introduction to improve clarity throughout the interview process. The introduction was considered an important part to a well-designed questionnaire, as it introduced the participant to the intentions of the research. The introduction reiterated to participants the purpose of the study, which was to pretest a questionnaire and identify any issues. This is important, as Bowling (2009) stated that participants should be reminded they are involved in a pretest study as they will be more likely to admit if there are issues with the questionnaire wording. Additionally, after interview #3, a new statement was added to the introduction explaining that four professional roles were included in the study and made it clear answering “I don’t know” was an acceptable response. This was partly due to the expectation not all participants would know all the answers to the questions (e.g., diagnosis questions) and also to prevent guessing by the participants if they did not know or have an answer. This was important as Oppenheim (1992) found people were reluctant to admit they do not know the answer to a question and are more likely to guess instead; guessed responses can skew the results of the questionnaire (Burns & Grove, 2005). A guessed response does not provide an accurate picture of dementia care practices and it is more useful to the RaDAR team to know what a team member’s knowledge is regarding the continuum of care.

By improving the wording of the introduction, it increased the likelihood that individual items represented the construct and strengthened the validity of questionnaire content. In

addition to the wording, the format of the questionnaire and delivery as a telephone interview were considerations to enhance validity.

**5.2.1.2 Format.** Format of questions in an instrument refers to how items or questions are structured to adequately reflect the construct (AERA & NCME, 1999). To reflect the construct of dementia care in rural settings, a mixture of structure for questions was the best strategy to get the details of how care was provided and the perspectives of care providers. The questions and items in the questionnaire fell within three categories for structure: scaled questions, closed-ended questions (with a singular word response), and open-ended questions. There were 41 scaled items in the questionnaire, with over half of these being answered with a provided response option by the participants. The remaining items had identified issues with responses. Scaled questions are the most widely used form of questioning in the research community, lending themselves to easy data analysis and comparison (Gillham, 2000). Including this form of questioning in the questionnaire was useful to compare the perspectives of different professions and to measure improvement of care over time.

Scaled questions have several issues associated with them, including never knowing why a participant selected a particular answer (Gillham, 2000). The questionnaire attempted to get around this by including *Explore* as a cue for the interviewer after several scaled questions; however this was deleted from the questionnaire early in the interview process for three reasons. First, due to the concern with the length of the questionnaire; secondly, due to the contradictory nature of combining an open-ended and scaled question; and thirdly the limited interview experience of the graduate student caused confusion of when to use the *Explore* option. If the ‘why’ behind the answer of the question is of greater interest to the RaDAR team for the results, or more information is desired from a question, it is recommended it be changed from a scaled question to an open-ended question.

Open-ended questions had overall good results from the participants, with the majority being answered as within the original aim of the question as it relates to the mapped categories. An issue with open-ended questions was in their delivery by the graduate student, which led to discrepancies between answers (described below in section 5.2.1.3). Although open-ended questions pose the challenge of analyzing, which requires more time, greater skill and knowledge; open-ended questions are particularly beneficial in a questionnaire as it allows the participant to answer somewhat freely and may provide unexpected or unintended information

(Gillham, 2000). This information would be useful in the context of identifying strengths and gaps in dementia care.

**5.2.1.3 Delivery.** When a questionnaire is provided as a structured interview, the delivery of the questionnaire becomes important for the outcome of the results. Guidelines for administering a questionnaire is another source of evidence for validity of test content (AERA & NCME, 1999). Conducting the pretest of the questionnaire was beneficial to identify what issues there may be with delivery by an individual not involved in its development (i.e., the graduate student). The delivery of the questionnaire in the pretest did appear to affect the results of the study in a minor way and this knowledge can be used to improve the guidelines for administration. It was discovered in data analysis that seven items (items 29, 31, 32, 57, 111, 128, 129) had insufficient data due to the graduate student reading or delivering the question incorrectly or differently between participants. One common example of this would be skipping the question accidentally, resulting in only some participants being asked the question. Variability in interviewer questioning is more common with open-ended questions (Sheatsley, 1983), and this was the case in the pretest, with all seven items being open-ended questions. In terms of interviewer error during administration of a questionnaire, Bradburn and Sudman (1979) found reading errors the most common source of interviewer variability followed by a failure to probe. Reading errors include adding or deleting words or rephrasing words (Bradburn & Sudman, 1979). Ideally, the interviewer should be consistent with each participant, read the questions as written and use non-directive probes when necessary (Singleton & Straights, 2002). Providing the above guidelines for subsequent interviewers of the questionnaire will be beneficial to improve results and evidence for validity of the questionnaire.

Reading errors are an example of measurement error with the instrument, and some degree of measurement error is expected when conducting an interview. Decreasing the amount of measurement error is beneficial to ensure the most accurate results from the instrument. Due to the inconsistency in the asking of the items, one potential contributing factor may be the layout of the questionnaire. The graduate student printed off individual copies of the questionnaire for each interview and following revisions, some bulleted items were attached to above items, making them difficult to locate. This may have caused the items to be asked inconsistently. A recommendation for future interviews, particularly if more than one interviewer will be using the questionnaire, is to ensure the questionnaire is ideally formatted for ease of



reading. Inexperience with structured interviewing by the graduate student was also likely a contributing factor. It is worth noting that Bradburn and Sudman (1979) have found in their research that reading errors made by interviewers generally have no effect on the outcome of the quality of the data.

**5.2.1.4 Expert Input.** Another source of evidence to support validity of an instrument is expert input (AERA & NCME, 1999). An expert in the subject area will have knowledge of what information will best represent the content area and can provide feedback on how to best attain it. The questionnaire was created and modified by experts in the field of dementia. This strategy is commonly used and was employed in the pilot study by Chin et al. (2014). Consultation of experts during creation of instrument content is helpful for creating a questionnaire pertinent to participants (Sheatsely, 1983).

Expert input from two RaDAR team members was received during the interview process to determine appropriate fit of questions with content. Accordingly, changes were made to improve the questionnaire based on this feedback. Following each interview, these two experts (who are also members of the thesis committee), reviewed the recorded interviews and notations of the graduate student. Using their expertise, they identified if the questions were providing the expected information about the continuum of care and they suggested changes to better elicit this information. In this way, expert input supported evidence for validity of the instrument content through communication with the graduate student after each interview.

**5.2.1.5 Triangulation.** In this pretest, the opinion of two experts plus the graduate student provided investigator triangulation, which enhanced the trustworthiness of the data and supported the evidence for validity of the instrument. This collaboration added another layer of rigour to the research design. Furthermore, data and methodological triangulation were embedded in the research process to aid in identifying sources of evidence for validity. Triangulation brings together multiple sources of information to support a construct, with data from different sources working together to corroborate or dismiss a finding. Triangulation is not meant to provide validation of an instrument, as absolute validity is unattainable, but to offer an alternative to validation and add rigour and depth to the results (Denzin & Lincoln, 2011). The multiple sources of data used in this research study (i.e., notations, analyses, expert input, participant feedback, and content analysis of transcripts) were all used to determine if there is

adequate evidence for validity that the construct of the instrument is well represented and the instrument provides the data needed.

Methodological triangulation was used in this study to obtain a richer depth of data. Simultaneous and sequential triangulation are approaches to combining quantitative and qualitative research methods (Marcus & Liehr, 1998). Simultaneous triangulation was used in the research design as both quantitative and qualitative data were collected concurrently (Marcus & Liehr, 1998). This approach is not the simple combining of research methods, but using both approaches amplifies the strengths of each. The format of the questionnaire itself, which incorporates both quantitative and qualitative questions, lends itself to being analysed in a pretest using both approaches.

**5.2.2 Response process.** Understanding why a participant answers the question the way they do is imperative for determining the effectiveness of an instrument. Evidence based on response process examines the relationship between a question's aim and the participant's response (AERA & NCME, 1999). Inclusion of guiding questions throughout the questionnaire was a specific strategy of the pretest to collect evidence for validity based on the response process. A pilot study examining a new questionnaire conducted by Chin et al. (2014) similarly used open-ended questions during the pilot to ask participants about their perception of the questionnaire. A more thorough way to gather evidence based on response process is to ask the participant after each question why they responded with that answer. This would provide support for evidence of validity of each question. This was simply not feasible given the length of the questionnaire, the time constraints of participants, and the resources of the pretest. The guiding questions were determined to be a realistic alternative and did provide sufficient validation of the questionnaire content.

The pretest design was also used to support evidence for response process. The interview process was an iterative approach, with the questionnaire design, wording and format changes based on integration of participant, graduate student, and expert comments after each interview. The process following each interview was identical and sequential to maintain continuity of the process. The recording of the telephone interview and related graduate student notations were sent to the RaDAR team members immediately following the interview and team members provided feedback and recommendations to change before the next interview took place. This dynamic approach is beneficial when developing a questionnaire as several iterations and

revisions of a questionnaire are usually required to create a good quality instrument (Singleton & Straits, 2002). This adaptability allowed the questionnaire to change to better fit the intended outcome of identifying strengths and gaps in care, thereby enhancing validity of the questionnaire.

**5.2.3 Consequences.** Evidence based on consequences refers to the unintended results or findings from an instrument (AERA & NCME, 1999). Consequences is a newer addition to the AERA and NCME (1999) sources of evidence and is considered a controversial source of evidence as it lacks a specific relationship with validity (Cook & Beckman, 2006). In the literature it is considered the least reported source of evidence for validity (Cook & Beckman, 2006). An unintended consequence of the questionnaire which was identified prior to the pretest and confirmed during data analysis is the variability in responses from different professions. The results of the questionnaire helped to identify what segments of the continuum of care each profession was most involved with based on their ability to answer the questions. This will be a beneficial outcome of the questionnaire as it will assist in identifying which team members are most involved along the continuum of care and what improvements can be made to improve an inter-professional approach.

In summary, based on the results of the pretest, the questionnaire, in its final form at the end of the twelve interviews and in the chosen method of delivery, is feasible and acceptable to participants. Several sources of evidence for validity were identified in the data analysis phase and based on the evidence identified; the questionnaire is ready for use in a larger study to identify strengths and gaps in dementia care in rural settings.

### **5.3 Strengths and Limitations**

Data collection and analysis strategies revealed strengths in the pretest study design. Multiple sources of data were used in the study to inform the feasibility, acceptability and evidence for validity of the questionnaire. Data sources came from participant comments across four healthcare provider groups, investigator notations, and interview transcripts, which provided triangulation of data. Triangulation of data sources allows multiple methods to build upon their individual strengths, while limiting the inherent weakness of using a single data source (Atkinson & Coffey, 2002). This method is particularly useful in a pretest design to gain the best possible information. Additionally, evaluations of the interviews came from multiple investigator sources, including the graduate student and two members of the RaDAR team who have expertise in

dementia care in rural settings. This process added to the strength of the interpretation of the interviews and contributed to the validity of additional feedback on how to improve the questionnaire. The consensus from team members on the final iteration of the questionnaire was a strength of the study design.

Limitations exist regarding the results of this study. One limitation with the research design is the potential for coder bias during data analysis. The questionnaire was mapped to Aminzadeh et al. (2012) seven key strategies and an eighth category for questions identifying strengths along the continuum of care. The purpose of this mapping was to identify the aim for each question. This was then used in the content analysis to identify evidence for validity of each question, if the participants answered as suggested or within the question's aim. By mapping the questions first, it may have potentially biased the analysis by leading the graduate student to unwittingly code to meet the aim of the question. To mitigate this, mapping could have occurred after content analysis to determine fit, the items could have been coded blindly without associated with the question or, simultaneously coded by a second individual separately and then compared between the two for consensus. This bias may have potentially led to the content analysis favouring the pre-determined categories.

Recruitment proved to be the biggest challenge for the pretest, especially with locating enough physicians for the study. At the outset of the study, 12 participants with three participants from each provider category were determined to be a feasible and sufficient amount. Ideally there would have been balance between the practitioner groups, but we were unable to locate a third physician to participate. Locating the second physician proved to be difficult and stretched the study period from two months to ten months. Recruitment issues also resulted in participants being located in different health regions, which have different processes for managing rural community care. Originally, only the home region of the study was to be utilized for recruitment, but when insufficient participants were located, an additional health region was added. It is unlikely this affected the results of the pretest, but remains a limitation.

Another limitation associated with recruitment was the total number of participants in the pretest. Additional participants would have been beneficial to adequately test all of the changes to the questionnaire made at the end of the pretest. A significant amount of the item's format (46 out of 132) were changed after interview #11 and therefore were perhaps not tested with an adequate number of participants to demonstrate whether the changed format better captured

information on strengths and gaps in dementia care. This represents one-third of the total number of items in the questionnaire not receiving adequate testing. It is unlikely there are substantial issues with these items, as no major issues were identified with the questions prior to the format changing, but when an item within an instrument is changed it should be retested to ensure it is accurate (AERA & NCME, 1999). Due to challenges with finding participants, it would have been too difficult to find more participants and would have stretched the timeframe for the study much longer.

#### **5.4 Implications for Future Research**

At conclusion of this study, consensus was reached among the research team the questionnaire was ready for use in a larger study. However, further testing of the questionnaire could be possible to further examine if it adequately provides information on strengths and gaps in rural dementia care. Future research could seek to use a larger sample size to test the questionnaire versus the purposive sampling of twelve participants as used in this study. Other sources of evidence for validity could be examined in future research. AERA and NCME (1999) outline five sources of evidence and two of these, evidence based on internal structure and evidence based on relation to other variables, were not the focus of this study. Future research could examine these sources. Evidence based on internal structure could group items within sections of the questionnaire and factor analysis could be conducted to examine how items cluster together. Future research could also examine the relationship of responses in the questionnaire against an external source or equal comparator. Data extracted from the questionnaire on strengths and gaps in dementia care could be compared with existing data on community care, such as that collected in other homecare based tools or government measured quality indicators. The challenge would be to find a comparable comparator, either in an existing tool or data set and this would need to be confirmed prior to study commencement.

Alongside these additional evidence for validity sources, a sequential triangulation approach could be utilized in future research. This may involve collecting the quantitative data in the questionnaire and using qualitative questioning with participants to determine why they answered the questions as they did. Multidisciplinary triangulation could also be incorporated into the pretest by involving team members in the research process. Future research could focus on a combination of these strategies to further support evidence for validity of the questionnaire.

## 5.5 Conclusions

Dementia is a dynamic syndrome which affects individuals differently and requires an adaptable healthcare system and workforce to meet those individual's needs. Added to this, individuals living in rural locations have the challenge of distance and limited proximity to necessary health services. Understanding the perspectives of rural healthcare providers regarding dementia care is beneficial for creating adaptable and practical strategies to improve care for those with dementia living in the community. Literature is sparse regarding the perspectives of care providers in rural settings and, what method is optimal for gaining access to this information. Collecting data on how healthcare providers meet the needs of those with dementia along the continuum of care was deemed by experts in the field to be possible via a semi-structured questionnaire provided via interview.

The purpose of this pretest was to determine if a questionnaire assessing healthcare provider's perceptions of rural dementia care was appropriately feasible and acceptable to participants and provided sufficient evidence for validity. The pretest was a beneficial first step for the larger research project, as it provided information on the feasibility and acceptability of the questionnaire, which was unknown prior to the pretest. Additionally, it was unknown prior to this study what data and responses would be yielded from the questionnaire and pretesting provided a basis for that knowledge. Based on the results of the iterative process, consensus was reached the questionnaire is supported to be feasible and acceptable when delivered as a telephone interview to diverse members of the primary healthcare team. Issues with the feasibility and acceptability of the questionnaire were identified in the iterative interview process and were resolved. Sources of evidence to support validity of the questionnaire were identified during the interview process and data analysis. In conclusion, the RaDAR team and graduate student have reached consensus that there was adequate evidence for validity of the questionnaire. Based on this consensus, the questionnaire is ready for use in a larger study to assess strengths and gaps in rural dementia care. Identification of strengths and gaps in rural dementia care using the questionnaire will fill a void in the literature and support better outcomes for patients with dementia living in the community.

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## APPENDIX A- CONSENT FORM

### *Participant Consent Form*

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**Project Title:** Evaluating the feasibility, acceptability, and validity of a questionnaire assessing healthcare provider perceptions of rural dementia care pathways

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**Purpose(s) and Objective(s) of the Research:**

The proposed pilot study will pretest a newly developed questionnaire that assesses healthcare providers' perceptions of dementia care pathways in rural settings. The purpose of the pretest is to determine if the questionnaire is clear, logical, and coherent and obtains the information we are seeking. The aim is for the questionnaire to identify strengths and gaps in current dementia care in rural primary health care teams. Following the pretest, the questionnaires will be used in a larger study conducted by the Rural Dementia Action Research (RaDAR) team (Principal Investigator: Dr. Debra Morgan) in a different rural health region from the pretest.

The objectives of the pretest will be to: (1) examine the feasibility and acceptability of the questionnaire, (2) provide evidence to support validity of the questionnaire and (3) provide recommendations for refinement of the questionnaire to be used in the larger study.

**Procedures:**

The questionnaire will be completed as a one hour audio-recorded interview over the telephone. Initial participants will receive the questionnaire via email prior to the telephone interview. You are not required to read or complete the questionnaire prior to the telephone interview. Providing you with a copy of the questionnaire is to allow you to take note of questions which may be unclear, which will assist with recall during the questionnaire. Later participants will not receive a copy of the questionnaire before the telephone interview, as this will be the process for the larger study and we wish to mimic this process later in the pretest.

The telephone interviews will be completed at a pre-determined time of your choosing and will take approximately one hour to complete. You must have access to your own telephone to complete the interview. The interviews will be audio-recorded.

**Funded by:**

Canadian Institute for Health Research (CIHR)

**Potential Risks:**

Potential risks from participation in the study are minimal but may include discomfort or stress if you feel your current practice is unsatisfactory or lacking in relation to dementia care. Ethics approval has been received from the University of Saskatchewan Research Ethics Board and the Saskatoon Health Region. The proposed study is purely descriptive and not evaluating an individual, employer, or region for current dementia care practices or gaps. The larger study conducted by the RaDAR team will examine current practices for rural dementia care, as this is not fully known. Furthermore, the goal of the study is to improve patient outcomes in dementia care and build upon existing infrastructure.

**Potential Benefits:**

Potential benefits for you include knowing the pretest will lead into a larger study, which will develop interventions and strategies to improve dementia care pathways in rural settings. Therefore, your participation in the pretest will be beneficial for rural dementia care in the province.

**Confidentiality:**

All participant information will remain confidential with the researcher and the RaDAR research team. No name or identifying information will be included in the final manuscript. All of the data will be kept in a locked data file accessible by only the graduate student and the principal investigator of the larger research study, Dr. Debra Morgan.

Data from this research study may be published and presented at conferences; however the data will not have any names or identifying information associated with it. This will make it impossible to identify individuals.

**Storage of Data:**

Data will be stored for a minimum of 5 years at the Canadian Center for Health and Safety in Agriculture under the RaDAR Principal Investigator Dr. Debra Morgan

**Right to Withdraw:**

Your participation is voluntary and you can answer only those questions that you are comfortable with. At any time you have the option to request the audio-recording be turned off.

You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.

Whether you choose to participate or not will have no effect on your position [e.g. employment] or how you will be treated.

Should you wish to withdraw, your data will not be included in the research study

**Questions or Concerns:** (see section 12)

- Contact the researcher(s) using the information at the top of page 1;
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board (BEH 14-474). Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

**Consent**

A copy of this consent form will be provided to you via email prior to the telephone interview. Oral consent will be obtained and audio-recorded at the beginning of the telephone interview. I, the researcher, will sign and date the consent form indicating

“I read and explained this Consent Form to the participant before receiving the participant’s consent, and the participant had knowledge of its contents and appeared to understand it.”

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*Name of Participant*

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*Researcher's Signature*

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*Date*



## **APPENDIX B- OUTLINE AND DESCRIPTION FOR RECRUITMENT PURPOSES**

### **Pretesting an interview guide for a study examining current dementia care pathways, practices, and priorities in rural primary health care**

Student: Kathleen Kulyk (Master of Nursing student, University of Saskatchewan)

Supervisors: Dr. Norma Stewart (College of Nursing), Dr. Shelley Peacock (College of Nursing)

Committee Members: Dr. Debra Morgan (RaDAR Team lead, Canadian Centre for Health & Safety in Agriculture/College of Medicine), Dr. Megan O'Connell (Dept of Psychology).

### **SUMMARY**

The Principal Investigator of this study is Dr. Debra Morgan at the University of Saskatchewan, who has been the Director of the Rural and Remote Memory Clinic at the U of S since 2004. The study interviews will be conducted by Kathleen Kulyk, who is a U of S Master of Nursing student and using this study as her thesis project. The purpose of the study is to pretest an interview guide for a larger project being conducted early next year in Sun Country Health Region. The interviews will focus on current experiences of health care professionals in providing care to individuals with dementia and their families. They would like to interview family physicians, nurse practitioners, occupational therapists, and home care nurses, since these are the professionals identified by Dr. Morgan's dementia care advisory group. Based on findings from this pretest, the interview guide will be revised and refined. The purpose of the larger project in Sun Country is to develop models of primary health care with integrated clinical support tools and education for rural PHC providers using a community-based approach involving local users and local adaptation of recommended best practices.

### **BACKGROUND**

This study is being conducted by Master of Nursing student Kathleen Kulyk. She will be pretesting interview guides for a larger study led by Dr. Debra Morgan and members of the Rural Dementia Action Research (RaDAR) team. The RaDAR team has operated the Rural and Remote Memory Clinic at the University of Saskatchewan since 2004. The interdisciplinary specialist clinic, which began as a research demonstration project and is now supported by the Ministry of Health, provides assessment, diagnosis, and management of atypical, complex cases of suspected dementia. Over the last 10 years the team has worked with decision-maker partners, including health care providers, people with dementia, and families, to identify other priorities for rural dementia care research and collaborate on research to address identified challenges.

A priority identified by the team's research partners is supporting primary health care (PHC) for dementia in rural and remote settings. The team was recently funded by the Canadian Institutes of Health Research as one of 20 teams in the Canadian Consortium on Neurodegeneration in Aging (CCNA). Over the next 5 years the RaDAR team will conduct a program of research, "Issues in Dementia Care in Rural and Indigenous Populations" that will focus on rural PHC. *Although there is considerable evidence about best practices in PHC for dementia, little is known about how these practices can be implemented in rural settings. The RaDAR team will develop models of primary health care with integrated clinical support tools and education for*

*rural PHC providers using a community-based approach involving local users and local adaptation of recommended best practices.*

The first phase of the research is aimed at understanding current dementia care pathways and practices from the perspective of rural PHC team members in one health region (Sun Country). This information on strengths and gaps will be used in the second phase of the research, where the RaDAR team will partner with one PHC team (initially) to develop and evaluate interventions aimed at addressing identified gaps in dementia care, drawing on the PHC team's existing strengths and innovations in management of other chronic diseases. Over time, the research will be scaled up to other PHC teams and health regions.

*To gather baseline data from PHC providers about their current experiences in providing care to individuals with dementia and their families, the RaDAR team has developed a telephone interview guide. Ideally all PHC team members would be included, but to keep the study manageable, the RaDAR team's advisory council recommended doing interviews with family physicians, nurse practitioners, occupational therapists, and home care nurses. For her thesis, Kathleen will pretest the interview guides with PHC providers outside of Sun Country Health Region. This work will ensure that the construction of the interview guide (e.g., format, flow, ease of understanding) is acceptable and appropriate, and that the interviews produce the desired information about current dementia care pathways and practices..*

*Kathleen would like to interview family physicians, nurse practitioners, occupational therapists and home care nurses working with rural PHC teams in Saskatoon Health Region. Participation would involve participation in an approximately one-hour telephone interview, to complete the questionnaire and provide feedback that will be used to improve it.*

### **Physician Recruitment Letter**

Dear \_\_\_\_\_,

We would like to invite you to participate in a research study entitled ***Evaluating the construction and validity of a questionnaire assessing healthcare provider perceptions of rural dementia care pathways.*** We are seeking the interest of three family physicians whose main area of practice is primary healthcare, who monitor patients with dementia and work in the rural area of Saskatoon Health Region. The principal investigator for the study is Dr. Debra Morgan at the University of Saskatchewan, who has been the Director of the Rural and Remote Memory Clinic at the U of S since 2004.

The study interviews will be conducted by Kathleen Kulyk, who is a U of S Master of Nursing student and using this study as her thesis project. The purpose of the study is to pretest an interview guide for a larger project being conducted early next year in a different Saskatchewan Health Region. The interviews will focus on current experiences of health care professionals in providing care to individuals with dementia and their families. We would like to interview family physicians, nurse practitioners, occupational therapists, and home care nurses, since these are the professionals identified by Dr. Morgan's dementia care advisory group. Based on findings from this pretest, the interview guide will be revised and refined. The purpose of the larger project is to develop models of primary health care with integrated clinical support tools

and education for rural PHC providers using a community-based approach involving local users and local adaptation of recommended best practices.

This research study will be conducted by telephone interview and will take approximately 1 hour to complete. The interview topics will focus on your role in assessment, diagnosis, and management of dementia.

If you have questions regarding this study, we would be happy to discuss them with you. Please feel free to contact \_\_\_\_\_.

This study has received ethical approval from the University of Saskatchewan Behavioural Research Ethics Board (BEH 14-474). Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306-966-2084)

***Please note:** You will be offered an honorarium of \$100 to participate in this research study. Family physicians may claim 1 Mainpro-M2 credit for 1 hour of educational activity (such as research participation).*

Sincerely,

## **APPENDIX C- ADDITIONAL GUIDING QUESTIONS FOR THE PRETEST**

### **Additional Interview Guiding Questions for the Pretest- Set One (Interviews 1 - 2)**

- 1.a Were there any particular questions you would like to comment on? Any reason for this?
- 2.a Did any of the questions in the previous section not make sense to you?
- 3.a Were there any particular question that could be improved or modified to make them clearer?

### **Additional Interview Guiding Question for the Pretest- Set Two (Interviews 3 – 4)**

- 1.b Were there any particular questions you would like to comment on? Any reason for this?
- 2.b Did any of the questions in the previous section not make sense to you?
- 3.b Were any questions in the previous section not relevant/applicable to your practice?

### **Additional Interview Guiding Question for the Pretest- Set Two (Interviews 5 – 12)**

The purpose of this interview is to identify how the questionnaire can be improved for future studies. Therefore, we are asking for your feedback on the content of the questionnaire, including but not limited to flow, wording, applicability, clarity, etc. With this in mind:

- 1.c Were there any particular questions you would like to comment on? Any reason for this?
- 2.c Did any of the questions in the previous section not make sense to you?
- 3.c Were any questions in the previous section not relevant/applicable to your practice?

## APPENDIX D- QUESTIONNAIRE

- *Comments that are bolded and bracketed ( ) represent changes made to the questionnaire throughout the interview process*
- *Numbers in { } represent each item in questionnaire used for data analysis*

### Individual Telephone Interview Questionnaire PHC Team

#### Preamble

- Introduction
- The main purpose of the interview is to pretest/pilot a questionnaire which examines strengths and gaps in current rural dementia care
- The main purpose for pretesting the questionnaire is to ensure it makes sense, flows well, and provides information on current dementia care in rural settings. Based on your feedback regarding the questionnaire, it will be refined and used in a larger Saskatchewan based study on rural dementia care. This is why you have been provided a copy of the questionnaire in advance. During the questionnaire you can make note of questions you would like to come back to at certain points in the interview and we can discuss it.
- Is it OK to audio-record? (**Switched this bullet with below bullet after Interview #5**)
- I provided the consent form to you, do you have any questions about the consent form?
- Do you (**Eliminated word ‘continue’ after Interview #6**) consent to participate?
- Do you have the questionnaire with you?
- This questionnaire is being used with all members of the PHC team, including family physicians, nurse practitioners, home care registered nurses and occupational therapists. Therefore, to include all team member’s areas of practice, there are questions on all aspects of care and some specific treatments or managements may not be a regular part of your practice. It is OK if you do not know all of the answers to all of the questions. We are interested in the whole continuum of care and your feedback is valuable to us. (**This bullet added after Interview #3**)
- We are interested in patients who were assessed and diagnosed in the community setting (**This bullet added after Interview #4**).
- Do you have any questions before we get started?

#### Current Position

1. {1} For FPs only: In what year did you receive your license to practise medicine? \_\_\_\_\_
2. {2} For HCPs only: What is your professional background?
  - Registered Nurse
  - Nurse Practitioner
  - Occupational Therapist
  - Social Worker
  - Other (specify): \_\_\_\_\_

3. {3} For HCPs only: What is your highest level of education? (check one box only)
- College diploma (e.g., SIAST, NAIT)
  - Bachelors degree
  - Masters degree
  - Masters degree plus a post-graduate degree (advanced practice nurse, nurse practitioner or RN)
  - Other (please specify):\_\_\_\_\_

{4} In what year did you receive your highest level of education? \_\_\_\_\_ **(Question added after Interview #1)**

4. {5} For HCPs only: What is your position on the PHC team (e.g., Nurse Practitioner, Occupational Therapist, Home Care nurse, or other)? \_\_\_\_\_

5. {6} How many years have you practiced with your current PHC team? \_\_\_\_\_

6. {7} What is your current work setting? **(Question added after Interview #1)**

- Primary care clinic
- Health center (LTC or hospital)
- Home care
- Other (Please specify):\_\_\_\_\_

7. {8} Do you interact on a regular basis with other multidisciplinary team members? **(Question added after Interview #1)**

#### Demographics

8. {9} What is your year of birth? \_\_\_\_\_

9. {10} Gender

- Female
- Male

10. I will list some elements of comprehensive primary health care dementia models. Please indicate whether you strongly agree, agree, are neutral, disagree, or strongly disagree that these elements can be found in your PHC team, specifically regarding patients with dementia:

Element of PHC Dementia models	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1. {11} Multidisciplinary team care for patients with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. {12} Ongoing care management for patients with dementia, coordinated by a nurse or another health care professional (i.e., coordinator works closely with the patient, attending physician, and other health care professionals)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. {13} Access to formal dementia training for health care professionals and other clinic staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. {14} Access to interactive case-based experiential learning about dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. {15} Access to specialists for dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. {16} Use of (Added 'use of' after Interview #7) standard tools, protocols, or guidelines to support consistent care for dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. {17} Access to IT resources (e.g., EMR, decision support tools) (Eliminated word 'for dementia' at end of question after Interview #7) <ul style="list-style-type: none"> <li>{18} Do you personally have access to the EMR? (Bullet question added after Interview #11)</li> </ul>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. {19} Regular patient follow-up to monitor care, for patients with dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. {20} Education for patients or caregivers in collaboration with community agencies such as the Alzheimer Society (e.g., First Link)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. {21} Support for patients with dementia or caregivers in collaboration with community agencies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Assessment (patients living in the community, not LTC)

When answering the following questions, I would like you to think of patients of your PHC team who were first suspected of having dementia. It may be helpful to keep the last few patients in mind for some of these questions.

- {22} How did you first become aware of changes in cognition or behavior in these patients that caused you to suspect dementia (e.g., via patient visits, regular screening, family members, community members, other)?
- {23} When a member of the team first became aware of changes in cognition or behavior that caused them to suspect dementia, how was this information communicated to the rest of the PHC team (if at all)?

13. Now I'm going to ask you some questions about the assessment process that you followed for these patients who were first suspected of having dementia. Please keep in mind that these questions reflect current best practices found in several different publications – so this is a comprehensive listing of ideal best practices and we certainly don't expect that you will be able to perform all of these actions with your patients.

To begin, when the PHC team conducted assessments of patients with suspected dementia, did the assessment always, occasionally, rarely or never involve the following?\*\*\* (**Preceding statement added after Interview #11**)

If the respondent answers 'no' to any of the following 'yes/no' questions, explore the reasons, e.g. "was there a particular reason for that decision?"

- {24} Was a complete medical history conducted? (BCGuidelines, 2014)
- {25} Was a physical exam conducted? (Ngo and Holroyd-Leduc 2014)
- {26} Was collateral information obtained from family and caregivers to assist with assessment (BCGuidelines, 2014), for instance, information on basic activities of daily living and instrumental activities of daily living (Parmar et al. 2014)?
- {27} Was a formal cognitive assessment conducted using a standardized (**Changed from 'validated' to 'standardized' after Interview #11**) test for individuals with suspected cognitive impairment? (Murphy et al. 2014)
  - {28} Explore – which scale was used (e.g., MMSE, clock-drawing test, Montreal Cognitive Assessment, i.e., MOCA, or other)? (Parmar et al. 2014)
  - {29} Why this particular scale vs. another scale?
- {30} Were patients assessed for co-morbid depression using a validated tool? (Murphy et al. 2014)
  - {31} Explore – which scale was used? (e.g., Geriatric Depression Scale)?
  - {32} Why this particular scale vs. another scale?
- Were patients referred for comprehensive bloodwork? (Parmar et al. 2014)
  - {33} Complete Blood Count? (RRMC, Jan 2015; Parmar et al. 2014)
  - {34} Electrolytes? (RRMC, Jan 2015; Parmar et al. 2014)
  - {35} Creatinine? (RRMC, Jan 2015)
  - {36} Urea? (RRMC, Jan 2015)
  - {37} Blood glucose? (RRMC, Jan 2015; Parmar et al. 2014)
  - {38} Folate? (Ngo and Holroyd-Leduc 2014)
  - {39} Calcium? (RRMC, Jan 2015; Parmar et al. 2014)
  - {40} Thyroid Stimulating Hormone? (RRMC, Jan 2015; Parmar et al. 2014)
  - {41} Vitamin B12? (RRMC, Jan 2015)
  - {42} ECG (electrocardiogram)? (RRMC, Jan 2015)
- Were the following causes of cognitive impairment ruled out? (BCGuidelines, 2014)
  - {43} Delirium?
  - {44} Alcohol dependence?
  - {45} Co-morbid diseases?
  - {46} Adverse drug effects and polypharmacy?
  - {47} Other causes?
- {48} Were the patients referred for an MRI or head/brain computed tomography (CT) scan? (Murphy et al. 2014; BCGuidelines, 2014)
  - {49} If not, why?
  - {50} Were consensus criteria for diagnosis used? (If they inquire, the 4<sup>th</sup> Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD4)?)



**(Eliminated including statement in brackets () as part of full question and only providing information on CCCDTD4 if they inquire after Interview #7)**

- {51} Was a standardized scale for staging dementia used (e.g., Global Deterioration Scale, Clinical Dementia Rating Scale)? (BCGuidelines, 2014; Parmar et al. 2014 notes “documented diagnosis of dementia and its severity”)
- Are patients typically referred {to a specialist for assessment}, in the following cases **(Phrasing in brackets{} changed from ‘for diagnosis’ to above wording after Interview #2)?**
  - {52} Early onset (before age 65) (BCGuidelines, 2014)
  - {53} Rapidly progressive (BCGuidelines, 2014) defined as “a condition that develops within 12 months after the appearance of first cognitive symptoms” (Moore et al. 2014)
  - {54} Diagnostic uncertainty or atypical features (BCGuidelines, 2014)
  - {55} Management issues that are difficult to resolve (BCGuidelines, 2014)
  - {56} Risk of harm to self or others (BCGuidelines, 2014)
- {57} Is there anything else that you would like to add about the assessment of patients with suspected dementia, for instance, other procedures or tests that were involved?

14. {58} In terms of assessing patients with suspected dementia, what was your role vis-à-vis the rest of the team? Explore.

15. {59} Thinking specifically about the assessment phase **(Preceding statement added after Interview #1)**, what are the top 2 or 3 challenges faced by your PHC team in assessing patients with dementia? {60} What are the main strengths of your PHC team in assessing patients with dementia?

16. {61} Please reply to this statement: Thinking specifically about the assessment phase **(Preceding statement added after Interview #7)**, as a whole my PHC team effectively assesses patients with suspected dementia. Explore.

- Strongly agree       Agree       Neutral       Disagree       Strongly disagree

Pretest Guiding Questions: Assessment Section

The purpose of this interview is to identify how the questionnaire can be improved for future studies. Therefore, we are asking for your feedback on the questionnaire, including but not limited to, flow, wording, applicability, clarity, etc. With this in mind **(The three preceding sentences added after Interview #3):**

1. Were there any particular questions you would like to comment on? Any reason for this?
2. Did any of the questions in the previous section not make sense to you? **(Changed from ‘Did all the questions in the previous section make sense to you?’ to above wording after Interview #2)**
3. Were there any particular questions that could be improved or modified to make them clearer? **(Question deleted after Interview #2)**
4. Were any questions in the previous section not relevant/applicable to your practice? **(Question added after Interview #2)**

Diagnosis (patients living in the community, not LTC)

I would like you to think now of patients of your PHC team who have been diagnosed with dementia (rather than patients that were suspected to have dementia). It may be helpful to keep the last few patients in mind for some of these questions.

17. {62} Would you say that patients' diagnoses were (always, frequently, sometimes, rarely, or never) conveyed to the patient (Murphy et al. 2014)?
18. {63} Are you aware of cases where patients were not informed of their diagnosis? If yes, what were the circumstances?
19. {64} Was a family member (or members) (always, frequently, sometimes, rarely, or never) present when the patient was informed of their diagnosis? If not, were family members informed later?
20. {65} What was your role vis-à-vis the rest of the team, in informing patients of their diagnosis? Explore.
21. {66} When a member of the PHC team (*or a specialist outside of the team*) informed patients of their diagnosis, how was information concerning that diagnosis communicated to the rest of the PHC team (if at all) [for instance, in team meetings, one-on-one with individual team members, via the electronic medical record, or other]?
22. {67} Please reply to this statement: As a whole, my PHC team effectively communicates diagnoses (of dementia) to patients with dementia. Explore.  
 Strongly agree       Agree       Neutral       Disagree       Strongly disagree
23. {68} Please reply to this statement: As a whole, my PHC team effectively communicates diagnoses (of dementia) to the rest of the team. Explore.  
 Strongly agree       Agree       Neutral       Disagree       Strongly disagree
24. {69} Would you say that when patients were diagnosed with dementia, their diagnosis was (always, frequently, sometimes, rarely, or never) documented in their chart or electronic medical record? Explore - what factors affected whether or not a diagnosis was documented (e.g., diagnosis is not always documented if it is not the main reason for the visit)?
25. {70} Thinking specifically about diagnosing patients with dementia (**Preceding statement added after Interview #1**), what are the top 2 or 3 challenges faced by your PHC team in diagnosing patients with dementia? {71} What are the main strengths of your PHC team in diagnosing patients with dementia?

26. {72} Please reply to this statement: Thinking specifically about diagnosing patients with dementia (**Preceding statement added after Interview #7**), as a whole, my PHC team effectively manages the process of diagnosing individuals with dementia. Explore.
- Strongly agree       Agree       Neutral       Disagree       Strongly disagree

Pretest Guiding Questions: Diagnosis Section

The purpose of this interview is to identify how the questionnaire can be improved for future studies. Therefore, we are asking for your feedback on the questionnaire, including but not limited to, flow, wording, applicability, clarity, etc. With this in mind: (**The three preceding sentences added after Interview #3**):

5. Were there any particular questions you would like to comment on? Any reason for this?
6. Did any of the questions in the previous section not make sense to you? (**Changed from ‘Did all the questions in the previous section make sense to you?’ to above wording after Interview #2**)
7. Were there any particular questions that could be improved or modified to make them clearer? (**Question deleted after Interview #2**)
8. Were any questions in the previous section not relevant/applicable to your practice? (**Question added after Interview #2**)

27. {73} Are you aware of clinical practice guidelines or recommendations for the diagnosis and treatment of dementia? (If they inquire, Recommendations of the Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia are the latest Canadian guidelines, i.e., CCCDTD4, released in 2012).
28. I will now list some standardized tests that may be administered to individuals with suspected dementia. Please indicate how frequently you perform (**Eliminated listing out each potential response to question after Interview #6**) these tests AND whether you (**Eliminated listing out each potential response to question after Interview #6**) think these tests provide useful information (modified Team 19’s question):

	I use this test:					This test provides useful information (*ask only if “I use this test” = never, rarely, occasionally, often)				
	Never	Rarely	Occasionally	Often	Don't know the test	Disagree	Somewhat disagree	Somewhat agree	Agree	Not applicable
{74/75} Mini Mental State Examination (MMSE, Folstein)	1	2	3	4	DK	1	2	3	4	N/A
{76/77} Montreal Cognitive Assessment (MoCA)	1	2	3	4	DK	1	2	3	4	N/A
{78/79} Clock Drawing Test	1	2	3	4	DK	1	2	3	4	N/A
{80/81} Trail Making Test	1	2	3	4	DK	1	2	3	4	N/A
{82/83} Mini-Cog	1	2	3	4	DK	1	2	3	4	N/A
{84/85} Geriatric Depression Scale	1	2	3	4	DK	1	2	3	4	N/A
{86/87} Activities of Daily Living (e.g., Bristol)	1	2	3	4	DK	1	2	3	4	N/A
{88/89} Instrumental Activities of Daily Living (e.g., Lawton)	1	2	3	4	DK	1	2	3	4	N/A
{90} Other (please specify):	1	2	3	4	DK	1	2	3	4	N/A

29. {91} For HCPs only : Do you typically perform cognitive tests (Team 19’s question):

- Independently or autonomously
- In close collaboration/consultation with a physician
- Only when a physician requests it

Management (patients living in the community, not LTC)

I would like you to think now of patients of your PHC team, who have received treatment and management following a diagnosis of dementia. It may be helpful to keep the last few patients in mind for some of these questions.

30. I’m going to ask you about the treatment and management process that you followed. Please keep in mind that these questions reflect current best practices found in several different publications – so this is a comprehensive listing of **ideal** best practices and we certainly don’t expect that you will be able to perform all of these actions with your patients.

To begin, after a formal diagnosis was made, did the management process always, occasionally, rarely or never involve the following?\*\*\* (**Preceding statement added after Interview #11**)

*If the respondent answers 'no' to any of the following 'yes/no' questions, explore the reasons, e.g. "was there a particular reason for that decision?"*

- {92} Were patients' records "flagged" to indicate they had been diagnosed with dementia? (Question from Wanda, as teleconference April 28/14 with Wanda, Sheena G, Debra, Julie).
  - {93} Were patients prescribed anti-dementia medications, for instance, cholinesterase inhibitors such as Aricept, as appropriate? (Ngo and Holroyd-Leduc 2014)
  - {94} Were non-pharmacologic management options discussed with patients, for instance exercise and recreation? (Ngo and Holroyd-Leduc 2014)
  - {95} Were patients referred for Home Care assessment? (Megan, Jan. 2015)
  - Were patients made aware of the following changes as dementia progresses, as part of managing for the future?
    - {96} Changes in driving capacity (Megan, Jan. 2015; Murphy et al. 2014)
    - {97} Functioning independence (Megan, Jan. 2015)
    - {98} Medication management (Megan, Jan. 2015)
  - {99} Was advice given about patient safety issues (Glasser and Miller, 1998), e.g., wandering and household safety?
  - {100} Was Saskatchewan Government Insurance notified about patient's medical condition re: driving ability? (Julie added, see <http://ssot.sk.ca/mandatory-reporting-to-sgi>)
  - {101} Were caregivers (**Changed to 'caregivers' from 'patients' after Interview #4**) given advice re: respite care? (Murphy et al. 2014)
  - {102} Were patients provided information on community services? (Glasser and Miller, 1998)
  - {103} Were patients referred to Alzheimer Society First Link? (Debra, Jan. 2015)
  - {104} Were patients assessed for behavioural and psychological issues? (BCGuidelines 2014; Parmar et al. 2014)
  - {105} Were patients assessed for behavioural and psychological issues at regular 3-month intervals? (Ngo and Holroyd-Leduc 2014)
  - {106} Were medicolegal issues discussed (personal directives, power of attorney, capacity assessment)? (Parmar et al. 2014)
  - {107} Were caregivers asked about how they were managing (e.g., burden as per Parmar et al. 2014, mental health, physical health)? (Megan, Jan. 2015)
    - {108} Did you recommend a support group if necessary? (Glasser and Miller, 1998)
  - {109} Were caregivers of patients provided, or referred for, caregiver training {outside of the primary healthcare team} (**Phrasing in brackets{} added after Interview#2**), [if it is available in your community] (**Statement in brackets [] added after Interview #12**)? (psychosocial management)? (Murphy et al. 2014)
  - {110} Thinking about all aspects of care for patients with dementia (medication, behavioural, social, etc) (**Preceding line added after Interview #1**), in what situations are patients referred for management of dementia {outside of the primary healthcare team} (**Statement in brackets{} added after Interview#2**)?
  - {111} Is there anything that you would like to add about the management process following a diagnosis of dementia?
31. {112} What was your role vis-à-vis the rest of the team, in the ongoing management of patients who were diagnosed with dementia? Explore – medication management, behavioural management, psychosocial management, other as per above.

32. {113} How is information concerning the details of patients' management process communicated to the rest of the PHC team (if at all) [for instance, in team meetings, one-on-one with individual team members, via the electronic medical record, or other]?
33. {114} In your PHC team, do you hold case discussion meetings for each patient with dementia?  
 Never       Rarely       Occasionally       Generally       Always
34. {115} In your PHC team, are flow sheets that incorporate clinical practice guidelines, or other similar tools, used to manage the ongoing care of patients with dementia? **(Eliminated scale 'never, rarely, occasionally, generally, always' from question after Interview #12)**
35. {116} If yes to the previous question, are these flow sheets part of patients' electronic medical records (EMR)?
36. {117} Thinking specifically about the management phase **(Preceding statement added after Interview #1)**, what are the top 2 or 3 challenges faced by your PHC team in the ongoing management of patients with dementia? {118} What are the main strengths of your PHC team in the ongoing management of patients with dementia?
37. {119} Please reply to this statement: Thinking specifically about the management phase **(Preceding statement added after Interview #7)**, as a whole my PHC team effectively manages patients following a diagnosis of dementia. Explore.  
 Strongly agree       Agree       Neutral       Disagree       Strongly disagree

Pretest Guiding Questions: Management Section

The purpose of this interview is to identify how the questionnaire can be improved for future studies. Therefore, we are asking for your feedback on the questionnaire, including but not limited to, flow, wording, applicability, clarity, etc. With this in mind: **(The three preceding sentences added after Interview #3):**

9. Were there any particular questions you would like to comment on? Any reason for this?
10. Did any of the questions in the previous section not make sense to you? **(Changed from 'Did all the questions in the previous section make sense to you?' to above wording after Interview #2)**
11. Were there any particular questions that could be improved or modified to make them clearer? **(Question deleted after Interview #2)**
12. Were any questions in the previous section not relevant/applicable to your practice? **(Question added after Interview #2)**

38. For FPs and NPs only **(Added 'and NPs' after Interview #1):** When you need help with assessment, diagnosis, or management of patients with dementia, to whom do you refer? It may be helpful to keep the last few patients in mind for some of these questions.

	Never	Sometimes	Often	Always	Not available
{120} To neurologists	1	2	3	4	5

{121} Where is this practice located?					
{122} To neuropsychologists	1	2	3	4	5
{123} Where is this practice located?					
{124} To the Rural and Remote Memory Clinic in Saskatoon <b>(Changed from ‘To a memory clinic. Where is memory clinic located?’ to above wording after Interview #7)</b>	1	2	3	4	5
{125} Other #1 Where is ‘other’ located?	1	2	3	4	5
{125} Other #2 Where is ‘other’ located?	1	2	3	4	5

39. Thinking about the typical follow-up process directly after a referral:

- Is your team provided with the results of the specialist visit?
- Does your team follow up with the patient or the specialist after the referral? If yes, what does the follow-up involve? **(Entire question deleted after Interview #10)**

40. {126} Please reply to this statement: As a whole, there is adequate access to specialist support for assessment, diagnosis, and management for your patients with dementia. Explore.

- Strongly agree       Agree       Neutral       Disagree       Strongly disagree

Additional Questions concerning assessment, diagnosis, and management

41. I am now going to ask you a few questions regarding driving concerns in individuals with dementia. **(Preceding statement added after Interview #10)** {127} Under what circumstances do you ask your patient with dementia about driving concerns?  
 {128} How do you approach the issue of driving with patients and family members? {129} What are some of the barriers to approaching the issue of driving? (questions contributed by Gary Naglie)

42. I will read a list of functions with respect to dementia care. As I read this list, please tell me if you consider these functions to be part of your role (Note: Team 19’s original question asked ‘what are the roles and functions of the nurses in your medical team, and provided the following list which has been slightly revised to suit our interview guide):

- {130} Consulting with **(Word ‘informal’ eliminated after Interview #5)**caregivers of patients with dementia
- {131} Prescribing medication for dementia
- {132} Case finding and screening
- {133} Assessment
- {134} Diagnosis (not included in Team 19’s initial question)
- {135} Care Planning
- {136} Implementation and management of care plan
- {137} Pro-active monitoring of patients (with dementia)
- {138} Review

43. What would you say are the top 2 or 3 challenges facing your PHC team regarding issues of assessment, diagnosis, and management of individuals with dementia? What are your team’s main strengths? **(Question eliminated after Interview #1)**

44. {139} Based on your experience and knowledge working in your community, what do you think is most needed to improve dementia care? **(Question added after Interview #10)**

Continuing Education

45. {140} Have you taken any courses or been involved in any academic detailing or inservices related to dementia? {141} Describe and indicate the years.

46. {142} Would you be interested in case-based learning for dementia? Explore. [*Note.* Case-based learning “engages students in discussion of specific scenarios that resemble or typically are real-world examples” (Centre for Teaching and Learning, Queen’s University)].

Pretest Guiding Questions: Conclusion

The purpose of this interview is to identify how the questionnaire can be improved for future studies. Therefore, we are asking for your feedback on the questionnaire, including but not limited to, flow, wording, applicability, clarity, etc. With this in mind: **(The three preceding sentences added after Interview #3):**

- 13. Were there any particular questions you would like to comment on? Any reason for this?
- 14. Did any of the questions in the previous section not make sense to you? **(Changed from ‘Did all the questions in the previous section make sense to you?’ to above wording after Interview #2)**
- 15. Were there any particular questions that could be improved or modified to make them clearer? **(Question deleted after Interview #2)**
- 16. Were any questions in the previous section not relevant/applicable to your practice? **(Question added after Interview #2)**

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- Explain the honorarium rules:
  - We are offering a \$100 honorarium in the form of a Visa Gift card to participants of this research study. It is taxable, and therefore the University requires us to collect name, mailing address, and a signature from those who will receive the honorarium. If you would like to receive this honorarium, complete the form which I sent in a previous email and fax to the number provided on the sheet. Your honorarium will be mailed to you.
  - Would you like to receive this? Do you have the honorarium form?
- Thank you for your time.

**APPENDIX E- EVIDENCE FOR VALIDITY BY ITEM**

Item Number	Evidence for Validity
1-10	Demographics
11	√
12	√
13	√
14	√
15	√
16	√
17	√
18	!
19	√
20	√
21	√
22	√
23	√
24	Δ
25	Δ
26	Δ
27	Δ
28	√
29	!
30	Δ
31	!
32	!
33	Δ
34	Δ
35	Δ
36	Δ
37	Δ
38	Δ
39	Δ
40	Δ
41	Δ
42	Δ
43	Δ
44	Δ
45	Δ
46	Δ
47	Δ
48	Δ
49	√
50	Δ
51	Δ
52	Δ
53	Δ
54	Δ

Item Number	Evidence for Validity
55	Δ
56	Δ
57	!
58	√
59	√
60	√
61	√
62	X
63	√
64	√
65	√
66	√
67	√
68	√
69	√
70	√
71	√
72	√
73	X
74	√
75	√
76	√
77	√
78	√
79	√
80	√
81	√
82	√
83	√
84	√
85	√
86	√
87	=
88	√
89	√
90	√
91	√
92	Δ
93	Δ
94	Δ
95	Δ
96	Δ
97	Δ
98	Δ
99	Δ

Item Number	Evidence for Validity
100	Δ
101	Δ
102	Δ
103	Δ
104	Δ
105	Δ
106	Δ
107	Δ
108	Δ
109	Δ
110	√
111	!
112	√
113	√
114	=
115	X
116	!
117	√
118	√
119	√
120	√
121	√
122	=
123	√
124	=
125	√
126	√
127	√
128	!
129	!
130	√
131	√
132	X
133	√
134	√
135	X
136	X
137	√
138	√
139	X
140	√
141	X
142	√

Legend:

√ : Item answered as suggested or within question aim,  $n=65$

! : Item with interviewer error,  $n=9$

= : Item with responses related to a scaled item,  $n=4$

Δ : Item with format change after Interview #11,  $n=46$

X : Item with varied response,  $n=8$