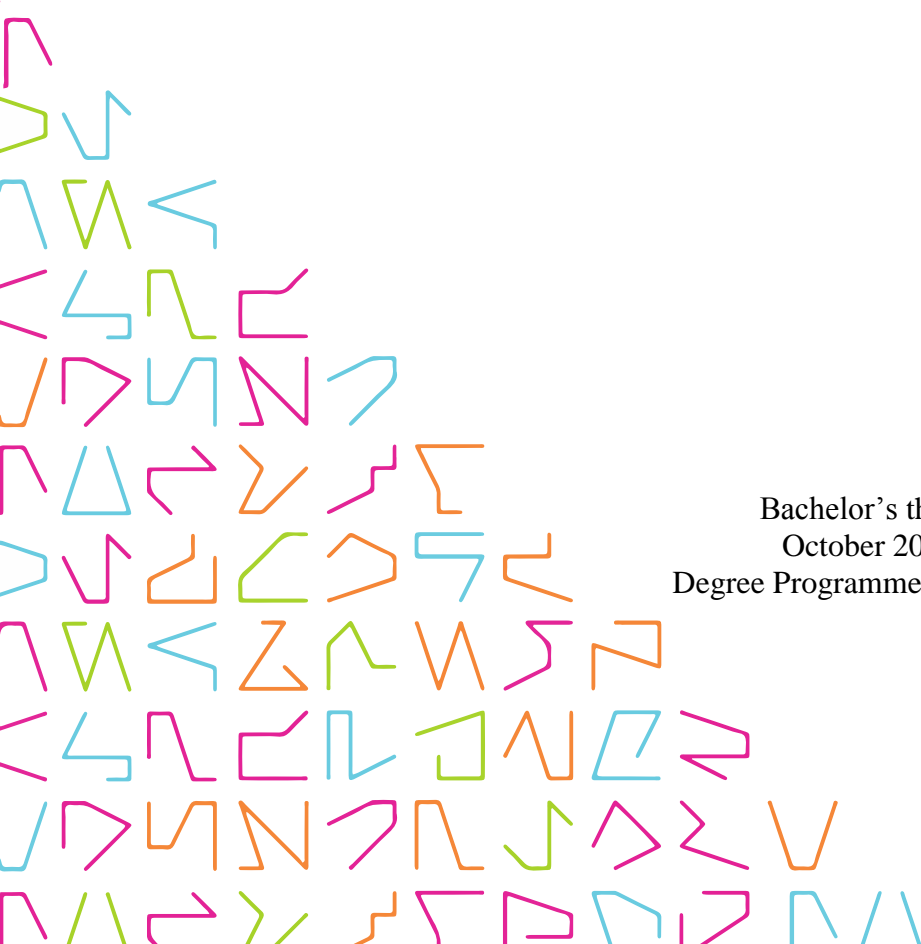


# **PREPARING FOR THE INEVITABLE**

Alzheimer's disease: the importance of an early  
diagnosis and advanced care planning

Tiffany Salo

Bachelor's thesis  
October 2016  
Degree Programme in Nursing



## ABSTRACT

Tampereen ammattikorkeakoulu  
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SALO, TIFFANY:

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Alzheimer's disease is a world-wide problem which is growing exponentially. It is in society's best interest to prolong the early phase of this disease as long as possible. Often people go undiagnosed. After diagnosis, another obstacle can be found in the implementation of an advanced care plan.

A literature review was used for the purpose of answering this study's two research questions: how does an early diagnosis of dementia and/or Alzheimer's disease help patients and their caregivers cope, and secondly, how does advanced care planning benefit patients with AD, as well as, their caregivers? The objective of this review is to provide nursing students and practicing nurses with current and relevant information relating to best practices in AD patient care. Eight articles met the requirements established in the selection criteria and were consequently critically appraised to evaluate the quality of their research.

Receiving a diagnosis enables patients, and their caregivers to do the following: to accept their new diagnosis and move forward accordingly; to access treatment which was not previously available; to access information, as well as, to prepare and plan for the future. Results also highlighted that an early diagnosis decreases treatment costs and actually prolongs patient institutionalization. An advance care plan helps those with dementia or Alzheimer's disease by offering them time to think and prepare for their future. It also allows for patient preferences in care to be known, contributing to a better quality of life. Legal aspects of care planning were also discussed.

In conclusion, an early diagnosis and advanced care planning provides the ammunition needed to more effectively prepare for the long battle with Alzheimer's disease.

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Key words: Alzheimer's disease, dementia, early diagnosis and advanced care planning

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Alzheimerin tauti ja aikaisen diagnoosin sekä ennakkohoitosuunitelman tärkeys.

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Alzheimerin tauti on eksponentiaalisesti kasvava maailmanlaajuinen ongelma. Taudin hoitaminen on henkisesti ja taloudellisesti lamauttavaa, joten on yhteiskunnan edun mukaista venyttää taudin alkuvaihetta mahdollisimman paljon. Valitettavasti tauti vaatii varhaisen diagnoosin. Diagnoosi voi useasti jäädä myös tekemättä. Diagnoosin jälkeen potilaat sekä heidän läheisensä kohtaavat yleensä seuraavan ongelman, joka on ennakkohoitosuunitelman toteutus.

Opinnäytetyössä tutkittiin aiheesta julkaistua kirjallisuutta ja haettiin vastausta kahteen kysymykseen: miten varhainen diagnoosi dementiaasta tai Alzheimerin taudista auttaa potilasta ja hänen hoitajiansa selviytymään? Toisekseen, kuinka etukäteen tehty hoitosuunnitelma hyödyttää potilasta sekä hänen hoitajiaan.

Dementia ja/tai Alzheimerin tauti –diagnoosin jälkeen on mahdollisuus tarkastella elämää uudelleen. Diagnoosi mahdollistaa pääsyn hoitoihin, joita ei ole ollut aikaisemmin saatavilla; saada tietoa sairaudesta, erityisesti ennusteesta; tulevaisuuden suunnittelun, mukaan lukien potilasturvallisuuden ja mahdollisten kriisien välttämisen. Voidaan myös korostaa, että varhainen diagnoosi vähentää taudin hoitoon liittyviä kokonaiskustannuksia, ja siirtää potilaan laitoshoidon aloittamista eteenpäin.

Ennakkohoitosuunnitelma auttaa tarjoamalla potilaalle aikaa ajatella sekä valmistautua tulevaisuuteensa. Se mahdollistaa myös potilaan mielipiteiden huomioonottamisen parantaen elämänlaatua. Opinnäytetyö tarkastelee myös ennakkohoitosuunitelman laillisia näkökulmia.

Varhainen diagnoosi ja hoidon suunnittelu etukäteen auttavat potilasta ja hänen hoitajiansa pitkässä taistelussa Alzheimerin tautia vastaan. Opinnäytteen tarkoituksena oli yhteenvetää parhaita hoitokäytäntöjä niille, jotka kärsivät dementiaasta ja/tai Alzheimerin taudista. Näitä konsepteja voidaan myös helposti käyttää opetusmateriaalina sairaanhoitajien ja sairaanhoidon opiskelijoiden kesken.

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Avainsanat: Alzheimerin tauti, dementia, varhaisen diagnoosin ja ennalta hoitosuunnitelma

## CONTENTS

1	INTRODUCTION .....	7
2	THEORETICAL STARTING POINTS .....	8
2.1	The difference between Alzheimer’s disease and dementia .....	8
2.1.1	Alzheimer’s disease is a terminal illness .....	9
2.2	The importance of an early diagnosis of dementia- Alzheimer’s onset... 10	
2.2.1	Barriers to an early diagnosis .....	11
2.3	Advanced Care Planning in Alzheimer’s Disease Treatment.....	12
3	PURPOSE AND OBJECTIVE OF BACHELOR ´S THESIS .....	13
4	METHODOLOGY .....	14
4.1.	Selection Criteria .....	14
4.2.	Critical Appraisal .....	17
4.3	Data Collection and Analysis .....	18
5	RESULTS (Part 1).....	20
5.1	Finally..... A diagnosis. ....	20
5.2.	Acceptance and moving forward .....	22
5.3.	Access to treatment .....	23
5.4.	Information and prognosis .....	24
5.5.	Safety and avoiding crisis .....	25
5.6	Reducing costs and prolonging institutionalization.....	25
5.7	Planning for the future .....	25
6	RESULTS (Part 2).....	27
6.1	A new reality/new circumstances: thinking about and preparing for the future .....	27
6.2.	Less stress, anxiety and depression.....	27
6.3.	Allows patients’ care preferences to be known .....	28
6.4	Legal help .....	29
7	DISCUSSION .....	32
7.1	Findings .....	32
7.2.	Trustworthiness .....	33
7.3.	Limitations .....	34
7.4.	Ethical considerations.....	35
7.5.	Recommendations.....	36
8.	CONCLUSION .....	37
	REFERENCES.....	38
	APPENDICES .....	41

APPENDIX 1. Methodological & Evaluation Matrix 1(4) .....	41
APPENDIX 2. Quantitative Critical Appraisal Guide.....	45
APPENDIX 3. Qualitative Critical Appraisaln Guide.....	47
APPENDIX 4. Quantitative Critical Appraisal Table.....	50
APPENDIX 5. Qualitative Critical Appraisal Table.....	52

**ABBREVIATIONS AND TERMS**

ACP	Advanced care plan (or planning, depending on the context)
AD	Alzheimer's disease
ADI	Alzheimer's Disease International (the international federation of Alzheimer's disease associations around the world).
ADRC	Alzheimer's Disease Research Centre at the University of Pittsburgh
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DPOA	Durable powers of attorney
INTERDEM	An European-wide group of researchers whose aim is the Early detection and timely INTERvention for DEMentia.
LW	Living will
NICE	National Institute for Health and Care Excellence
PubMed	Public/Publisher MEDLINE (National Library of Medicine journal articles database)
TAMK	Tampere University of Applied Sciences
UK	United Kingdom

## 1 INTRODUCTION

Alzheimer's disease (AD), the world's most common form of dementia, is projected to boom in the coming years (Arvesen 2015, 1). According to Alzheimer's Disease International (ADI 2015), there are 46.8 million people suffering from dementia worldwide, and this figure is expected to nearly double every 20 years. The cost of treating this disease is financially crippling. The National Institute on Aging (NIA) (2015, 1) state that total health care spending for people with dementia during the last five years of their life was more than a quarter-million dollars per person. This figure is approximately 57 percent greater than costs associated with death from other diseases, including cancer and heart disease (Mitchell, McCollum & Monaghan 2013, 18; ADI 2015, 3; NIA 2015, 1).

According to the Finnish Ministry of Social Affairs and Health (2013), more than 13,000 people in Finland are diagnosed with a dementing disease every year. In addition, it is estimated that half have not been yet been diagnosed in Finland, and of those diagnosed with AD, only a quarter have been prescribed appropriate medication. There are as many as 120,000 Finnish citizens diagnosed with a mild cognitive impairment (MCI). MCI is recognized as a precursor stage for more severe memory disorders and requires diagnostic attention. (Finnish Ministry of Social Affairs and Health 2013, 7.)

The aim of this review is to provide learning material for both nursing students and practicing nurses with current information regarding the question of how an early diagnosis and advanced care planning (ACP) supports patients with AD, and/or dementia. The information gained from this review will translate into best practices in care for those suffering from AD, in addition, better support for their families.

The working life connection is Tampere University of Applied Sciences (TAMK). This review will not only serve as learning material for students in various health care fields at TAMK, but it will also offer practicing nurses current, evidence based information relating to best practices in AD and/or dementia care.

## 2 THEORETICAL STARTING POINTS

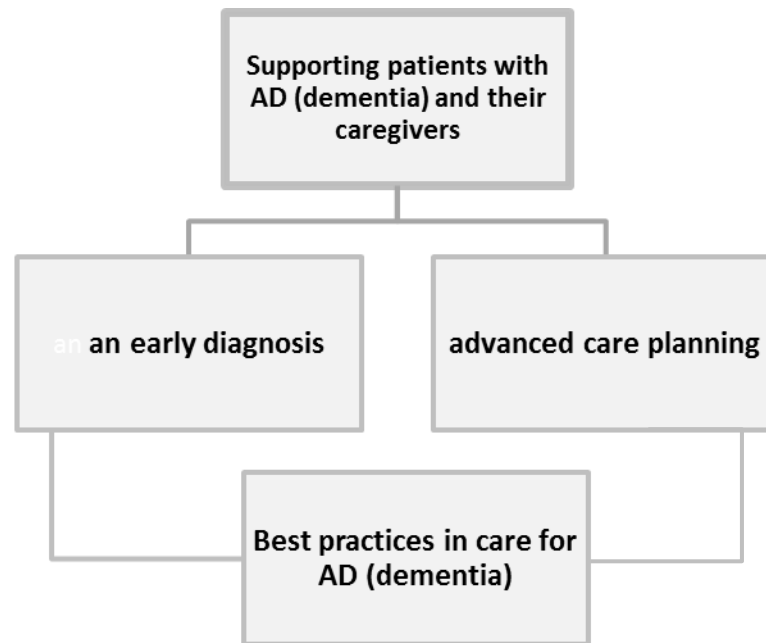


Figure 1. Flow chart of key concepts

### 2.1 The difference between Alzheimer’s disease and dementia

Dementia is a syndrome where as Alzheimer’s is a progressive terminal disease. Brook and Kirk (2014, 490) define dementia as, “A syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and ability to carry out daily activities.” Mitchell et al. (2013, 18) adds that dementia is a collective group of syndromes characterized by cognitive decline and is almost always associated with age. All forms of dementia are the result of an excess collection of proteins (proteinopathy) in the brain (Beatty 2006, 33). Beatty further explains that specific types of proteinopathies are associated with different types of dementia. The most common types of dementia are: AD, vascular dementia and dementia with Lewy bodies (Alzheimer’s Society 2016). AD is by far the most prevalent, accounting for approximately two-thirds of all cases (Beatty 2006, 33; Chapman et al. 2006, 3; ADI 2015; Alzheimer’s Society 2016).

According to the NIA (2015), AD is a progressive form of dementia that slowly affects parts of the brain that control thought, memory and language. These are also common for those with dementia, but additional accompanying symptoms



are specific to AD in the early part of the disease: depression, apathy, impaired judgement, confusion, behavioral changes, and difficulty speaking or swallowing (Alzheimer's Society 2016). In the later stages of the disease symptoms mentioned before are exasperated. In addition, late symptoms of AD are: aggression, insomnia, incontinence, delusions, hallucinations, and neurologic problems such as sporadic muscle contractions or gait disturbances are also common occurrences with the progression of this disease (Chapman et al. 2006, 3–4 Alzheimer's Society 2016). AD causes gross neuronal loss and brain atrophy, resulting in a reduction in brain weight of 20-40% (Beatty 2006, 34). The exact cause of AD is unknown, but the known risk factors for contracting AD are: age, sex (female), family history and genetics (before age 60) (Beatty 2014, 33; Alzheimer's Society 2016).

Note: for the purposes of this literature review, the terms AD and dementia will be used interchangeably.

### **2.1.1 Alzheimer's disease is a terminal illness**

Dementia is often thought of as just an illness of the aging mind, but Beatty (2006, 33) states that it is not a part of normal aging process. While some still believe that people die with AD instead of from it, other experts in the field believe otherwise (Beatty 2006, 33; Brunnström & Englund 2009, 488; Garand, Dew, Lingler, DeKosky 2011, 7; Brooke & Kirk 2014, 490; Dempsey, Dowling, Larkin & Murphy 2015, 128; Sachs, Shega & Cox-Hayley 2015, 1057). Beatty (2006, 33) states that dementia is the fourth leading cause of death in the United States. Sachs et al. (2015, 1057) supports this and further explains that while memory loss is indeed an early indicator of dementia, it is more accurately defined as a fatal brain failure, a terminal illness, not unlike heart disease or cancer, in which it physically ends a person's life. Compared to other terminal illnesses, such as cancer, patients of AD live longer with their disease, even twice as long (Alzheimer's Society 2016). As a result of this extended time frame, physicians and family members often have difficulty coming to terms with the fact that their loved ones are actually dying from dementia. Often death certificates erroneously give other reasons

for death; like for example, pneumonia or urinary tract infections (Sachs et al. 2015, 1058, Alzheimer's Society 2016).

## **2.2 The importance of an early diagnosis of dementia- Alzheimer's onset**

Finland's Ministry of Social Affairs and Health (2013, 13) claims that an early diagnosis lowers the risks involved with memory disorders by prolonging declining symptoms, and promoting the patients' functioning levels and overall quality of life. Early intervention not only helps the patient, but their families as well. Especially in the early stages, loved ones or caregivers might not understand their behavior; they may even become irritated or angry due to changes in behavior. An early diagnosis will not only help the patient get the appropriate treatment for dementia symptoms, but will also help the caregiver to plan for future care (Relkin 2000, 11; Black et al. 2013, 2092; Finnish Ministry of Social Affairs and Health 2013, 2). A delay in early diagnosis could also translate into possibly being overlooked for updates in treatment (Iliffe, Manthorpe & Eden 2003, 376; Bossen, Kissel & Carpenter 2006, 273; De Lepeleire et al. 2008, 570; Pringle-Specht & McKenzie 2009, 9; Morgan et al. 2014, 114).

An early diagnosis, treatment and rehabilitation of memory disorders can not only improve patients' functioning levels and quality of life, but also, significantly reduce costs with the prolongation of the disease at a milder stage (Relkin 2000, 11; Iliffe et al. 2003, 278; De Lepeleire et al. 2008, 570; Mukadam et al. 2011, 1070, Finnish Ministry of Social Affairs and Health 2013, 7). According to the Finnish Ministry of Social Affairs and Health (2013), in 2010 the average annual cost of 24-hour care in Finland was 46,000 euros per person, while the average cost of home care was 19,000 euros per person. Furthermore, they state that systematic action is required for early diagnosis and preventative techniques to enable patients to live in their own homes. (Finnish Ministry of Social Affairs and Health 2013, 7.)

Another reason in favor of an early diagnosis of AD is the fact that as the disease progresses, communication and cognitive abilities decline making it more difficult for physicians to obtain the care preferences or needs from the patient (Dempsey et al. 2015, 130).

### **2.2.1 Barriers to an early diagnosis**

According to the ADI (2015), only 20–50% of dementia cases are recognized and documented in primary care and this number is compounded with low and middle income countries. In India the projection rate for undiagnosed dementia cases is suggested to be as high as 90%. Those living in rural areas or those that ethnic minorities are also at a disadvantage for receiving an early diagnosis (Mukadam, Cooper, Basit & Livingston 2011, 1070; Morgan et al. 2014, 112). There is a general lack of education of the dementia disease process itself and the ability to identify complications which are encountered in end-stage dementia by healthcare providers, families and caregivers (Dempsey, Dowling, Larkin & Murphy 2015, 128).

While an early diagnosis is crucial, Aversen (2015, 14) and Demsey et al. (2015, 130) agree that an early diagnosis is often hard to obtain due to the greater diagnostic uncertainty earlier in the disease. Supportive evidence advises that because initial symptoms are often subtle, information provided by caregivers with mild AD might be a critical step needed in its early identification (Chapman et al. 2006, 4). And while there is evidence supporting the importance of caregiver testimony in early detection of AD, there is also conflicting evidence warning against the over reliance of caregiver reports which could lead to an inaccurate diagnosis (Chapman et al. 2006, 4; Lichtenberg 2012, 42). Lichtenberg (2012, 42) blames the overabundance of attention given to AD in recent years as skewing physicians' judgement, erroneously leading to the misdiagnosis of cognitive impairment as AD.

### 2.3 Advanced Care Planning in Alzheimer's Disease Treatment

The National Institute for Health and Care Excellence (NICE) recommends and outlines guidelines for a continuum of care, or pathway, for those with AD. This pathway begins prior to diagnosis with preventative care and high quality medical staff capable of recognising symptoms of dementia, and continues after diagnosis with appropriate care planning and execution along with the progression of the disease. (NICE 2016.)

Advanced care planning conjures up ethical considerations as mentioned by Chi-ong (2013, 409) in her research regarding decision making for those with dementia. The issue at hand is whether it is best to take a patient's wishes about their treatment in their pre-illness state or later in the course of their disease when cognitive capabilities are diminished. Supporting evidence published by Hamann et al. (2011, 2045) agrees that ethical and practical implications do exist for those with MCI or early AD pertaining to their care preferences and impaired decisional capacity.

Initiating a discussion on end-of-life care at an early stage in the illness ensures that patient's wishes pertaining to their care is heard and documented (Dempsey et al. 2015, 136). Advanced care planning also enables patients to get their legal affairs in order, including appointing a healthcare proxy or power of attorney (De Lepeleire et al. 2008, 570; Garand et al. 2011, 7; Iliffe et al. 2003, 377; Kissel & Carpenter 2007, 275; Relkin 2000, 1112; Robinson et al. 2012, 403). And lastly, a care plan can help protect those with AD from catastrophic events, such as car accidents and major financial losses, which unfortunately, are not uncommon among this population (Relkin 2000, 1112; Kissel & Carpenter 2007, 276; Mukadam 2011, 1070).

### **3 PURPOSE AND OBJECTIVE OF BACHELOR'S THESIS**

The purpose of the study is to conduct a literature review which examines the following two questions:

- How does an early diagnosis of dementia and/or AD help patients and caregivers cope?
- How does advanced care planning help patients with AD, as well as, their caregivers?

Ultimately, the aim of this review is to answer the questions listed above in hopes of providing nursing students and practicing nurses with current and relevant information relating to best practices in AD patient care. This information and gained knowledge can translate into better understanding and care for those, and their loved ones, suffering from AD.

## 4 METHODOLOGY

For the purpose of this study, Polit and Beck (2012) and Aveyard (2014) serve as sources for best practices in conducting literature reviews. By using two sources, the reviewer seeks to maximize critical examination, and minimize bias. As suggested in Polit and Beck (2012, 146), the following steps have been taken during this review: research questions were developed, a search strategy was designed, a search for articles was undertaken, relevant sources were found and information was collected and critiqued, and finally, a summary of findings and processes was written. Polit and Beck (2012, 119) state that one of the most critical components of conducting a literature review lies within the careful examination of the information gathered from the studies selected for analysis. As a result, a formal protocol by means of a methodological matrix (Appendix 1) was adapted and constructed in order to organize material from the eight selected articles for this review (Polit and Beck 2012, 106; Aveyard 2014, 143).

Polit and Beck (2012, 108) further state that literature reviews should have 3 matrices: a methodological matrix, a results matrix and an evaluation matrix. As mentioned above the methodological matrix can be seen in Appendix 1. The results matrices are detailed in Table 2 and Table 3. And finally, as an alternative suggested by Polit and Beck (2012, 119) the evaluation matrix (a study's strengths and weaknesses) has been incorporated into the methodological matrix (Appendix 1).

### 4.1. Selection Criteria

Aveyard (2014, 90) states that while there is no single strategy to make sure that all information related to your research question can be obtained, there are ways to enhance trustworthiness. Polit and Beck (2012, 97) state that a reviewer should be flexible in their approach for gathering data in hopes of obtaining new data sources. As a result, the reviewer has employed different strategies for the selection of articles to ensure that the best material was retrieved for this study. This process is outlined in this section.

From the key concepts listed in the theoretical starting points section, an electronic Boolean meta-search was completed. As recommended by both Polit and Beck (2012, 100 and 103) and Aveyard (2014, 81– 82) databases

which are associated with health and social sciences were used: The Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed/MEDLINE. After many different word combination and truncation attempts, the reviewer found that the best results came from using the following search terms: “Alzheimer’s disease”, “early diagnosis”, and “care planning.”

Based on the keywords from both of the electronic searches, 79 articles were uncovered as possible candidates. Table 1 (below) details the inclusion and exclusion criteria used for the 79 articles during the research selection process (diagram 3). Aveyard (2014, 78–79) and Polit and Beck (2012, 96) assert that an inclusion and exclusion table provides the reader with a clear picture of the strategy that was used to select articles that are directly related to research questions.

TABLE 1: Inclusion and exclusion criteria applied to articles identified from searches

INCLUSION	EXCLUSION
Dementia and/or Alzheimer’s disease	Diseases other than dementia and/or Alzheimer’s disease.
Late-onset dementia and/or Alzheimer’s disease: persons > 65 years of age.	Early-onset dementia and/or Alzheimer’s disease: persons < 65 years of age.
Published from 1.1.2006 – 3.31.2016	Publications prior to 2006
Peer reviewed articles	Articles which are not peer reviewed
English language	Languages other than English
Full text articles	Articles which are not full text
Abstract available	Abstracts not available
Research articles which addressed three topics: Alzheimer’s disease and/or dementia, early diagnosis and care planning.	Research articles which excluded any of the following topics: Alzheimer’s Disease and/or dementia, early diagnosis and care planning.

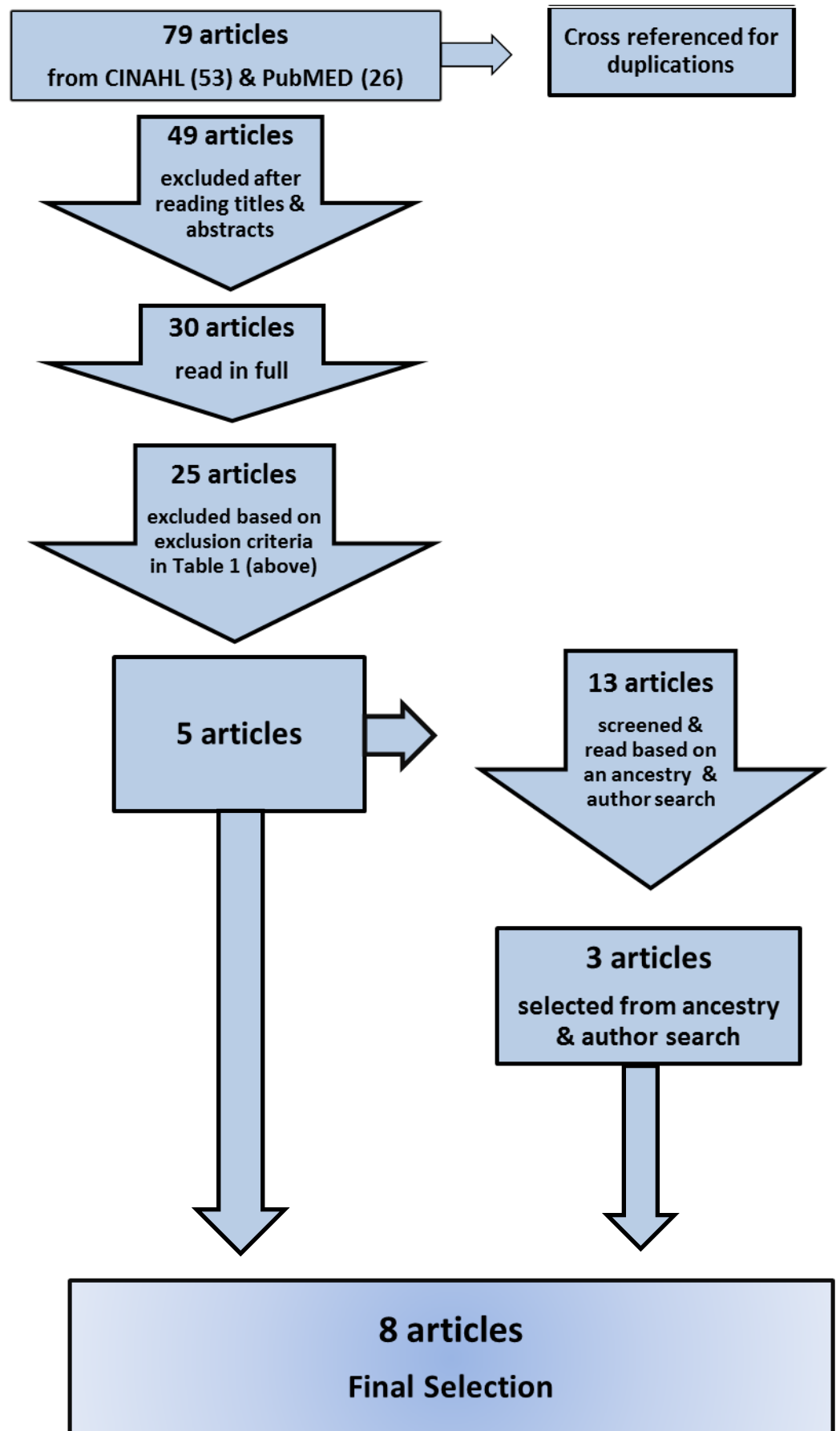


FIGURE 2. Search and screening process



Polit and Beck (2012, 97) state that a reviewer should be flexible in their approach for gathering data in hopes of obtaining new data sources. Accordingly, during the selection process (diagram 3) the ancestry and an author search was undertaken in order to track down additional sources (Polit & Beck 2012, 109 & Aveyard 2014, 91). Because this step involves examining previously cited research from articles, publications prior to 2006 were permitted. In addition, during the ancestry screening process one well written article, which would have originally been excluded due to the fact that some of their participants had early-onset dementia, was now included due to its high quality and direct relevance to this study's topic. The exception was made for the research article written by Garand, Dew, Lingler & DeKosky (2011).

#### **4.2. Critical Appraisal**

Both Polit and Beck (2012, 118) and Aveyard (2014, 109) state that a good literature review focuses on the methodologic aspects used and whether or not the quality of the evidence or value of the literature selected is high. Furthermore, they advise to be sceptical during the evaluation of selected materials, and Aveyard (2014, 105) supports this claim, as she warns the reviewer not to take anything at face value. Aveyard (2014, 138) asserts that without critical appraisal, the contribution of this evidence to addressing the research question cannot be assessed.

For this literature review one quantitative and seven qualitative studies have been chosen. Both Polit and Beck (2012) and Aveyard (2014) served as exemplary models for critically appraising qualitative and quantitative research. Polit and Beck (2012, 236) state that solid quantitative research should aim to minimize bias and control confounding variables, so that cause-and-effect relationships and statistical significance can be made. Other systematic aspects of importance are data analysis techniques, theoretical and methodological frameworks (Polit & Beck 2012, 112–114). Aveyard (2014, 116) simply and clearly explains that the critical appraisal of quantitative research should focus on two things: validity and reliability. Validity, or whether the study measures what it set out to measure, and reliability, whether the measurement is reliable and would it produce the same outcome if repeated again. Consequently, by minimising threats to

validity, the reliability of the study is strengthened. (Polit and Beck 2012, 256; Aveyard 2014, 116.)

And while qualitative research is more difficult to measure, both Aveyard (2014, 124–127) and Polit and Beck (2012, 115–117) offer guidelines for critically appraising qualitative research. Aveyard (2014, 121) suggests that it is a researcher's responsibility to become intimately familiar with a study's information and data set, in order to get broader picture of the phenomena studied. Qualitative analysis should focus on the identification of themes, patterns, regularities, as well as, inconsistencies in information (Polit & Beck 2012, 125; Aveyard 2014, 121). Aveyard (2014, 121) states that generation of themes is a rigorous process and heavily relies on the interpretation of the researcher, and therefore, is open to interpretation.

While general information regarding how to critically appraise quantitative and qualitative research was gathered from Aveyard (2014, 115–138), the following tables from Polit and Beck were specifically chosen and used as a tool to evaluate the eight articles selected for this review: quantitative critical appraisal table (Appendix 2) and qualitative critical appraisal table (Appendix 3). Appendix 4 (quantitative critical appraisal) and appendix 5 (qualitative critical appraisal) are the results, or final outcome, from the critical evaluation of these eight articles according to the questions and stipulations presented by Polit and Beck (Appendix 2 & 3).

### **4.3 Data Collection and Analysis**

Polit and Beck (2012, 108 & 111) state that in order to discern themes, concepts or categories in the pattern of results, developing multiple results matrices is advisable. Accordingly, two results matrices have been completed due to the fact that there are two research questions in this review. In the results matrix (Table 2) the reviewer has identified seven themes for the first research question: how does an early diagnosis of AD or dementia help patients and caregivers cope? And in the second results matrix (Table 3) four themes were uncovered for the second research question: how does advanced care planning help patients with AD (dementia), as well as, their caregivers?

It should be noted, that care planning appears in both matrices, as a result, this theme and/or category has been combined and addressed under the second research question in hopes of avoiding repetition. Also, for purposes of clarity regarding the second research question, the following definition of ACP has been provided: A process of discussing an individual's preferences for care they would like to receive at time when they may no longer be able to make such decisions or their wishes known (Poppe, Burleigh and Banerjee 2013, 1).

TABLE 2. Results Matrix #1.

Adapted from Aveyard 2014 (146)

How does an early diagnosis of AD or dementia help patients and caregivers cope?

	DeLepeleire et al. 2008	Garand, et al. 2011	Iliffe et al. 2003	Kissel & Carpenter. 2007	Morgan et al. 2014	Mukadam et al. 2011	Poppe et al. 2013	Robinson et al. 2012
<b>Theme 1:</b> Finally.... a diagnosis	pp. 569, 570		pp. 376, 377	p. 273	pp. 111, 115	pp. 1072, 1074, 1075		
<b>Theme 2:</b> Acceptance and moving forward	p. 570		p. 377	pp. 274, 276	pp. 114, 115, 117.	p. 1075		
<b>Theme 3:</b> Access to treatment	pp. 570, 571, 573		p. 376		pp. 111, 114, 116	p. 1070		
<b>Theme 4:</b> Information and prognosis	p. 570		pp. 376, 377	p. 276	p.114, 117	p. 1070		
<b>Theme 5:</b> Avoiding crises and patient safety	p. 570		p. 377	p. 276	pp. 114, 115	pp. 1070, 1073. 1074		
<b>Theme 6:</b> Reduce overall costs and prolonging institutionalization	p. 570		p. 378			p. 1070		
<b>Theme 7:</b> Planning for the future	p. 570	pp. 2, 6, 7	p.377	pp. 273, 276, 278	pp. 114, 115 116	p. 1070	pp. 1, 4	p. 405

## 5 RESULTS (Part 1)

For transparency and ease of reading, the results are described below in sections according to the results presented above in the results matrix #1 (Table 2). These results answer the first research question: how does an early diagnosis of AD, or dementia, help patients and caregivers cope?

### 5.1 Finally..... A diagnosis.

This literature review found that obtaining the diagnosis of dementia or AD is a long and difficult process (Iliffe et al. 2003, 367; Kissel & Carpenter 2007, 273; De Lepeleire et al. 2008, 569; Mukadam et al. 2011, 1072; Morgan et al. 2014, 111). This pattern consistently presented itself in five of the eight selected articles, or just over 62 percent. Due to the problematic nature of diagnosing dementia, it often goes undiagnosed (Iliffe et al. 2003, 376; Kissel & Carpenter 2007, 273; Morgan et al. 2014, 111). Morgan et al. (2014, 111) states that obtaining a diagnosis of dementia requires considerable diligence by caregivers and delays were not uncommon. As a matter of fact, they stated that the average time from first recognising signs to actually receiving a diagnosis was 3.1 years. Iliffe et al. (2003, 379) detailed that the diagnosis process can be drawn out and involves a variety of assessments and dialogues among those involved. Additional delays occur due to the fact that often dementia is but one of multiple comorbidities (Mukadam et al. 2011, 1072).

After interviewing rural family caregivers six months after a diagnosis of dementia for their loved ones, Morgan et al. (2014, 115 & 117) found that caregivers perceived receiving a diagnosis as a relief or the “climax of their help-seeking process.” Afterwards, both caregivers and patients alike, were found to experience less uncertainty over their situation (Iliffe et al. 2003, 376; Morgan et al. 2014, p 114). Morgan et al. (2014, 8 & 14) found that knowing the nature of the problem was found to be a prerequisite for taking control of the situation, furthermore, at the six month point post-diagnosis, caregivers exhibited a reduced sense of urgency and stress, regardless of their loved ones diagnosis. While Iliffe et al. (2003, 377) argues that it is caregivers that receive the greatest benefit from a

diagnosis, Mukadam's et al. (2011, 1075) findings present otherwise, stating that of the 18 minority ethnic caregiver participants, many felt that the diagnosis of their loved one was of no help (although exact numbers were not stated).

In their research, Kissel and Carpenter (2007) explore the pragmatics behind disclosing a diagnosis of dementia to patients and caregivers. They conducted a qualitative study, with semi-structured interviews of ten physicians whom worked in the Alzheimer's Disease Research Center. Although the sample size was small, the ten physicians represented different disciplines and were considered experts in their field. They reported that a few physician's felt that families whom pushed too early for a diagnosis of dementia, did so at their loved ones expense, contributing to their decline and loss of autonomy. (Kissel & Carpenter 2007, 276.) De Lepeleire et al. (2008, 570) contradicts this and claims that an early diagnosis actually improved the quality of life for both patients and caregivers.

Furthermore, Kissel and Carpenter (2007) found opposing attitudes among physicians. Although exact numbers were excluded, they state that the majority of the physicians felt that disclosing a diagnosis of dementia to patients was especially imperative in the early stages, but with the progression of the disease, became more important to disclose to their caregiver. In addition, they found three circumstances where postponing a diagnosis was deemed acceptable: when the patient was severely demented; secondly, by special requests of caregivers from different cultural backgrounds; and lastly, when a patient exhibits extreme fear or suicidal and homicidal ideation. (Kissel & Carpenter 2007, 275.)

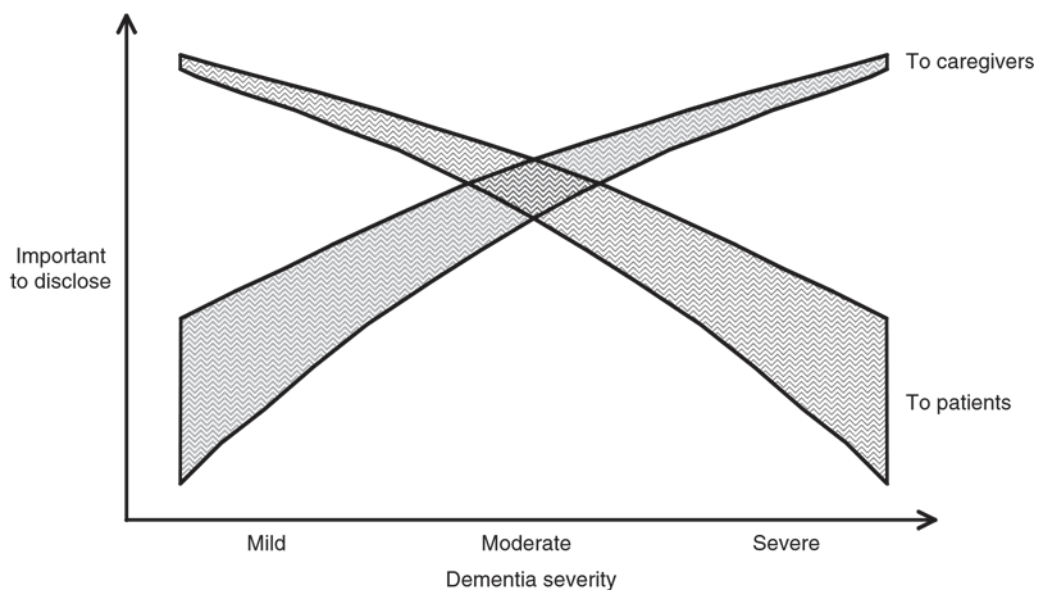


Figure 3. Variability in perceived importance of disclosing a diagnosis to patients and caregivers, by disease severity (Kissel & Carpenter 2007, 278).

De Lepeleire et al. (2008) conducted a qualitative study with participants from eight European countries regarding diagnostic processes in primary care for a diagnosis of dementia. Participants included 23 experts in dementia care from different disciplines. Participants completed questionnaires from which the answers were tabulated and then sent back to the participants in preparation for two focus groups meetings. The results from their study concludes simply, but poignantly, that there are no empirical disadvantages to a diagnosis, only advantages. (De Lepeleire et al. 2008, 568–576.)

## 5.2. Acceptance and moving forward

There was solid evidence in the theme of acceptance and moving forward, availing itself in five of the eight articles (Iliffe et al. 2003, 377; Kissel & Carpenter 2007, 276; De Lepeleire et al. 2008, 570; Mukadam et al. 2011, 1075; Morgan et al. 2014, 114–115 & 117). Acceptance of the new diagnosis of dementia or AD, was divided in two components: first, acceptance of the situation and secondly, acceptance of the impairments and symptoms.

Morgan et al. (2014) explored caregivers' hopes and expectations of the assessment, and their experiences in six months following disclosure. A qualitative design with interviews were performed during the diagnostic process and then again at a six month follow-up appointment. There were 30 participating caregivers and the setting was in a Canadian memory clinic. As a result of their research they found that following a diagnosis, participants had a sense of acceptance for their "new reality" or situation. They also referred to it as a "place of acceptance" from where they can move forward. (Morgan et al. 2014, 111–118). Iliffe et al. (2003, 377) suggests that this process of "coming to terms" with the new diagnosis, provides stability in family dynamics.

The second component of this theme deals with accepting the impairment or symptoms as a result of diagnosis. It places behaviors into context and helps loved

ones combat stigma associated with the disease (Kissel & Carpenter 2007, 276; Morgan et al. 2014, 115). One caregiver explained (Morgan et al., 2014):

Even people in church and people will stop me on the street and say you know like how's (patient) doing? Because like they see him and he just seems like, and I, I tell them. I mean what, there's no, no secret. There's no shame in it. It's just what it is, you know.

Another caregiver's perspective summarises the impact of a diagnosis for his wife, "...it made a difference. Then you can carry on without being frustrated." Not being able to comprehend the changes in their loved ones behavior is upsetting for caregivers. (Morgan et al. 2014, 114–116.)

### **5.3. Access to treatment**

Another reoccurring pattern as a result of an early diagnosis, was seen in the access to treatment (Iliffe et al. 2003, 376; Kissel & Carpenter 2007, 276; De Lepeleire et al. 2008, 570 & 571; Mukadam et al. 2011, 1070 & 1073; Morgan et al. 2014, 111, 114 & 116). This commonality occurred in half of the articles. These articles mentioned accessing treatment by two avenues: agency and social support and medication therapy treatment.

Iliffe et al. (2003,) conducted a large qualitative study of nearly 1000 professionals in the UK health care system, to explore the viewpoints of primary care physicians regarding the early diagnosis of dementia. A nominal group approach was employed. Of the findings, it was mentioned that an early diagnosis would enable access to agencies and support networks that can possibly relieve distress that caregivers often exhibit. (Iliffe et al. 2003, 376–381.) An opposing view suggests that there is a gap in service provisions to meet the needs of those diagnosed too early (De Lepeleire et al. 2008, 573). Because of the nature of the disease, caregivers are often with their loved one with dementia 24 hours a day. Referrals to services such as Home Care, that were previously unknown before diagnosis, can provide enormous relief to both the patient and the caregiver (Morgan et al. 2014, 116). Caregivers can also take advantage of services such as family counseling and Alzheimer's society groups (De Lepeleire et al. 2008, 570; Morgan et al.

2014, 116). In contrast to these studies, Mukadam et al. (2011, 1073), documented that there were delays in receiving services as a result of a mistrust of the healthcare system itself or a lack of information from the healthcare system.

The second piece of the access to treatment theme involves access to medication. A diagnosis of dementia or AD enables the use of therapeutic advances, particularly, cholinesterase inhibitors (Iliffe et al. 2003, 376; De Lepeleire et al. 2008, 570; Morgan et al. 2014, 114). However, Morgan and his associates failed to mention specifically what type of medication was beneficial to those with dementia.

#### **5.4. Information and prognosis**

Information was a concept that was consistently repeated throughout five of the eight articles, roughly 62 percent. Information was broken down into two areas: general information needed by caregivers and patients after diagnosis of AD and secondly, information relating to the prognosis of the disease.

Three studies found that an early diagnosis enabled information to be accessed. Kissel and Carpenter (2007, 276) and De Lepeleire et al. (2008, 570) reported this from the families perspective, particularly in regards to undertaking their own investigations about the disease, while Mukadam et al. (2011, 1070) doesn't stipulate one or the other. De Lepeleire et al. (2008, 570) states that an early diagnosis also enables healthcare professionals to provide appropriate advice and information to the patients and families.

An early diagnosis also aids those with dementia and their families by allowing them to gather information about the prognosis of the disease. Iliffe et al. (2003, 377) and Morgan et al. (2014, 114) suggests that caregivers want to know what symptoms they should expect as the disease progresses, as well as, when to expect these changes. It was reported that 41 percent of caregivers wanted information on prognosis, furthermore, knowing the nature of the problem was considered a prerequisite for taking control of their situation (Morgan et al. 2014, 114 & 117).



## **5.5. Safety and avoiding crisis**

Safety and avoiding crisis was a theme which unveiled itself in five of the eight articles. There was strong evidence that obtaining an early diagnosis of dementia or AD helps with safety issues, by enabling the anticipation and planning of future problems (Iliffe et al. 2003, 377; Kissel & Carpenter 2007, 276; De Lepeleire et al. 2008, 570; Mukadam et al. 2011, 1075; Morgan et al. 2014, 114–115 & 117).

The concept of safety is one that is important for all parties: the patient, the caregiver, healthcare staff, and society. From the angle of the patient with dementia or AD, Mukadam et al. (2011, p 1073) and Morgan et al. (2014, 115) state that getting lost and financial recklessness is not uncommon. On the other end of the spectrum, society at large is vulnerable to the potential hazards of driving dangerously (Kissel & Carpenter 2007, 276; De lepeleire 2008, 570). There is a fine line between compromising a patient's privacy and their overall health, with the safety and security of others (Kissel & Carpenter 2007, 276; Morgan et al. 2014, 115).

And lastly, an early diagnosis allows caregivers the time to anticipate and plan for future obstacles that may arise, thus improving the quality of life for patients and caregivers. (Iliffe et al. 2003, 377; De Lepeleire et al. 2008, 570; Mukadam et al. 2011, 1070).

## **5.6 Reducing costs and prolonging institutionalization**

The subject of costs and institutionalization was a common pattern occurring in three articles. There were two articles that supported the notion that an early diagnosis could inevitably lead to overall cost reductions, including savings from delaying patient institutionalization (De Lepeleire et al. 2008, 570; Mukadam et al. 2011, 1070), while another article written by Iliffe et al. (2003, 378) warned otherwise, stating that if diagnostic efforts improved, the number of cases would double, putting a strain on local service providers' financial situation.

## **5.7 Planning for the future**

The last theme has the strongest evidence appearing in all of the articles. An early diagnosis is important due to the fact that it enables patients, families and healthcare professionals to plan for the future (Iliffe et al. 2003, 377; Kissel & Carpenter 2007, 273, 276 & 278; De Lepeleire et al. 2008, 570; Garard et al. 2011, 2, 6 & 7; Mukadam et al. 2011, 1070; Robinson et al. 2012, 405; Poppe, Burleigh & Banerjee 2013, 1 & 4; Morgan et al. 2014, 114–116). This theme over-laps with this study's second research question, and therefore will be described in detail, following the Results Matrix #2.

TABLE 3. Results Matrix #2.

Adapted from Aveyard 2014 (146)

How does advanced care planning help patients with AD (dementia), as well as, their caregivers?

	<b>De - Lepeleire et al. 2008</b>	<b>Gar- and et al. 2011</b>	<b>Iliffe et al. 2003</b>	<b>Kissel &amp; Car- penter. 2007</b>	<b>Morgan et al. 2014</b>	<b>Mukdam et al. 2011</b>	<b>Poppe et al. 2013</b>	<b>Robinson et al. 2012</b>
<b>Theme 1:</b> A new reality: thinking about and preparing for the future	p. 570	pp. 2, 6	p. 377	p. 276	p.115, 116		p. 1	
<b>Theme 2:</b> Less stress, anxi- ety and depres- sion	p.570				p.115		p.1	
<b>Theme 3:</b> Patients' care preferences known and in- creased quality of life	p. 570	p. 2		pp. 275, 276, 278			pp. 1, 3	pp. 401, 403
<b>Theme 4:</b> Legal help	p. 570	pp. 2, 7	p. 377	pp. 275, 276				pp. 403, 404

## 6 RESULTS (Part 2)

For transparency and ease of reading, the results are described below in sections according to the results presented above in the results matrix #2 (Table 3). These results answer the second research question: how does advanced care planning help patients with AD (dementia), as well as, their caregivers?

### 6.1 A new reality/new circumstances: thinking about and preparing for the future

This common theme was well represented throughout six of the eight articles, an impressive 75 percent occurrence rate. ACP helps those with dementia or AD and their caregivers by helping them come to terms with their new reality or situation. This pattern of allowing patients and their caregivers' time to think and plan for the future was very significant (Iliffe et al. 2003, 377; Kissel & Carpenter 2007, 276; De Lepeleire et al. 2008, 570; Garard et al. 2011, 2; Poppe et al. 2013, 1; Morgan et al. 2014, 115–116).

Although some physicians express reluctance at giving a “life-changing diagnosis” or “don’t see the harm” in a delayed diagnosis, others agree that an early diagnosis can assist everyone involved by giving them a time-limited opportunity to plan for the future (Iliffe et al. 2003, 377 & 379; Kissel & Carpenter 2007, 276; De Lepeleire et al. 2008, 570; Garard et al. 2011, 2 Morgan et al. 2014, 115–116). These articles mentioned the importance of planning for the following areas: medical, financial and other major life decisions, such as long term placement.

### 6.2. Less stress, anxiety and depression

This theme was present in three of the eight articles. Results show people with dementia, and their caregivers, experience less stress and anxiety as a result of completing an ACP (De Lepeleire et al. 2008, 570; Poppe et al. 2013, 1; Morgan et al. 2014, 116). Poppe et al. (2013, 1–5) conducted a qualitative study with in-depth interviews surrounding the topic of ACP in early dementia. There were a

mix of patients, caregivers and staff from a memory clinic and a community mental health team: twenty-six participants in total. One important finding was that patients exhibited less stress after their ACP session, due to the fact that they made their care preferences known. Supporting this finding, Morgan et al. (2004, 116) found that pre-diagnosis, caregivers were stressed, and had a “sense of urgency” about them, which was replaced with relief six months post diagnosis, regardless of the diagnosis outcome. De Lepeleire et al. (2008, 570) concurs with Morgan’s depiction of the situation.

### **6.3. Allows patients’ care preferences to be known**

An ACP benefits patients’ with dementia, and their loved ones, by establishing patients’ care preferences in the early stages of dementia (Kissel & Carpenter 2007, 275–276 & 278; De Lepeleire et al. 2008, 570; Garard et al. 2011, 2; Robinson 2012, 401; Poppe et al. 2013, 1 & 3). This was a yet another common thread of strong evidence, occurring in five of the eight articles.

Poppe et al. (2013) conducted a qualitative study for the purposes of evaluating the use and acceptance of an ACP for those shortly after a diagnosis of dementia. In-depth interviews were given for a mix of 26 participants: patients, caregivers and health care staff. Interestingly enough, only one-third of the patients interviewed had even thought of an ACP prior to their interview. One finding from this study (Poppe et al. 2013, 1) corresponds well to this review’s theme. They found that after the ACP process, three quarters of their participants with dementia reported relief and less stress over their future, while only one-third found this process distressing and difficult to fathom due to the fact that they could not predict what their future had in store for them. In addition, all of the caregivers felt the ACP process was beneficial. They felt more equipped to make decisions that were more in line with their loved ones wishes. (Poppe et al. 2013, 1–5.) De Lepeleire et al. (2008, 570) warns that problems, such as non-compliance with taking medication, often occur when patient wishes are not taken into consideration.

Supporting evidence by Kissel and Carpenter et al. (2007, 276 & 278) suggest that physician’s believe that ACP enables patients to establish their wishes for care,

and also, to be more involved in their own therapies and planning. Contrastingly, three participant physicians in this study warned that intervening too early could lead to the general decline of the patient and add to increased dependency.

Through a qualitative study, Robinson et al. (2012) examined professionals' experiences of advanced care planning in dementia and palliative care. Purposive sampling was employed in the recruitment process of obtaining participants. Experienced qualitative researchers, conducted both focus groups and individual interviews for 95 participants representing a wide-range of professions from the UK: nurses, palliative specialists, physicians and attorneys. The study found that while participants believed the idea of an ACP was good, a gap in services exists in supporting patient's preferences, particularly with the terminal illness- dementia. Professionals agree that there are many barriers to successfully enacting an ACP. Some participants expressed doubt over the value of an ACP, and furthermore, concern over their inability to 'deliver' patient preferences for care. (Robinson et al. 2012, 401–408.)

#### **6.4 Legal help**

The concept of legality was a pattern that presented itself in five of the eight articles. From a legal point of view, an ACP helps patients and caregivers make appropriate arrangements for their future (Iliffe et al. 2003, 377; Kissel & Carpenter 2007, 275–276; De Lepeleire et al. 2008, 570; Garand et al. 2011, 2 & 7; Robinson et al. 2012, 403–404).

Garand et al. (2011) conducted a quantitative study to determine the ACP completion rates and patterns of 127 participants whom had no advanced directives at the time of their diagnosis of MCI or AD. The study was completed at the University of Pittsburgh Alzheimer's Disease Research Centre (ADRC). Consent was obtained from participants prior to a complete examination from different disciplines: medical and neurological history and examination, brain imaging, psychosocial assessment, psychiatric interview, and neuropsychological testing. All ADRC participants had to have a caregiver, or informant, whom would have regular contact with the patient and is familiar with their current situation, so up-to-date information can be provided during interviews. Beginning with the

first psychosocial evaluation, and every annual interview thereafter, the social worker asked the participant and informant if a living will (LW) and a durable powers of attorney (DPOA) has been completed. If these advanced directives had not been completed, the social worker verbally explained their purpose and then provided them with written material which supported the information which was given verbally. And lastly, the social worker asked if the patient and informant would like a referral to an Elder Law Attorney in their community. Data was extracted during annual interviews with patients from their informants. Participants' situation was followed over a five year period. (Garand et al. (2011, 712–720.)

Garand et al. (2011, 6) discovered that regardless of their diagnosis (MCI or AD), only a minority (39%) of participants managed to complete an ACP during this five year period. In support of this finding, Poppe et al. (2013, 4) states that it is crucial that professionals initiate discussion of ACP, because patients and families are unlikely to do so otherwise. And lastly, the role of families of those diagnosed play a key role in treatment (Morgan et al. 2014, 116), and particularly, in making sure that an ACP take place (Gerand et al. 2011, 6).

While Gerand et al. (2011) focused on understanding ACP completion rates for patients, Robinson et al. (2012) examined the other side of the coin, by targeting the experiences of professionals relating to the implementation of an ACP. The latter study uncovered legal inconsistencies surrounding the implementation of an ACP. (Robinson et al. 2012, 401–408.) According to Mukadam et al. (2011, 1074), physicians (and paramedics) in the UK expressed the most uncertainty regarding aspects of the ACP, which can be seen as a significant problem since they are typically the first point of contact for patients with cognitive impairment. While physicians make daily judgements regarding a patient's capacity, many had reservations of putting anything in a legally binding document due to potential litigation (Robinson et al. 2012, 404). Interestingly, with the exception of attorneys and palliative care specialists, all professional participants felt inept to implement an ACP, regardless whether or not they had received previous training on the subject (Robinson et al. 2012, 405). Iliffe et al. (2003, 376) stated that physicians feel inadequately trained to respond to their patients' with dementia

and their families. Other legal barriers to the implementation of an ACP included: confusion about the many forms used in documentation and whether or not they were legally transferable to other settings, confusion regarding whom was legally responsible for the completion of advanced directives, and costs associated with legal services for patients and their families.

## 7 DISCUSSION

### 7.1 Findings

The purpose of this study was to answer the following two questions: how does an early diagnosis of dementia and/or AD help patients and caregivers cope and how does advanced care planning help patients with AD, as well as, their caregivers? Through the meticulous search and discovery of themes during this review (Table 2 & Table 3), the answers to the research questions have unravelled themselves.

The thematic analysis uncovered an overwhelming amount of evidence supporting the research question that an early diagnosis aids those with AD, as well as their caregivers, however, the process also proved that obtaining a diagnosis was lengthy and often problematic. This has implications for nursing, as well as, primary care. It is at the primary care level where patients and caregivers first seek help. It was also shown that all professionals at the primary care level, particularly physicians and nurses, could benefit from continuing education.

And as for the second research question. The thematic analysis showed that while ACP was found to be an overall positive and essential component of care for those with AD, it was also detected that the implementation of care plans were often challenging for all those involved, but particularly professionals. This has implications for nursing and can be seen as an opportunity to improve care. Education needs to be top priority and paper work needs to be simplified. Also, it was found that professionals have a hard time implementing an ACP due to the fact that there is a large gap in service providers to accommodate these needs.

And lastly, the findings from the thematic analysis are in line with local policy here in Finland. Finland's National Memory Programme (2013) views an early diagnosis as "crucial," as does this literature review. Furthermore, the last "pillar" of their "memory-friendly" programme, which is strengthening research and education, corresponds to the need for continuing education for primary care professionals discovered in this review. They also see an early diagnosis as a conduit to treatment and rehabilitation which can ultimately improve quality of life for



those with AD (and their caregivers) and curb rising costs (Finish Ministry of Health 2013, 7). And while this programme doesn't specifically mention ACP, they state that case management is a key component to high quality individualized care for those with dementia. Finland does however, use personalised palliative care plans in the late stage of dementia as a way for professionals to coordinate care so that families anguish can be diminished and quality of care toward the end of life can be achieved (2013, 14).

## **7.2. Trustworthiness**

Polit and Beck (2012, 174–175) states that when considering literature review, it is the quality of the research that justifies trustworthiness. Aveyard (2014, 123) explains that the research process should have 'truth value.' Trustworthiness in this review can be seen beginning with the careful article selection process (Figure 2), including the use of an inclusion and exclusion table (Table 1). Aveyard (2014, 79) asserts that clear inclusion-exclusion guidelines informs the reader that these criteria were carefully considered and fit the needs of the review. Databases from reputable health and social sciences field, such as CINAHL or PubMed were used to enhance trustworthiness (Polit & Beck 2012, 100 & 103; Aveyard 2014, 81–82).

Aveyard (2014, 10) states that in regards to article selection that "no stone should be left unturned." Correspondingly, this reviewer has also used and documented other methods, such as an author search and an ancestry search, in the article retrieval process. In addition, only primary sources were used in the selection of articles (Aveyard 2014, 64; Polit & Beck 2012, 94). As recommended by Aveyard (2014, 123), the reviewer clearly and thoroughly documented the research procedure and was transparent in the data analysis process as seen in the methodological matrix and the evaluation matrix (Appendix 1), critical appraisal evaluations seen in (Appendix 4 & 5) and finally, the results matrices (Table 2 & 3). And lastly, trustworthiness can be seen in that this study answers its two research questions.

On a side note, the reviewer received permission to use Kissel and Carpenter's figure (Figure 3) by the authors themselves on August 29, 2016 and then by the publisher of their article, Taylor and Francis, on October 12, 2016.

### **7.3. Limitations**

Aveyard (2014, 160) claims that in order to place the results of the study into context, it is important to look at the limitations of the researcher. As a result, limitations for this study are described accordingly. The first, and perhaps most significant limitation, is that this reviewer lacks experience and has completed this project alone. For example, due to lack of experience in processes, steps have had to be repeated on several occasions. While this repetition of procedures was time consuming, it strengthened the reviewer's knowledge and confidence in correctly completing a literature review. This information will benefit the reviewer in future research endeavours. And while performing this literature review alone enabled freedom of creativity, having a partner would have decreased the likelihood of bias and increase objectivity as suggested by Polit and Beck (2012, 97). Aveyard (2014, 93) ascertains that it strengthens the rigour of the process when another researcher is there to compare your results against. And while another library was visited on two occasions to retrieve articles, there were other articles that were available via internet libraries that were off limits due to the associated costs of each article. But overall, this interpretations of this study are in alignment with the limitations of this literature review.

The transferability of the results of a study to another setting or group is yet another aspect that builds trustworthiness. Three of the selected articles might have transferability issues due to the nature and size of the populations studied, regardless of the fact that their research was well written and transparent in manner in which their methodologies, as well as, limitations were described. For example, Mukadam et al. (2011) studied ethnic minority caregivers of those with AD in the UK and Morgan et al. (2014) studied Canadian caregivers of loved ones with dementia living in rural areas. Also, Kissel and Carpenter's (2007) study only had 10 participants as a sample, even though these participants were physicians with a great deal of experience and were considered experts in their field.

#### **7.4. Ethical considerations**

Patton (2002, 51) explains clearly that “neutrality is not an easily attainable stance, so all credible research strategies include techniques for helping the investigator become aware of and deal with selective perception, personal biases, and theoretical predispositions.” While every effort was used to be impartial and avoid personal bias, as recommended by Polit and Beck (2012, 97), it must be noted that the researcher performed this study individually, therefore increasing the risk for researcher bias. Ethical guidelines from Polit and Beck (2012, 168) were followed by writing clearly and transparently throughout the review. Processes were described in detail and systematic in nature, following the methodological guidelines established by Polit and Beck (2012) and Aveyard (2014). And while the results section of this paper is open for interpretation, the selection process was detailed to the point that another researcher could easily reproduce this study. Transparency can be seen by the production of two results matrices, where not only are the themes recorded, but page numbers in which these themes arise are documented. Being able to reproduce results is a sign that the study was completed in an ethical manner (Polit & Beck 2012, 97).

This literature review was approved and deemed as ethically appropriate by TAMK. For this review, guidance and advice was warmly received from the working life connection at TAMK, as well as, from two undergraduate nursing students.

As far as the articles selected for this review, five of the eight were granted approval by an ethics board. Two were not mentioned specifically due to the fact that one was a nationwide educational study in the UK (Iliffe et al. 2003) and the other was an European-wide study consisting of eight countries within Europe, of which, all participating experts belonged to the INTERDEM group (De Lepeleire et al. 2008). Only one study did not mention ethical standards employed (Kissel & Carpenter 2007).

## 7.5. Recommendations

In the process of completing all of the attached matrices, it has become clear there are gaps in care or treatment that need to be studied. As a result the reviewer has listed recommendations according to the two research topics of this literature review: an early diagnosis and an ACP.

### Recommendations to foster an earlier diagnosis of AD:

- 1) Based on Mukadam's et al. (2011, 1077) study, a study to determine whether or not an educational intervention for ethnic minority caregivers would help them with seeking for help earlier for their loved ones.
- 2) Further studies would be beneficial after educational interventions have been completed. For example, evidence suggest that primary care physicians require more education regarding disclosing dementia, and dementia itself, in order to successfully diagnose earlier. Educate first, then study the effects of the educational intervention. Or another idea is simply, what type or form of education would best suit physicians and other primary care professionals?
- 3) A study regarding what type, or form, of information should be given to the public in order to raise awareness about the importance of an early diagnosis.

### Recommendations to foster the completion of an ACP:

- 1) Evidence suggests that there are gaps in services for those with AD. A study relating specifically to these service needs of those with AD and their caregivers over the course of the disease.
- 2) From professionals' point of view, how could ACP be simplified in order to increase completion rates?
- 3) Another idea stems off of Garand's et al. (2011, 6) research, which is to examine modifiable factors that influence ACP completion rates among those at high risk of future cognitive incapacity.

And finally, in addition to the above mentioned recommendations. Material gathered from this literature review could serve as teaching material for students in health care programs at TAMK, but particularly the nursing program.

## **8. CONCLUSION**

The evidence gathered from this study clearly shows that there are overwhelming benefits associated with an early diagnosis and ACP for those with AD, as well as their caregivers. And yet while this is true, it was also discovered that barriers exist in both obtaining a diagnosis and in the implementation of an ACP. The process of obtaining an early diagnosis was found to be long and problematic. And although an ACP was recognized as a positive and essential component of care for those with AD, it was found that the implementation of care plans were challenging for professionals.

The implications from this literature review are significant. The information presented from this literature review provides nursing students, and practicing nurses, with current and relevant information relating to best practices in care for those with AD. This ultimately translates into better understanding and care for those suffering from AD, as well as their significant others.

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## APPENDICES

## APPENDIX 1. Methodological &amp; Evaluation Matrix

1(4)

AUTHORS, YEAR & COUNTRY OF ORIGIN	SAMPLE SIZE	METHOD- OLOGY	MAJOR FINDINGS	STRENGTHS	WEAKNESSES
De Lepeleire et al.  2008  Belgium, France, The Netherlands, Ireland, It- aly, Portu- gal, Spain, and the UK.	23 experts of differ- ent disci- plines from eight different countries	Qualitative	Three key themes found to aid in the diagnosis of de- mentia in primary care: a “timely diagnosis,” need for guidelines, appropriate re- ferral paths and diagnostic strategies with multi-collab- oration.	A wide range of profes- sionals and researchers working in dementia care from eight different coun- tries in Europe. Recruit- ing scrutiny, thematic analysis and synthesis were strong.	There was not enough participants from the social care field. Ma- terial lost in translation due to different lan- guages. The content of the diagnostic meth- ods in dementia care within the GP voca- tional training was not examined. No quanti- tative measures were performed.
Gerand et al.  2011  USA	127 par- ticipants (72 with MCI or early AD and 55 with mod- erate to severe AD) with no prior advanced directives.	Quantitative	Only a minority of the sub- jects completed an ACP. Further studies need to in- vestigate how to accom- plish this, particularly when persons are in the early stages of dementia. ACP should address medical, fi- nancial and other signifi- cant life decisions.	Large sample. Well writ- ten and systematic. First study examining ACP & advance directive com- pletion rates for those at high risk for severe cog- nitive delays in the fu- ture.	Since this is a second- ary analysis, they couldn’t directly ask participants questions. Also, study partici- pants sought out a di- agnosis and 89.8% were European Ameri- can. This data might not properly represent the general population as a whole. The study design did not allow for the type of DPOA (financial vs. healthcare). The com- pletion of advanced di- rectives were based on the caregiver testi- mony.

<p>Iliffe et al. 2003 Great Britain</p>	<p>990 Parti- cipants, (247 GPs, 146 com- munity nurses, 36 nurses, 79 mental health nurses and others (working in a range of hospi- tal, resi- dential and com- munity settings)</p>	<p>Qualitative</p>	<p>Three areas of importance was found. First, the idea that there is “no harm done” in delaying a diagnosis which has so many negative associations. Second, dementia is a process and it should first be “recognized” and then later diagnosed. And finally, there is concern that an early diagnosis would not necessarily translate into better care due to a gap in services available.</p>	<p>Large sample contributes to better understanding of phenomena. Professionals with different positions add depth and different reference standpoints.</p>	<p>Workshops attracted participants interested in dementia and older people, so results might not be transferable across settings. This study does not take into account patients’ or caregivers’ perspectives. The workshop atmosphere doesn’t foster in-depth discussions or details and participants are apt to give erroneous, overly positive responses about interactions and collaboration between service providers. No quantitative measures were taken.</p>
<p>Kissel and Carpenter 2006 USA</p>	<p>10 physi- cians</p>	<p>Qualitative</p>	<p>Physicians’ disclosure strategies vary from patient to patient. There are numerous factors that Physicians consider before giving a diagnosis of AD and/or dementia, including: the utility of the disclosure in combination with the need to instigate care planning; family dynamics; patient and family preferences; the physicians’ level of diagnostic certainty; the patients’ and families’ education level and prior knowledge of dementia; and the time restrictions of a medical visit.</p>	<p>Material can contribute to practice guidelines. Sample is made up of experts in the field of assessment and diagnosis of dementia from the Alzheimer’s Disease Research Center.</p>	<p>Small sample and from only one agency, which could pose as a possible transferability issue. No quantitative measures conducted. No external review board mentioned.</p>

<p>Morgan et al.</p> <p>2013</p> <p>Canada</p>	<p>30 participants</p>	<p>Qualitative</p>	<p>There is significant value to a diagnosis of dementia for caregivers, even though obtaining a diagnosis is often a long and complicated process. Pre-diagnostic interview results show that caregivers needed to know or wanted a name for the problem. Accessing treatment, knowing what to expect and receiving guidance was also important. At the six month post-diagnostic mark caregivers reported that the diagnosis provided relief, validation and improved access to services. No “timely diagnosis” translates into missed opportunities for therapeutic and social interventions, as well as, a general decline in overall emotional state.</p>	<p>The strength of this study lies within its methodological processes and interpretation of findings. The transparency in the documentation of steps and the interpretation of findings enhanced credibility and reduced bias. Measures taken were very well detailed.</p>	<p>This does not take into account the patients’ perspective. This data was gathered from a memory clinic, therefore, results might be different if it were from a general practice setting. Participants were from rural areas, which might influence the help-seeking process, or effect generalizations to other settings. No quantitative measures were completed.</p>
<p>Mukadam et al.</p> <p>2011</p> <p>UK</p>	<p>18 ethnically diverse family members whom provide support for their loved one with dementia.</p>	<p>Qualitative</p>	<p>Being in a minority ethnic group in the UK is actually a hindrance to an early diagnosis of dementia. Due to their sense of familial obligations and their negative outlook towards psychiatric services, seeking an early diagnosis is not highly regarded. This population typically seeks help as a result of a specific incidence (an accident, someone outside of the family noticing or when caregivers can no longer cope).</p>	<p>This qualitative method allows for descriptively rich accounts of the phenomena studied. Even though the sample was small, it was varied. One of the researchers coding was blind to the ethnicity of the participants, reducing the possibilities of bias. Translators were available for those whom needed it.</p>	<p>A small sample and no quantitative measures were taken. Socioeconomic positions were not taken into account. Even though interviews were translated and transcribed and sent to participants for their review, it was possible that some information was lost in translation. The results might not transfer to other settings. Patient views were not considered.</p>

Poppe et al.  2013  UK	12 patients, 8 care givers who had participated in ACP discussions, and 6 staff members from a memory clinic, and a community health team.	Qualitative	There were positive outcomes associated with the practice of ACP, including: lower stress levels for patients and their care givers concerning the future and higher participation levels regarding care preferences. In addition, collaboration amongst care providers was emphasized.	That all viewpoints were taken into account during interviews: professionals, patients and caregivers. The methodological process was top notch. Triangulation was achieved.	No quantitative measures were taken. Sample size was small. Findings might not transfer to other settings.
Robinson et al.  2012  UK	95 participants	Qualitative	In theory professionals agree that an ACP is beneficial, but in reality it is difficult to implement. Findings presented obstacles for ACP and ideas for future improvement.	A wide range of professionals across different clinical settings. This enabled researchers to view the challenges of implementing the ACP from within and outside the healthcare environment.	Study was conducted in only one area of the country. These findings do not necessarily apply to other settings. No quantitative measurements were taken. Study did not take into account patients or caregivers views regarding ACP.

**APPENDIX 2. Quantitative Critical Appraisal Guide.  
Polit and Beck (112–114)**

1(3)

<b>TITLE QUALITY</b>	Is the title a good one, succinctly suggesting key variables and the study population?
<b>ABSTRACT QUALITY</b>	Does the abstract clearly and concisely summarize the main features of the report (problem, methods, results, conclusions)?
<b>INTRODUCTION</b>	
<b>Statement of the problem</b>	<p>Is the problem easy to identify?</p> <ul style="list-style-type: none"> <li>• Does the problem statement build a clear, persuasive argument for the new study?</li> <li>• Does the problem have significance for nursing?</li> <li>• Is there a good match between the research problem and the methods used? Is a quantitative approach appropriate?</li> </ul>
<b>Hypotheses and/or research question</b>	<ul style="list-style-type: none"> <li>• Are research questions/hypotheses explicitly stated? If not, is their absence justified?</li> <li>• Are questions/hypotheses appropriately worded, with clear specification of key variables and the study population?</li> <li>• Are the questions/hypotheses consistent with the literature review and the conceptual framework?</li> </ul>
<b>Literature review</b>	<ul style="list-style-type: none"> <li>• Is the literature review based mainly on primary sources?</li> <li>• Does the review provide a current evidence on the problem?</li> <li>• Does it provide a sound basis for the new study?</li> </ul>
<b>Conceptual/ theoretical framework</b>	<ul style="list-style-type: none"> <li>• Are key concepts adequately defined?</li> <li>• Is there a conceptual/theoretical framework, rationale, and/or map, and (if so) is it appropriate? If not, is the absence of one justified?</li> </ul>
<b>METHODS</b>	
<b>Method (protection of)</b>	<ul style="list-style-type: none"> <li>• Were appropriate procedures used to safeguard rights of the study participants?</li> <li>• Was the study externally reviewed (IRB/ethics review board)?</li> <li>• Was the study designed to minimize risks and maximize benefits to participants?</li> </ul>
<b>Research design</b>	<ul style="list-style-type: none"> <li>• Was the most rigorous possible design used, given the study purpose?</li> <li>• Were appropriate comparisons made to enhance interpretability of the findings?</li> <li>• Was the number of data collection points appropriate?</li> <li>• Did the design minimize biases and threats to the internal, construct, and external validity of the study?</li> </ul>
<b>Population and sample</b>	<ul style="list-style-type: none"> <li>• Is the population described?</li> <li>• Is the sample described in sufficient detail?</li> <li>• Was the best possible sampling design used to enhance the sample's representativeness?</li> <li>• Was sampling biases minimized?</li> <li>• Was the sample size adequate?</li> </ul>

<b>Data collection and measurement</b>	<ul style="list-style-type: none"> <li>• Are the operational and conceptual definitions congruent?</li> <li>• Were key variables operationalized using the best possible method (e.g., interviews, observations, and so on) and with adequate justification?</li> <li>• Are specific instruments adequately described and were they good choices, given the study purpose, variables being studied, and the study population?</li> <li>• Does the report provide evidence that the data collection methods yielded data that were reliable and valid?</li> </ul>
<b>Procedures</b>	<ul style="list-style-type: none"> <li>• If there was an intervention, is it adequately described, and was it rigorously developed and implemented? Did most participants allocated to the intervention group actually receive it?</li> <li>• Were data collected in a manner that minimized bias? Were the staff who collected data appropriately trained?</li> </ul>
<b>RESULTS</b>	
<b>Data analysis</b>	<ul style="list-style-type: none"> <li>• Were analyses undertaken to address each research question or test each hypothesis?</li> <li>• Were appropriate statistical methods used, given the level of measurement of the variables, number of groups being compared, and assumptions of the tests?</li> <li>• Was the most powerful analytic method used (e.g., did the analysis help to control for confounding variables)?</li> <li>• In intervention studies, was an intention-to-treat analysis performed?</li> <li>• Were problems of missing values evaluated and adequately addressed?</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>• Is information about statistical significance presented?</li> <li>• Are the findings adequately summarized, with good use of tables and figures?</li> <li>• Are findings reported in a manner that facilitates a meta-analysis, and with sufficient information needed for EBP?</li> </ul>
<b>DISCUSSION</b>	
<b>Interpretations of findings</b>	<ul style="list-style-type: none"> <li>• Are all major findings interpreted and discussed within the context of prior research and/or the study's conceptual framework?</li> <li>• Are causal inferences, if any, justified?</li> <li>• Are interpretations well-founded and consistent with the study's limitations?</li> </ul>
<b>Implications and recommendations</b>	<ul style="list-style-type: none"> <li>• Do the researchers discuss the implications of the study for clinical practice or further research—and are those implications reasonable and complete?</li> </ul>
<b>GLOBAL ISSUES</b>	
<b>Presentation</b>	<ul style="list-style-type: none"> <li>• Is the report well-written, organized, and sufficiently detailed for critical analysis?</li> <li>• In intervention studies, is a consort flow chart provided to show the flow of participants in the study?</li> <li>• Is the report written in a manner that makes the findings accessible to practicing nurses?</li> </ul>

3(3)

<b>Researcher credibility</b>	<ul style="list-style-type: none"> <li>• Do the researchers' clinical or methodologic qualifications and experience enhance confidence in the findings and their interpretation?</li> </ul>
<b>Summary</b>	<ul style="list-style-type: none"> <li>• Despite any limitations, do the study findings appear to be assessment valid—do you have confidence in the truth value of the results?</li> <li>• Does the study contribute any meaningful evidence that can be used in nursing practice or that is useful to the nursing discipline?</li> </ul>

**APPENDIX 3. Qualitative Critical Appraisal Guide  
Polit & Beck 2012 (115–117)**

1(3)

<b>TITLE</b>	<ul style="list-style-type: none"> <li>• Is the title a good one, succinctly addressing the phenomena and population being studied?</li> </ul>
<b>ABSTRACT</b>	<ul style="list-style-type: none"> <li>• Does the abstract clearly and concisely summarize the main features of the report (problem, methods, results, conclusions)?</li> </ul>
<b>INTRODUCTION</b>	
<b>Problem Statement</b>	<ul style="list-style-type: none"> <li>• Is the problem easy to identify?</li> <li>• Does the problem statement build a persuasive argument for the new study?</li> <li>• Does it have significance for nursing?</li> <li>• Is there a match between the problem and tradition, paradigm, and methods?</li> </ul>
<b>Research questions</b>	<ul style="list-style-type: none"> <li>• Are research questions explicitly stated? If not, is their absence justified?</li> </ul>
<b>Literature review</b>	<ul style="list-style-type: none"> <li>• Is there a good summary of existing knowledge related to the problem or phenomena of interest?</li> <li>• Is there a sound basis for the new study?</li> </ul>
<b>Conceptual underpinnings</b>	<ul style="list-style-type: none"> <li>• Are key concepts defined?</li> <li>• Are concepts, tradition, and ideology appropriate for studying this topic?</li> </ul>
<b>METHOD</b>	
<b>Protection of participants' rights</b>	<ul style="list-style-type: none"> <li>• Were procedures used to safeguard the rights of study participants? Was the study subject to external review by an IRB/ethics board?</li> <li>• Was the study designed to minimize risks and maximize benefits to participants?</li> </ul>
<b>Research design and research tradition</b>	<ul style="list-style-type: none"> <li>• Is the identified research tradition congruent with the methods used to collect and analyze data?</li> <li>• Was an adequate amount of time spent in the field or with participants?</li> <li>• Did the design unfold in the field, giving researchers opportunities to capitalize on early understandings?</li> <li>• Was there an adequate number of contacts with study participants?</li> </ul>

<b>Sample and setting</b>	<ul style="list-style-type: none"> <li>• Was the group or population adequately described?</li> <li>• Were the setting and sample described in sufficient detail?</li> <li>• Was the approach used to recruit participants or gain access to the site appropriate?</li> <li>• Was the sample size adequate? Was saturation achieved?</li> </ul>
<b>Data collection</b>	<ul style="list-style-type: none"> <li>• Were the methods of gathering data appropriate? Were data gathered through two or more methods to achieve triangulation?</li> <li>• Did the researcher ask the right questions or make the right observations, and were they recorded in an appropriate fashion?</li> <li>• Was a sufficient amount of data gathered? Were the data of sufficient depth and richness?</li> </ul>
<b>Procedures</b>	<ul style="list-style-type: none"> <li>• Are data collection and recording procedures adequately described and do they appear appropriate?</li> <li>• Were data collected in a manner that minimized bias?</li> <li>• Were the staff who collected data appropriately trained?</li> </ul>
<b>Enhancement of trustworthiness</b>	<ul style="list-style-type: none"> <li>• Did the researchers use effective strategies to enhance the trustworthiness/integrity of the study, and was the description of those strategies adequate?</li> <li>• Did the researcher document research procedures and decision processes sufficiently that findings are auditable and confirmable?</li> <li>• Is there “thick description” of the context, participants, and findings, and was it at a sufficient level to support transferability?</li> </ul>
<b>RESULTS</b>	
<b>Data Analysis</b>	<ul style="list-style-type: none"> <li>• Are the data management and data analysis methods sufficiently described?</li> <li>• Was the data analysis strategy compatible with the research tradition and with the nature and type of data gathered?</li> <li>• Did the analysis yield an appropriate “product?”</li> <li>• Do the analytic procedures suggest the possibility of biases?</li> </ul>
<b>Findings</b>	<ul style="list-style-type: none"> <li>• Are the findings effectively summarized, with good use of excerpts and supporting arguments?</li> <li>• Do the themes adequately capture the meaning of the data? Does it appear that the researcher satisfactorily conceptualized the themes or patterns in the data?</li> <li>• Does the analysis yield an insightful, provocative, authentic, and meaningful picture of the phenomenon under investigation?</li> </ul>
<b>Theoretical integration</b>	<ul style="list-style-type: none"> <li>• Are the themes or patterns logically connected to each other to form a convincing and integrated whole?</li> <li>• Are figures, maps, or models used effectively to summarize conceptualizations?</li> </ul>



<b>DISCUSSION</b>	
<b>Interpretations of the findings</b>	<ul style="list-style-type: none"> <li>• Are the findings interpreted within an appropriate social or cultural context?</li> <li>• Are major findings interpreted and discussed within the context of prior studies?</li> <li>• Are the interpretations consistent with the study's limitations?</li> </ul>
<b>Implications and recommendations</b>	<ul style="list-style-type: none"> <li>• Do the researchers discuss the implications of the study for clinical practice or further inquiry and if so, are they reasonable?</li> </ul>
<b>GLOBAL ISSUES</b>	
<b>Presentation</b>	<ul style="list-style-type: none"> <li>• Is the report well written, organized, and sufficiently detailed for critical analysis?</li> <li>• Is the description of the methods, findings, and interpretations sufficiently rich and vivid?</li> </ul>
<b>Researcher credibility</b>	<ul style="list-style-type: none"> <li>• Do the researchers' clinical qualifications and experience enhance confidence in the findings and their interpretation?</li> </ul>
<b>Summary</b>	<ul style="list-style-type: none"> <li>• Do the study findings appear to be trustworthy?</li> <li>• Does the study contribute any meaningful evidence that can be used in nursing practice?</li> </ul>

**APPENDIX 4. Quantitative Critical Appraisal Table.****Adapted from Polit and Beck 2012 (112–14)****1(2)**

	<b>Garand et al., 2011</b>
<b>TITLE</b>	Using the term cognitive impairment is not specific enough. This term includes other cognitive impairments which are not addressed in this study (amnesia, delirium, substance-abuse cognitive impairment, etc). This study only examines MCI, dementia and AD.
<b>ABSTRACT</b>	All elements present and succinctly defined. Approach was systematic.
<b>INTRODUCTION</b>	
<b>Problem statement</b>	Problem was easily identified and well described. Care planning is an essential element for dying well, this is especially true for those with terminal illnesses. So understanding predictors of ACP completion will help nurses identify populations that have statistically lower completion rates, therefore, enabling nurses the opportunity to offer more education and counseling to these patients. The methods used for extraction suited the research problem.
<b>Hypothesis</b>	The hypothesis is clearly stated with the population and key variables indicated. The hypothesis and literature review are congruent with one another.
<b>Literature Review</b>	This review provides a solid background of the existing evidence and gives a clear indication of the need of the study. There is an abundance of primary sources supporting this literature review.
<b>Theoretical Framework</b>	Concepts were easily identified, and well explained.
<b>METHODS</b>	
<b>Methods</b>	The University of Pittsburgh Institutional Review board approved this study. Participating participants signed a consent form. The study design was advantageous to participants.
<b>Research Design</b>	The retrospective analysis of data design suits the nature of this study. The number of data collection points were more than enough: two for the first year, and subsequently every year after. Necessary comparisons of data ensured trustworthiness in findings. The design was detailed and transparent, minimising bias.
<b>Population and Sample</b>	The population and sample were amply defined. Bias was not detected. Size of sample was sufficient: 127 participants.

## APPENDIX 4. Quantitative Critical Appraisal Table

2(2)

<b>Data collection and measurement</b>	Semi-structured interview with a checklist format was employed to determine variable outcomes. There were two steps used for the analytic approach. Two-sided P-values indicated significance between variables/groups studied.
<b>Procedure</b>	If it was found at the annual reviews that participants had not completed advanced directives, they were given education on advanced directives and also referrals for lawyers. Data was gathered in a manner that minimized bias. Staff was trained and qualified.
<b>RESULTS</b>	
<b>Findings</b>	Analyses were completed to determine the likelihood of ACP completion rates over a five year period. These rates varied in relation to baseline data, sociodemographic and other participant characteristics. Chosen statistical measures perfectly matched the variables (3) and groups (2) studied. There were no missing values present.
<b>Data analysis</b>	Statistical information between group differences was determined significant if P-value was less than .05. Two figures and three tables clearly exhibited findings. Findings were written in a way that gives credibility to the subject studied.
<b>DISCUSSION</b>	
<b>Interpretations from findings</b>	Interpretations are consistent with limitations of the study. Previous research supported the interpretation of key findings. There were only a few casual inferences, which were justified.
<b>Implications and recommendations</b>	Ideas for further research mainly focus on examining the factors that influence ACP completion within the cognitively impaired population. These recommendations are reasonable and justified.
<b>GLOBAL ISSUES</b>	
<b>Presentation</b>	Critical analysis was easily accomplished due to the fact that this research was well conducted and documented. The findings of this study are translatable to best practices in nursing. There was no participant flow chart.
<b>Researcher credibility</b>	Researchers' clinical qualifications and experience add to the believability of findings.
<b>Summary</b>	Results are sound and trustworthy. ACP is an critical component for end-of-life care, particularly for those with a terminal illnesses. So understanding predictors of ACP completion will help nurses identify populations that have statistically lower completion rates, therefore, providing nurses with the identification tools necessary to educate and counsel these populations.

**APPENDIX 5. Qualitative Critical Appraisal Table**

Adapted from Polit and Beck 2012, 115–117.

1(11)

	<b>De Lepeleire et al., 2008</b>	<b>Ilife et al., 2003</b>	<b>Kissel and Carpenter, 2006</b>
<b>TITLE</b>	Good title. Title succinct with study objective.	Great title. Eye catching and explains exactly what the study encompasses.	Great title- attention grabbing. It is simple, yet concise.
<b>ABSTRACT</b>	All elements clearly labeled and systematically detailed.	All elements clearly labeled and detailed. Systematic.	All elements were present, but in paragraph form. As a result, elements were not easily detectible for the reader. Some key words were missing.
<b>INTRODUCTION</b>			
<b>Problem statement</b>	Problem statement was mentioned, and builds a good argument as to why this study is needed. This study does have implications for nursing... particularly in regards to diagnosing dementia in primary care. The focus group approach incorporated with the use of thematic analysis from the nominal group methodology suits the population studied.	Problem clearly defined and it builds a strong argument for this study. The purpose is to discover the barriers regarding recognising dementia in primary care. Although this study primarily focuses on physicians' role in the diagnosis of dementia, it trickles down to all those involved in primary care. The nominal group approach is suitable for the population studied.	Problem statement was easy to identify. The researchers present a convincing argument for the need of the study. The qualitative approach with semistructured interviews was appropriate for the population examined.
<b>Research questions</b>	Research statement is clearly stated.	Research objective or statement is stated and easy to identify.	Research questions are stated.
<b>Literature review</b>	There is sound reason for this study and decent summary of existing information regarding this topic.	Concise summary of existing information and problem, as well as, a sound basis for the need of the study.	The good summary of supporting information and a justified need for this research.
<b>Conceptual underpinnings</b>	Three of the four concepts were discussed in the introduction.	All concepts were not clearly defined in the introduction.	The concepts were addressed and alligned with the topic.

## APPENDIX 5. Qualitative Critical Appraisal Table

2(11)

<b>METHODOLOGY</b>			
<b>Protection of participants' rights</b>	Nominal group method. No mention of participant rights. This could be due to the fact that it was an european-wide project among professionals. There was an "expert panel" consulted prior to distribution of literature. The study was designed to minimize risks and systematic and transparent in following proceedures.	No specific external review was completed, but possibly because this was for a nation-wide educational programe in the UK. Also, no mention of participants rights, but maybe this is because workshops were in group format.	No mention of safeguards for the population questioned, nor an external review board to assure that study was ethically sound.
<b>Research design and tradition</b>	A focus group approach with incorporated themes of nominal group methods was appropriate for this study. Good supporting evidence as to why this was the correct method for the job. Questionnaires were distributed, collected and analyzed by two people. Compiled results were then sent to participants two months prior to the workshops. Results were confirmed and validated once again at the workshops. Clear and concise details of methodological steps were taken. There was enough staff conducting the workshops.	Nominal group design appropriate for study purposes. Design minimized bias. There were 24 data collection points. There was a trained facilitator for workshops and then three researchers assigned from different, but related, professional backgrounds for thematic analysis.	This qualitative research with semi-structured interviews were well aligned with the methods used to collect and analyze data, which were based on a grounded theory framework. There was good detail about the interview itself, including sample questions. There was one interviewer for every interviewee.
<b>Sample and setting</b>	Measures were clear and transparent: bias undetected. Popluation (23 experts from eight Eruopean countries) details adequately provided. Participants were actively involved in research or service for people with dementia (or both). Setting details missing- where were the workshops? Recruitment mentioned, but no details of process.	There is a large sample size, which increases understanding of the phenomena. Measures to curb bias were sufficient. Population and sample was described, but they failed to give details about the 'other' medical professionals (job titles) that represented a rather large portion of their participants.	The population was described well, but the recruitment details and setting of the interviews were omitted. The sample size was small: 10 physicians.

## APPENDIX 5. Qualitative Critical Appraisal Table

3(11)

<b>Data</b>	Great methodological flow chart. Triangulation was achieved: information was crosschecked for accuracy and then submitted to workshop group for final confirmation.	Trained facilitators (GPs) collected key points in detail. Three researchers from different, but related disciplines, analyzed information independently, and then achieved consensus collectively through discussion.	Triangulation of data collection methods was achieved. The interviews were audio taped and transcribed verbatim. Three graduate assistants individually identified concepts. Then another assistant assigned codes and identified three concepts from the interviews.
<b>Procedures</b>	Bias was minimized through well defined recording and data collection procedures. There was no mention of training for the two individuals in charge of analysing themes nor about the facilitators of the workshops.	Facilitators were trained and experienced GPs, but no mention as to how. Furthermore, no mention as to why GPs were chosen as facilitators or what connections they had with this subject in the past. Measures for collecting data was simple, yet clearly described. Collection process itself was straight forward.	Data collection and recording procedures were succinctly described and were appropriate. Data was collected in a fashion in which bias was minimized. Training of staff was not explained.
<b>Enhancement of trustworthiness</b>	Researchers carefully documented steps to enhance trustworthiness, with the exception of staff training. Procedures are documented thoroughly, supporting transferability.	Information about methods, participants, data collection and processing was simply, yet clearly explained. Even one limitation was pointed out, strengthening trustworthiness. Study supports transferable.	Researchers were transparent and detailed in their research process (except for the mention of staff training). Descriptions were sufficient enough to allow for transferability.
<b>RESULTS</b>			
<b>Data analysis</b>	Data analysis methods were adequately detailed in the methods section and void of bias. The data analysis strategy was a good fit for the nature and type of data. The study produced four themes.	Data analysis methods were described in the methods section, but not mentioned here. Analysis strategy was compatible with the research tradition and fits the type of data. The yield was seven themes which were addressed in detail in its own section.	Analysis strategies were compatible with the research and data. The grounded theory framework was used in the analysis of data. The yield was three themes, presented in rich detail.

## APPENDIX 5. Qualitative Critical Appraisal Table

4(11)

<b>Findings</b>	Results effectively summarized. Themes included: need for a timely diagnosis, availability of guidelines, referral pathways, and diagnostic strategies. Themes capture meaning of data. There were no excerpts from participants.	Effectively summarized. Good use bold text for reoccurring themes in text. Use of italics not clearly understood. Themes adequately captured the meaning of the data. Themes: early diagnosis (benefits and hazards), screening, diagnosis and care pathways, professional resistance, avoidance behaviour, and descriptive about problems, but not analytic in finding solutions. Analysis gives a good picture of the study focus. There could of been more excerpts from the participants.	Findings were summarized and organized into three themes. The significance of the data was clearly represented in the themes. There were supportive excerpts scattered throughout the themes. This analysis was insightful and successful in producing one conceptualization of the process behind diagnosing dementia.
<b>Theoretical integration</b>	Themes are logically connected to each other. There are two tables for two of the four themes, which give in-depth insight and information.	No diagrams used. Last theme was informative, but stuck out as very different from the other themes.	Themes were logically connected and there was a great map pertaining to the perceived importance of disclosure in relation to the severity of dementia.
<b>DISCUSSION</b>			
<b>Findings interpretation</b>	Findings were given within an appropriate context, even though the participants were from eight different countries and had to express themselves in english. An abundance of supporting research was cited and strengthened these findings. Limitations were addressed head on, enhancing transparency.	Findings were interpreted within an appropriate social and cultural context. Prior studies were integrated into discussion and supported findings. Limitations were addressed head on from the beginning of the discussion and were in line with interpretations.	Findings were depicted within the framework of prior research. Limitations were acknowledged and explained, enhancing transparency and trustworthiness.

**Appendix 5. Qualitative Critical Appraisal Table****5(11)**

<b>Implications and recommendations</b>	The researchers began and ended their discussion with their implications for further studies. Implications for the development of a pan-European guidelines for dementia diagnosis in primary care is reasonable, but quite possibly unobtainable. But guidelines could be used for planning and evaluation and purposes within each country.	Three key findings from their analysis. They give ideas about gaps in services and policy. They also suggest education for physicians and stress the the idea of recognition of dementia instead of an early diagnosis. But in the end they fail to wrap up the discussion with specific recommendations for future studies.	Researchers give many insightful ideas regarding future studies. They stress that this information can serve as an educational tool for physicians and assist in establishing guidelines for practice.
<b>GLOBAL ISSUES</b>			
<b>Presentation</b>	The report was well written and the attention given to procedures and details was outstanding. There was one flow chart and two tables that provided added depth to the research.	The report was well written and systematically presented. It could of given more details about workshops and how they were divided, participants (others?) and training regimen for facilitators.	Researchers were transparent in their writing and detailed with their procedures and analyses. Depictions of findings were full of colorful testimony.
<b>Credibility</b>	The researchers clinical standing and professional history add to their credibility. Aging and Mental Health journal is a peer reviewed journal.	Confidence in the findings is strengthened by the fact that the researchers' are experienced and qualified. Furthermore, JAP is a peer reviewed journal.	Researchers qualifications and experience lend credibility to their research. The fact that Aging and Mental Health is a peer reviewed journal, adds to trustworthiness of the final product.
<b>Summary and assessment</b>	Findings are useful for nursing practice and primary care treatment for those with dementia. Limitations were addressed adding to transparency and trustworthiness in findings.	Findings are trustworthy and can be useful for the nursing profession, and dementia care as a whole.	Findings are trustworthy and can be useful for the health care community at large.



## APPENDIX 5. Qualitative Critical Appraisal Table

6(11)

	<b>Morgan et al., 2013</b>	<b>Mukadam et al., 2011</b>	<b>Poppe et al., 2012</b>	<b>Robinson et al., 2012</b>
<b>TITLE</b>	Title was weak considering the strength of the rest of the study. It did not reflect all of the key variables of the study.	Title could be clearer. For example, why not minority ethnic instead of just ethnic and why the use of services and not medical intervention or dementia treatment?	Title was succinct, with all variables mentioned.	Good title which completely presents the study variables.
<b>ABSTRACT</b>	Fantastic abstract: all variables present. Systematically written, albeit in paragraph form. Concise, clear and to the point.	All elements present and clearly laid out.	All pertinent information systematically recorded.	Abstract was good, but instead of a methods section, there was- design, setting and sample.
<b>INTRODUCTION</b>				
<b>Problem statement</b>	The problem is easy to recognize and builds a strong case for the need of this study. This has a significance for nursing in the sense that those living in rural areas are even less likely to get an early diagnosis of dementia, and therefore, the treatment and services that they need.	Problem easily understood and identified. There is a significance for nursing and dementia care as a whole. Ethnic minorities are seeking help later than their native peers. There is a solid match between the problem and methods (semi-structured interviews).	The problem is easily identified and there is a strong argument for the need of the study. This issue concerns nursing and best outcomes in care for those with dementia. The pairing of this problem and the decision to conduct a qualitative study is of sound reasoning.	The issue concerns nursing directly. The decision to conduct this as a qualitative study through focus groups and interviews is a good match considering the problem. The problem statement could have been clearer.
<b>Research questions</b>	Research intentions are clearly written.	The research question or objective was easily recognized.	The research goal is easily identified and understood.	The intentions of the research is spelled out clearly.

**APPENDIX 5. Qualitative Critical Appraisal Table****7(11)**

<b>Literature review</b>	Existing information on the subject is well presented and establishes a need for this study.	The summary of existing information is good and it clearly translates a need for the study.	The background content is strong and there is a definite need for this study.	The background summary was a bit on the lean side. There is a sound basis for this study though, due to the fact that ACP's completion rates are low.
<b>Conceptual underpinnings</b>	Key concepts are given, but could be more detailed. The conceptual framework suits the problem at hand.	Concepts were not completely and clearly defined in the introduction. Of the ones mentioned, they were in alignment with the topic.	Key concepts could of been written more clearly. They were difficult to identify, however, the ones that were identified were well aligned with this topic.	Most of the key concepts were addressed or defined in the introduction, but not all of them. Of the ones mentioned, they were in alignment with the topic.
<b>METHODOLOGY</b>				
<b>Protection of participants' rights</b>	The University of Saskatchewan behavioural Research Ethics Board deemed this study ethically sound. Participants were informed that they could exit the process at any time. Face-to-face interviews, as well as, video conferencing was used.	Three different ethics boards approved this study. No mention as to the rights of the participants, but they were sent the transcripts from the interview and asked to confirm (or correct) for accuracy.	Participants were informed of their rights and given a consent form to sign. There was an ethics committee that approved the study.	Ethical approval was granted by an ethics committee out of England. There was no mention of participant rights.

## APPENDIX 5. Qualitative Critical Appraisal Table

8(11)

<b>Research design and tradition</b>	The longitudinal, retrospective and prospective qualitative research design with semi-structured interviews was compatible with the methods used to collect and analyse data. More than enough time was spent with the participants in the field (2 face-to-face interviews and 4 teleconferences). Number of contacts matched the need of the study.	This qualitative study tradition with semi-structured interviews was with the methods of collecting and analysing data. Interviews lasted 30–45 minutes. The design unfolded in the field, in the sense that coding of themes started already after 5 interviews in order to uncover and use emergent themes for questioning.	The qualitative tradition with interviews matches the collection and analysis methods. There was sufficient time spent with participants: ACP initial discussions, letters in the mail, follow-up telephone calls, and a 45 minute interview. Interviewer-to-interviewee ratio was sufficient.	The qualitative tradition with focus groups and interviews corresponded to the selected collection and analysis methods. Focus groups were held (60–90 min) and interviews were held for those participants not able to attend the groups. Adequate amount of staff and time spent with participants in relation to type of study.
<b>Sample and setting</b>	An abundance of detail went into describing the sample and setting. Approach to recruit patients was appropriate for the study. Sample size was sufficient. Saturation was accomplished.	There was great detail and time went in to the recruiting process in order to obtain a diverse ethnic sample. The sample characteristics was also richly detailed (18 caregivers). There was no mention of the interview setting.	Fantastic. The recruiting, setting, sample and population was perfectly described. The sample size was on the small side: 12 patients, 8 caregivers and 6 professional staff.	Sample and setting was explained in detail. Purposive sampling was successfully used for recruiting participants. Sample size was good: 95 participants working in clinical areas.
<b>Data collection</b>	Triangulation was achieved: data was collected through more than one source. Interview questions were made into a table, increasing transparency. Data gathered was in depth testimony relating to the research questions.	Data was gathered through interviews, audio tapes and approved and revised transcripts which were sent to participants. Triangulation was achieved. Interview categories were mentioned, but not detailed. Interviews were audio-taped and transcribed. A copy of the transcript was mailed to the participants for their input. There was a sufficient amount of data collected.	Data from interviews were completed and collected from all angles: the patient, the caregiver and the professional staff. The interview questionnaire was produced with the input of patients, caregivers and staff members. Interviews were recorded and transcribed verbatim. Several methods of data collection were used achieving triangulation.	The constant comparison principle guided the collection and analysis of material from focus groups and interviews. A thematic approach was used to analyse the data. These processes were mentioned at great length. Triangulation was achieved. Topics covered were generated from a systematic literature review. They were recorded and transcribed verbatim. Data gathered produced an abundance of material for the themes.

## APPENDIX 5. Qualitative Critical Appraisal Table

9(11)

<b>Procedures</b>	Data collection and recording procedures were well documented and they used different strategies to ensure “analytic rigor.” There was no mention of training for staff, but great detail as to their procedures and collaboration.	Data collection and recording procedures were thoroughly described and detailed, to the extent that bias was minimized. The only staff members involved were the authors of this study.	The process for collecting and recording data was explicitly detailed in a manner that minimized bias and established trust. Staff were experienced and educated.	The collection and recording process was written in a way that maximized trust and minimized bias. Staff were experienced, but there was no mention of a specific training regimen.
<b>Enhancement of trust-worthiness</b>	A table was produced with questions for both interviews. Themes represented a whole picture of the problem studied.	The themes were logically outlined and fit well together. There was also one table about sociodemographic characteristics of the participating carers.	While there were no diagrams (excluding the interviewing tool ACP-ED), the themes were appropriately titled and flowed nicely together.	There were two tables as supporting material. Themes were appropriate for the study and blended nicely together to form a larger understanding of the phenomena.
<b>RESULTS</b>				
<b>Data analysis</b>	Data management and data analysis was thoroughly detailed and suitable for the data collected. The data produced themes full of descriptively rich material related to their topic. The analytic procedures do not infer bias.	The data management and analysis was a good match for the type of information collected. The analytic procedures do not infer bias. The analysis produced descriptively rich themes and gives a picture of the phenomena studied.	Analytic process was captured in detail and suitable for the type of data collected. The outcome was three themes detailed with rich testimony. No bias detected.	The thematic analysis procedure worked well for data collected from the professionals from the focus groups and the interviews. This process was well documented and transparent, as a result, bias was not detected. The outcome was eight themes.
<b>Findings</b>	Themes sufficiently inform the reader of its content. Findings were written with the supporting quotes from participants which added to richness and depth of the research.	Themes need attention. They seem a bit out of order and it almost looks as if two (or more) people wrote this section. It doesn't flow in places. There is an abundance of excerpts integrated into findings. The analysis yields authentic, insightful discord from this ethnic minority population.	The themes capture the essence of the data. The final outcome is a descriptively rich picture of advanced care planning from three different angles. The study is appropriately littered with excerpts from participants.	Themes are interwoven together giving a textured, complete view of the phenomena. The study offers insightful testimony that support the findings and give an interesting account into obstacles that professionals face when trying to implement an ACP.

**APPENDIX 5. Qualitative Critical Appraisal Table****10(11)**

<b>Theoretical integration</b>	Themes were well selected and logically connected to the phenomena studied. There were no diagrams in the results section.	Themes were well organized with sub-themes. There was no use of tables to support findings.	Themes are related to each other, but seemed a bit out of order. There were no use of tables to support findings.	The three main themes were clear indicators of context of findings, but one of the additional theme titles did not mesh well with the others. Themes could have been organized better, with subthemes following from the three main themes. But overall, the themes give the reader a clear indication of the phenomena studied. There were no tables used in the results section.
<b>DISCUSSION</b>				
<b>Findings and interpretation</b>	Findings were presented within the framework of past research. Limitations were addressed and were aligned with the interpretations.	Findings were interpreted within the appropriate cultural context. On three occasions an interpreter was used to help with the interview process. Limitations were addressed and were logical considering findings.	Limitations were stated and are understandable considering the parameters of the study. Findings were supported with the use of past research.	Findings were interpreted within the appropriate cultural context. A large amount of previous research was cited as supporting evidence to the findings of this study. Limitations were listed and in accordance with the study's findings.
<b>Implications and Recommendations</b>	Researchers gave several ideas for further studies, all of which, could benefit those with dementia.	Researchers provide a couple of ideas for additional research, and they are reasonable considering the need.	Researchers offer ideas for future studies, and these recommendations are appropriate considering the need.	Researchers offer recommendations for further consideration and research. They are reasonable considering the importance of ACP.

## APPENDIX 5. Qualitative Critical Appraisal Table

11(11)

GLOBAL ISSUES				
<b>Presentation</b>	This was incredibly well written and serves as a model for qualitative research. Measures taken throughout the process were detailed, to the point that there were no questions.	This report provides rich interpretations regarding the reasons why ethnic minorities delay seeking help for their loved ones with cognitive impairment.	This study is very well written and attention to detail regarding procedures and methods is second-to-none.	The methods, findings and interpretations were richly detailed, with interesting and valid excerpts from participants.
<b>Credibility</b>	The researchers' qualifications strengthened the outcome of their work. Also, Social Science and Medicine is a peer-reviewed journal.	Researchers qualifications add to their credibility, as does the fact that International Psychogeriatrics is a peer reviewed journal.	The researchers' qualifications, positions and experience enhances credibility in their research. PLOS ONE is a peer reviewed on-line journal.	Researchers are obviously experienced and qualified, thus enhancing the strength of their study. Furthermore, Palliative Medicine is a highly ranked peer reviewed journal.
<b>Summary</b>	Findings are trustworthy and the evidence can be used not only in nursing practice, but for all professionals involved in dementia care.	Findings are trustworthy and can be used in nursing practice. Understanding the dynamics involved in the delay of ethnic minorities from seeking help can help with providing treatment and services for this population.	Findings are trustworthy and transparent. This piece of research holds significance for nursing, and for all of those involved with dementia care.	Findings appear to be trustworthy. This research is significant for nursing, because it concerns best practices in ACP from professionals' frame of reference. Based on the results, the researchers give insightful tips regarding procedural preferences in completing an ACP.