
**A Scoping Interpretive Review of Literature on
Perspectives and Practices of Primary Care Physicians Vis-
à-vis Diagnosis and Management of Community Living
Older Persons with Dementia**

F. Aminzadeh, F. Molnar, W.B. Dalziel, C. Mounde, & D. Ayotte



February 2012

EXECUTIVE SUMMARY

Background: With the projected rise in the prevalence of dementia disorders in Canada and worldwide, the provision of dementia care has increasingly come under scrutiny, with primary care physicians (PCP) being at the center of international attention. Dementia is perhaps the most complex of all chronic diseases, characterized by an interaction of cognitive, functional, behavioral, and psychological symptoms that negatively affect various dimensions of health and quality of life of both persons with dementia (PWD) and their family caregivers. International studies, including a number of important recent Canadian reports, have consistently shown: a) significantly higher burden of chronic diseases; b) two to five times higher rates of health service utilization across the spectrum (including the use of home care; emergency departments, acute care and alternate level of care [ALC] hospital services; and long term care [LTC] institutions); and c) more negative clinical outcomes among PWD compared to older adults without dementia.

PCP are often the first point of contact and the professionals most consulted by PWD and their family caregivers. Thus, they are in a strategic position to provide preventive and responsive community care to PWD. Over the past decade, significant progress has been made in the diagnostic accuracy, risk management and symptomatic treatment of dementia, as well as the availability of community support services. Today, PCP have more resources than ever before to provide comprehensive care to PWD. However, there continues to be significant challenges in this setting. Primary care has been identified as the *Achilles' heel of dementia services*, with experts repeatedly calling for systematic approaches to strengthen *primary dementia care*.

Objective: The overall goal of this paper is to identify the barriers and enablers to providing optimal primary care to community living PWD/caregivers during the initial dementia diagnosis and management phase. To this end, the more specific objective is to critically examine Canadian and Western literature on the knowledge, attitudes, perspectives and

practices of PCP with regard to the diagnosis and early management of PWD (i.e., symptom recognition, diagnostic investigation, diagnosis disclosure, short term follow-up, education and support of PWD/caregivers). Relevant contextual factors related to the PWD/caregiver and the broader social milieu/systems of care are also examined, as appropriate.

Methods: An interpretative scoping review methodology was used to guide the review process. This is a novel methodology to systematically examine, synthesize and analyze an extensive body of heterogeneous literature. Over 900 manuscripts published in Western nations over the past decade were identified by an English language search of major electronic databases and other sources. After removing the duplicates and screening for eligibility, a total of 326 papers were included in the final review.

Summary of Major Findings and Discussion: Over the past decade, there has been a proliferation of international dementia position papers and clinical practice guidelines (CPG) reaffirming the importance of timely and responsive *primary dementia care*. According to these consensus papers, this should ideally begin with a recognition of early signs and symptoms of dementia, followed by a thorough multidimensional evaluation, sensitive diagnosis disclosure, collaborative care planning, and on-going monitoring and management of evolving needs of PWD/caregivers. However, evidence suggests that the current primary care systems in many countries, including Canada, face many challenges in providing responsive, comprehensive, safe and cost-effective dementia care, in accordance with the best practice recommendations.

This review has identified a multitude of highly inter-related obstacles to optimal diagnosis and early management of PWD/caregivers, including challenges related to: a) the complex biomedical, psychosocial, and ethical nature of dementia disorders; b) the gaps in knowledge, skills, attitudes and resources of PWD/caregivers and their PCP; and perhaps most importantly, c) the broader systemic and structural barriers negatively affecting the context of dementia care. In order to reduce the current levels of under-recognition, under-diagnosis, under-disclosure, and under-treatment/management of dementia disorders in primary care; to

prevent escalating negative impact on community, acute care hospital and LTC institutional services; and to adequately respond to the growing future care needs of PWD/caregivers, due attention should be devoted to all of these barriers.

To date, most Canadian and international efforts to improve *primary dementia care* have been isolated and limited in scope, typically addressing only a subset of these barriers, and often with only modest intensity and very limited coordination. However, many experts in Western countries have reached the conclusion that the myriad of efforts that are required at multiple levels in order to achieve sustained and meaningful improvements should be ideally orchestrated by national dementia strategies. In recent years, many Western governments have made dementia a national priority and have developed national frameworks for action on dementia in order to provide an overarching vision and structure to inform systematic and consistent policy, planning, service delivery and research initiatives. At present, there is no national strategy for dementia in Canada. Below, we use the three core elements of the existing Western national dementia frameworks to summarize some of the key findings of this review.

Timely Diagnosis and Quality Dementia Care: The evidence reviewed in this paper suggests that this is currently more an exception than a rule in many parts of Canada and other Western nations. Research has consistently shown that dementia diagnosis typically occurs in moderate to later stages of the disease, often made at a time of a breakdown or crisis (likely leading to emergency department use, hospitalization with ALC designation, and premature institutionalization), which could have been potentially prevented, if proper diagnosis and interventions had been in place. Dementia disorders, in mild to moderate stages of the disease, are on average diagnosed in about 50% of cases, with only a minority of these cases being followed by timely, responsive and comprehensive therapeutic interventions.

There is evidence that many PCP have difficulty recognizing the early symptoms of dementia and/or tend to overlook their importance. Many feel that they have not received sufficient training in diagnosing and managing this complex chronic illness; express a strong preference

to delegate the care of PWD to medical specialists; and/or identify the need for clear, credible and feasible guidelines and tools to facilitate their work. Some remain skeptical about the benefits of early diagnosis, and express concerns about the potential negative impact on the person/caregiver and/or the health care system. These concerns are compounded by the broader system level barriers (e.g., the lack of time, resources, and financial rewards for PCP), further impeding timely dementia diagnosis and interventions in primary care.

While there are controversies about the specific roles and responsibilities of PCP (versus specialist/specialized dementia services) vis-à-vis the diagnosis and management of dementia, there is a consensus that PCP need substantial support to adequately meet the complex bio-psycho-social needs of PWD/caregivers. This awareness has led to a growing international interest in the development and evaluation of integrated models of community-based dementia care, with the PCP being at the center of such initiatives. Overall, it appears that the most promising results can be produced from the more comprehensive and coordinated care management approaches, especially those that provide intensive dementia specific services in primary care.

These innovative intervention studies incorporate a combination of the following key strategies: a) the use of multidisciplinary teams of clinicians with relevant expertise; b) on-going care management, typically coordinated by a nurse or social worker; c) the provision of formal training for PCP (and other clinic staff), as well as interactive case-centered experiential learning opportunities, including access to an advanced practice geriatric nurse and/or medical specialists for educational detailing and consultation; d) the use of standard tools, protocols and guidelines to ensure active case finding and consistent care processes; e) access to various types of information technology resources; and f) the provision of education and support for PWD/caregivers, in collaboration with community agencies, such as local Alzheimer Societies.

Professional and Public Education: This is a key intervention to positively affect both help seeking and help provision behaviors in primary care. To date, much of the efforts to enhance

the knowledge and behaviors of PCP have focused on: a) improving their ability to recognize dementia symptoms; b) conduct medical investigations, including the use of screening instruments; c) make a differential diagnosis; and d) prescribe drug treatments. Although these are important components of any medical training, they have been criticized as being limited in scope. Educational agendas assuming that the core problem in the primary care of PWD is the lack of formal knowledge of the disease pathophysiology and pharmacology fail to take into account the evidence on the multiplicity of factors that influence the physicians' recognition of and response to dementia outlined in this paper.

Educational interventions need to address the gaps in knowledge, skills, attitudes, and behaviors simultaneously. The term "knowledge" should be used broadly to include pattern recognition, conceptual framework, and therapeutic solutions. The evidence suggests that the low awareness of the early indicators of dementia, and the delayed response of some PCP may be at least partly due to: a) their limited framework and understanding of the illness experience; b) problematic attitudes associated with therapeutic nihilism, stigma and ageism; and c) deficits in their communication, disclosure and management skills. Thus, medical education about dementia should evolve in form and content from its largely disease-focused emphasis towards a broader view of dementia as a complex, progressive and chronic condition that is responsive to timely, individualized and comprehensive treatment and management plans.

In recent years, different knowledge translation strategies have been developed and tested with mixed results. Generally, multifaceted interventions, which include two or more strategies, and incorporate more flexible and innovative approaches seem to be more effective than the traditional single interventions that use more passive strategies. Among various educational interventions, the following have received growing attention and have great potential for future research and development: a) small group interactive scenario-discussion workshops (especially in the context of interdisciplinary working groups); b) outreach academic detailing for a more contextualized and applied on-site training; and c) various low cost and adaptable technological facilitative tools. More work is needed to overcome some of

the pragmatic barriers associated with the implementation of these interventions to enhance their feasibility and effectiveness.

In the light of the many barriers related to the gaps in knowledge and attitudes of PWD/caregivers identified in the literature, the importance of public education should also be highlighted. As per physicians' training, public information campaigns should: a) address the low levels of awareness of the various ways in which dementia manifests itself at the early stages; b) emphasize the importance of timely help seeking; and c) encourage access to a range of therapeutic options available to support the PWD/caregivers.

Research and Development: The growing recognition of the magnitude and the impact of dementia disorders and the critical role of PCP has led to an unprecedented research interest in this topic over the past decade. The knowledge gained so far has helped identify the gaps in our understanding of the existing problems, and the need for a more systematic examination of the potential solutions. Western dementia strategies and the Alzheimer Society of Canada's "Rising Tide" report (2010) call for greatly increased research spending to develop national dementia research agendas to tackle these issues.

In particular, there is a need for substantially increased investments in Canadian health science research to capture our unique geographic, cultural, policy and practice challenges and opportunities. Future research should aim at overcoming some of the methodological shortcomings of the past studies, such as the use of small and non-representative samples, retrospective designs, and the exclusive reliance on the review of medical records and physicians' self-reports for data collection.

The CPG have been criticized by many PCP for their perceived insufficient and/or impractical guidance concerning many challenging aspects of *primary dementia care*. This suggests a continuing need for research to better understand the experiences of Canadian PCP, and their perspectives on their learning and support needs to provide quality dementia care. Related topics of interest include a more thorough examination of the: a) various dimensions of

competence required by PCP; b) effective training strategies and educational tools/resources to support PCP in their practice; c) the feasibility and long term cost-effectiveness of new and more integrated models of dementia care; d) the interface between primary and specialist/specialized dementia care services and the ways in which communication, coordination, information, and resource sharing can be maximized; and finally, e) incentives and barriers to PCP participation in the multidisciplinary/interagency dementia care service delivery systems.

With increased emphasis on the self-management of chronic illnesses, advances in biomedical and psychosocial dementia treatment and management strategies, and heightened public awareness, there will be higher expectations of PCP to provide more person-centered, collaborative, and comprehensive care to PWD/caregivers. There is a growing need to learn about the public and professional expectations of the roles and responsibilities of PCP as well as the PWD/caregivers during their triadic encounters; and the impact of various communication, interaction and decision making approaches on the processes and outcomes of dementia care. Large scale national Canadian surveys of representative samples of public and professional providers can be very helpful.

The priorities identified here for future research call for more interdisciplinary, pluralistic, and collaborative investigations in order to provide a more accurate, in-depth and comprehensive view of *primary dementia care* practices. Finally, in addition to the need for more research to generate new knowledge, there is a pressing need to effectively transfer the knowledge gained, and to translate the evidence into concrete practice and policy interventions.

Conclusion: Primary care, as the hub of elder care, must be strengthened to respond to the growing demands of the rising prevalence of dementia disorders. This interpretive scoping review is a comprehensive repository of international and Canadian literature published over the past decade. It identifies some of the key challenges currently faced in this setting, the potential solutions, and the priority directions for research, practice, policy and education. We

hope that this collection informs future constructive debates and decisive actions, ideally as part of a national dementia strategy in Canada.

TABLE OF CONTENTS

Executive Summary	2
List of Abbreviations	11
Section One: Introduction	12
Section Two: Objectives & Methods	16
2.1 Goals & Objectives	16
2.2 Methods	16
2.2.1 Design	16
2.2.2 Search & Selection Strategy	17
2.2.3 Data Extraction & Synthesis	18
Section Three: Results	
3.1 Brief Description & Critique of Studies	20
3.2 Best Practice Recommendations	22
3.3 Evidence of Actual Practice	29
3.4 Barriers to Best Practice:	44
3.4.1 Disease-Related Factors	44
3.4.2 Persons with Dementia/Caregiver Factors	46
3.4.3 Physician Factors	53
3.4.4 System/Societal Factors	77
Section Four: Discussion	88
4.1 Timely Diagnosis & Quality Dementia Care	90
4.2 Professional & Public Education	96
4.3 Research & Development	103
References	107
Appendix: Collection of 300 Published Manuscripts	131

LIST OF ABBREVIATIONS

ALC – Alternate Level of Care

ASC – Alzheimer Society of Canada

ASO – Alzheimer Society of Ontario

CCCD – Canadian Consensus Conference on the Diagnosis and Treatment of Dementia

CIHI – Canadian Institute for Health Information

CPG – Clinical Practice Guidelines

ICES –Institute for Clinical Evaluative Sciences

LTC – Long Term Care

MCI – Mild Cognitive Impairment

MMSE – Mini Mental Status Examination

MoCa – Montreal Cognitive Assessment

PCP – Primary Care Physicians

PWD – Person with Dementia

SECTION ONE

INTRODUCTION

With the aging of our population, dementia has become a growing public health concern in Canada and worldwide. Currently, about half a million Canadians have dementia, with an estimated 100,000 new cases per year, there are projections of a 2.5 fold increase in the prevalence of dementia over the next forty years (Alzheimer's Society of Canada [ASC], 2010). Given that dementia is one of the main causes of disability among older adults, the human, societal and economic costs of this growing epidemic are far reaching (ASC, 2010; Bronskill et al., 2011; Canadian Institute for Health Information [CIHI], 2011a, 2011b).. The recently published "Rising Tide" report of the ASC (2010) warns about the projected increase in the prevalence of dementia, the ensuing growing demands for acute and chronic care services, and the escalating costs of dementia care in Canada (from about \$15 billion per year in direct health care expenditures in 2010 to \$153 billion per year by 2038). The report maintains that unless specific and targeted action is taken, our already strained health care system will be overwhelmed by the growing demands.

Dementia is perhaps the most complex of all chronic diseases, characterized by an interaction of cognitive, functional, behavioral, and psychological symptoms that negatively affect various dimensions of health and quality of life of both PWD and their family caregivers (Barth et al., 2011; Bond et al., 2005; Boustani et al., 2007a; Bronskill et al., 2011; Bruce & Paterson, 2000; Eisele et al., 2010; Froelich et al., 2009; Hebert et al., 2001; Yaffe et al., 2002). International studies, including a number of important recent Canadian reports, have consistently shown: a) significantly higher burden of chronic diseases; b) two to five times higher rates of health service utilization across the spectrum (including the use of home care; emergency departments, acute care and alternate level of care [ALC] hospital services; and long term care [LTC] institutions); and c) more negative clinical outcomes among PWD compared to older adults without dementia (ASC, 2010; Bronskill et al., 2011; CIHI, 2011a, 2011b; Fick et al., 2005; Pedone et al., 2005; Rudolph et al., 2010; Zilkens et al., 2009).

A recent Canadian report by the Institute for Clinical Evaluative Sciences (ICES) examining health system use by frail Ontario seniors clearly indicates that PWD have a higher prevalence of co-morbid conditions, receive a greater number of prescription medications, and are more intensive users of health services compared to older adults without a diagnosis of dementia (Bronskill et al., 2011). According to the report, just under half (43%) of the community living PWD living in Ontario visited an emergency department in the year 2006-2007, compared to about one quarter (25%) of older persons without dementia. Also of interest is the fact that twice as many visits made by PWD (11%) were considered to be for potentially preventable conditions, compared to those made by elderly without dementia (5%). Furthermore, almost 10% of PWD visited the ED as a result of a fall, which is over three times higher than the rates for those without dementia (3%). About one in five PWD was hospitalized in the course of the year, a rate double that of older adults without dementia. Moreover, the length of hospital stay for PWD was nearly twice as long as those without dementia (14.2 days compared to 8.6 days). Finally, while in hospital, PWD were more likely to have an ALC designation (17%) compared to older patients without dementia (5%).

The latter findings are consistent with a recent CIHI report (2011a) on the ALC challenge, which concluded that dementia is a key diagnosis related to ALC use in Canada. In 2007-2008, over half of all hospitalizations with dementia as the main diagnosis (57%), and one-quarter of those with dementia as a co-morbidity had at least one ALC day. Overall, dementia accounted for almost one-quarter of all ALC hospitalizations and more than one-third of all ALC days. In the same report, the hospitalizations with a diagnosis of dementia had a significantly longer ALC length of stay (23 days) compared to the average for typical ALC patients (10 days). Among the ALC hospitalizations, the predominant discharge destination was a LTC institution, a finding consistent with another CIHI report (2011b) indicating that dementia is the primary cause of LTC placement among older Canadians. The intensive use of costly and limited hospital and LTC services by many PWD has led to calls for more adequate community support for this most vulnerable population of older adults.

Primary care physicians (PCP)¹ are often the first point of contact and the professionals most consulted by PWD and caregivers for both primary and continuous dementia care in the community (Bronskill et al., 2011; Rockwood & Keren, 2010; Schoenmakers et al., 2009; Wilkinson et al., 2004). Moreover, in Canada, PCP often act as the gatekeepers in accessing specialists and community support services. Thus, they are in a strategic position to provide early diagnosis, on-going treatment, care management and support to PWD/caregivers. Several recent published Canadian and international position papers, consensus statements, and clinical guidelines have emphasized the central role of PCP in the community care of PWD, both as care providers and as care planners (Callahan et al., 2009; Cummings et al., 2002a, 2002b; Feldman et al., 2008; Hogan et al., 2008; Iliffe & Manthorpe, 2002; Iliffe et al., 2009b, 2010; Villars et al., 2010).

Early symptom recognition and timely and accurate diagnosis of dementia are the first important steps for an effective *primary dementia care*. Missed cases are lost opportunities for optimal treatment and management of PWD/caregivers, resulting in increased risk for adverse clinical and quality of life outcomes for both PWD and their caregivers (i.e., excess disability; medication errors; accidents and injuries; caregiver burnout; use of emergency, acute care and ALC hospital services; premature institutionalizations) (Aupperle et al., 2003; Bond et al., 2005; Boustani et al., 2007b; Bradford et al., 2009; Froelich et al., 2009; Hebert et al., 2001; Villars et al., 2010).

While there is emerging international evidence showing some improvements in *primary dementia care* practices over the past decade (Maeck et al., 2008; Milne et al., 2005; Iliffe et

¹ *For the purpose of this paper, the term primary care physician is used broadly to include family physicians, general practitioners, general internists, and other physician generalists providing primary medical care to community living older adults.*

al., 2009b), there continue to be significant challenges in this setting, resulting in under-recognition, delayed diagnosis, inadequate diagnosis disclosure, and sub-optimal management of dementia (Boustani et al., 2003, 2007b; Bradford et al., 2009; Fortinski, 2007; Koch & Iliffe, 2010; Iliffe et al., 2005, 2009a; Villars et al., 2010). These shortcomings exist despite recent educational efforts to improve knowledge and practice behaviors of PCP, including the promotion of clinical practice guidelines in Canada and other Western nations (Boustani et al., 2007; Chertkow, 2008; Cummings et al., 2002a, 2002b; Fortinsky, 2007; Kock & Iliffe, 2010; Iliffe et al., 2009b; Iliffe & Manthorpe, 2004; Maslow et al., 2002; Perry et al., 2011; Villars et al., 2010).

Over the past decade, significant progress has been made in the diagnostic accuracy, risk management and symptomatic treatment of dementia illnesses, as well as the availability of community support services. Today, PCP have more resources than ever before to provide responsive and comprehensive care to PWD/caregivers (Callahan et al., 2009; Chertkow, 2008; Feldman et al., 2008; Holmes & Adher, 2005). This has led to a growing commitment to a more proactive approach to the community care of PWD, which begins with early detection and timely diagnosis and management of the disease (Callahan et al., 2009; Hogan et al., 2008; Feldman et al., 2008; National Institute of Health and Clinical Excellence [NICE], 2011; Villars et al., 2010; Waldemar et al., 2007a, 2007b). This renewed international interest has generated an unprecedented volume of published studies and scientific papers investigating and debating various topics related to the community care of PWD/caregivers.

SECTION TWO

OBJECTIVES & METHODS

2.1 Goal & Objective

The overall goal of this paper is to identify the barriers and enablers to providing optimal primary care to community living PWD/caregivers during the initial dementia diagnosis and management phase. To this end, the more specific objective is to critically examine Canadian and Western literature on the knowledge, attitudes, perspectives and practices of PCP with regard to the diagnosis and early management of PWD (i.e., symptom recognition, diagnostic investigation, diagnosis disclosure, short term follow-up, education and support of PWD/caregivers). Relevant contextual factors related to the PWD/caregiver and the broader social milieu/systems of care will also be examined, as appropriate. The focus is on the detection and early interventions for individuals in the early to moderate stages of disease. It is beyond the scope of this paper to systematically review the extensive body of research on the drug treatments for dementia disorders. As much as possible, an attempt will be made to examine the applicability of the results of international studies to the Canadian context of care.

2.2 Methods

2.2.1 Design

An interpretative scoping review methodology based on the framework developed by Arksey & O'Malley (2005) and the more recent work of Davis and colleagues (2009) was used to guide the review process. This is a novel methodology to systematically examine, synthesize and analyze an extensive body of heterogeneous literature. The comprehensive nature of a scoping review provides a mechanism to thoroughly, systematically, and methodically map all forms of the existing evidence (including a wide range of primary research and non-research sources, such as expert opinions, reviews, and consensus guidelines). The interpretive

approach ensures an in-depth coverage and critical analysis of the findings in order to inform future research, policy and practice.

2.2.2 Search & Selection Strategy

An experienced librarian with expertise in geriatric topics conducted the electronic database searches. Six databases were searched: Medline, EMBASE, PsycINFO, AgeLine, CINAHL, and Cochrane Database of Systematic Reviews. The literature search was limited to English language published between January 2000 and December 2011.

Box 1 presents the keywords and subject headings that were used in various combinations to search the electronic databases (there were slight variations in the index terms used across databases, as appropriate).

Box 1. Search Strategy

“Primary care”, or “primary health care”, or physician*, or primary care physician*, or family doctor*, or family physician*, or “family medicine”, or “general practice”, or general practitioner*

AND

“Dementia*” or “Alzheimer’s Disease”, or “cognition”, or “cognitive disorders”

AND

“physician’s role”, or “diagnosis”, or “diagnos*”, or “detect”, or “attitude”, or “health attitudes”, or attitude*, or “knowledge”, or “knowledge level”, or experience*, or “support”, or need*, or “unmet needs”, or barrier*, or communication barrier*, or “collaboration”, or “consultation”, or referral*, or patient referral*, or practice*, or belief*, or perception*

The search strategy was reviewed by the first author and the citations and abstracts were scanned to ensure their relevance. After removing the duplicates, a total of 903 articles were listed in the final search results. The identified articles were then carefully screened for eligibility by title and abstract by two authors.

To ensure a broad and comprehensive coverage, all Western literature that addressed any aspect of the review objective was considered eligible. Excluded were manuscripts that had the following focuses and target populations: a) institutional dementia care, b) primary nursing care, c) advanced dementia care, d) end of life dementia care, e) recruitment to clinical trials, f) drug treatments, g) genetic testing, and h) mild cognitive impairment (MCI). Application of the above screening criteria yielded a total of 319 articles which were selected for a full review. After the initial review, an additional 35 articles were excluded either because they did not meet the study inclusion criteria (this was not initially evident based on the abstract review), or they were commentaries, editorials, clinical papers, and non-systematic reviews which did not appear to make any substantial contribution to the review.

In an attempt to be as comprehensive as possible, an additional 42 manuscripts, including dissertations, guidelines, and frameworks were identified by screening the reference lists of the identified articles, searching websites, and other sources. This resulted in a total of 326 papers included in this review. Figure 1 presents a flow chart of the manuscript identification and selection process.

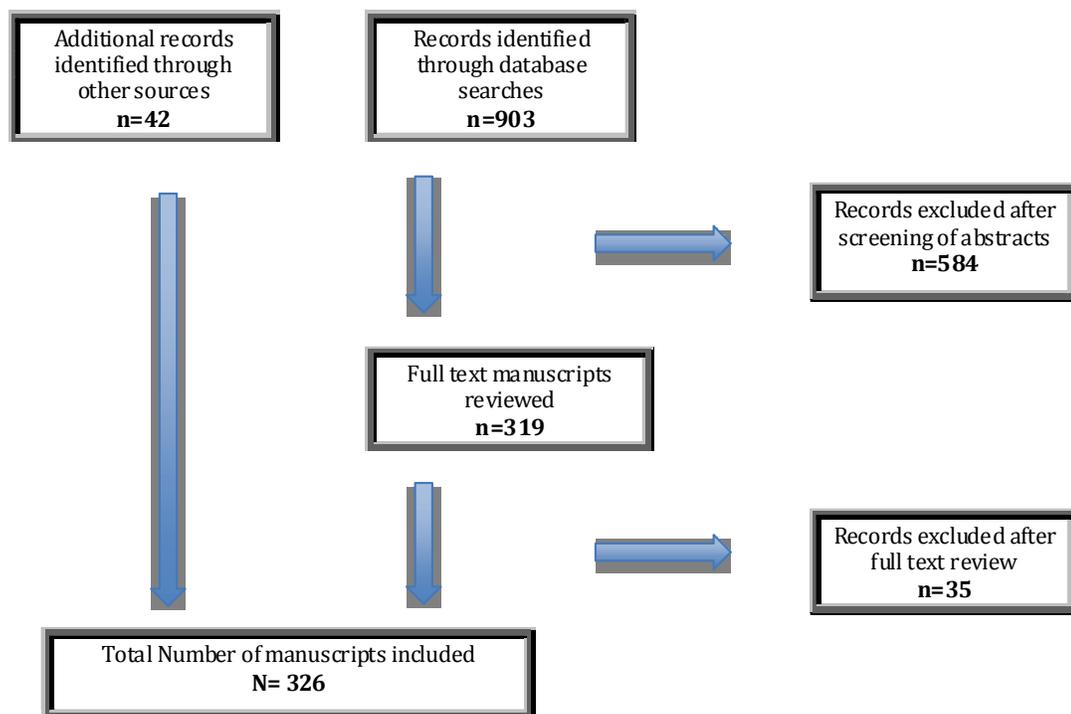
2.2.3 Data Extraction & Synthesis

The data extraction began with compiling a detailed summary of all the retrieved articles, including general citation information, country of origin, study methods, key findings, main conclusions, and risk of bias/limitations in order to create a large narrative database. Although no studies were excluded due to the methodological shortcomings, each research paper was critically reviewed and appraised in terms of methodology, sampling criteria, response rates, and appropriateness of analysis. The non-research publications were also

carefully reviewed in order to gather background information, identify key concepts, interpret research results, and screen for potential leads to other relevant papers.

An initial scan of the narrative summaries revealed overriding themes which were used to organize the data. In the next step, the key information pertinent to each theme was sorted and extracted in charts. In keeping with a ‘descriptive-analytical’ method, the charting approach was akin to a ‘narrative review’ and as much as possible included the necessary details in order to contextualize the results (Arksey & O’Malley, 2005). In the final step, the charted data were critically examined and presented in both a narrative account of the findings as well as in summary tables.

Figure 1. Flow Chart of Manuscript Identification and Selection

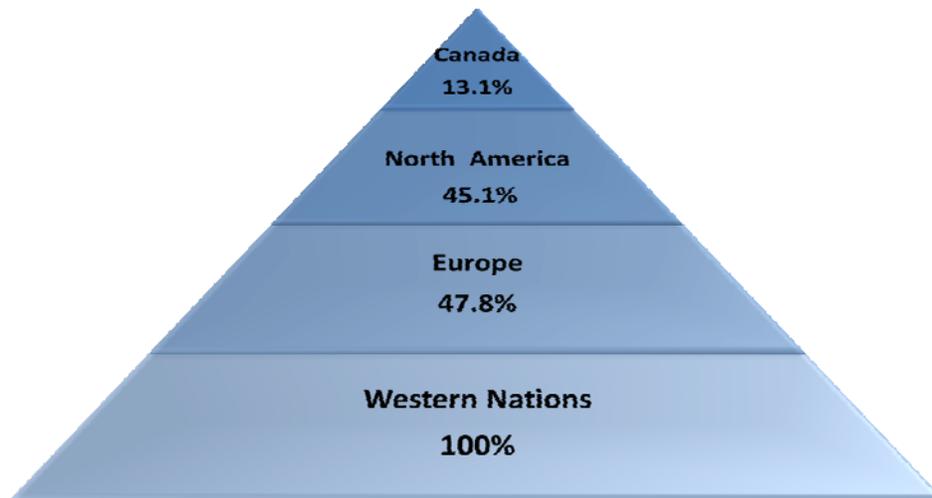


SECTION THREE RESULTS

3.1 Brief Description and Critique of Studies

As shown in Figure 2, all manuscripts reviewed in this paper were published in Western nations, nearly half were European (of which about half were from the United Kingdom [UK], followed by the Netherlands, Germany and France), and a slightly smaller percentage were North American. Among the latter group, only about one-fourth of the retrieved manuscripts were Canadian (about 13% of the total papers reviewed), of which less than half were primary research papers. Most Canadian studies involved surveys or interviews with PCP, and a small number included a review of patients' medical records. About one-third of these studies targeted both PCP and family caregivers, a similar proportion exclusively explored the views and experiences of caregivers, and the rest involved mixed samples of PCP and medical specialists.

figure 2. Manuscripts' Country of Origin



Consistent with the broad scope of this paper, the international literature reviewed was heterogeneous both in terms of its focus and methodology. Although it is beyond the scope of this review to provide a detailed description of each study's methods and their inherent limitations, we highlight here some of the most common methodological shortcomings of the published studies that should be considered in interpreting the results.

First, many studies reviewed relied on non-representative samples, using convenience sampling techniques, often recruiting exclusively from urban or sub-urban primary care settings, at times targeting university and/or hospital affiliated primary care practices, or even recruiting physicians attending various educational forums whose views and experiences may not be reflective of the broader and more diverse groups of PCP. As much as possible, we will compare the findings of these studies with the results of the larger, more representative and even population-based international studies. A common problem, even in some of the large scale randomized studies, was low physician response rates (in many cases at or lower than 50%). Non-response bias is an important and common threat to external validity of research with PCP internationally (Cahill et al., 2006; Hillmer et al., 2006; Yaffe et al., 2008). It is possible that PCP practicing in larger urban areas, especially those affiliated with academic settings; physicians attending educational forums, particularly events focusing on dementia and other geriatric topics; and finally, those responding to dementia-related surveys may be generally more interested in, knowledgeable about, and engaged in dementia care, thus resulting in a more positive picture of the realities of *primary dementia care* than actually exists.

There were also potential biases related to the retrospective design of most studies and their limited data collection methods, such as the exclusive reliance on the review of medical records and/or physicians' self-reports of their knowledge, skills, and practices. While the latter method may result in overly positive evaluations of physicians' performance, the former strategy discussed in the previous paragraph may underestimate it. It is well known that, often due to time pressures, physicians' documentations of their medical encounters may not accurately reflect their actual practices (Camicioli et al., 2000; Pimlott et al., 2006). In

particular, there seems to be an under-documentation of psychosocial and educational interventions compared to diagnostic and drug prescriptions. As appropriate, these limitations will be pointed out, when discussing the study findings in the next sections. Moreover, when available, the findings from some of the consumer research on the perspectives and experiences of PWD/caregivers during medical encounters will be presented to complement the results of research with PCP.

Finally, it is expected that the perspectives and practices of PCP are influenced by the unique geographic, cultural and policy environments of each country and region. While discussing the generic key themes that emerged across international studies, as much as possible, we will identify the issues unique to the Canadian perspective and milieu of care.

3.2 Best Practice Recommendations

Over the past decade, there has been a proliferation of dementia consensus position papers and clinical practice guidelines (CPG) in Western countries, which is an indication of the recognized importance of effective dementia management. Despite the variations in the systems of care, there seems to be substantial consistency in the core recommendations of most Western contemporary clinical practice guidelines regarding the diagnostic evaluation and management of dementia, which indicates reasonable consensus of what constitutes best dementia diagnostic and early care practices (Boise, 2005; Callahan et al., 2006; Chertkow, 2008; Cummings et al., 2002a, 2002b; De Lepeleire et al., 2008; Delrieu et al., 2009; Feldman et al., 2008; Maslow et al., 2002; Musicco et al., 2004; National Institute of Health and Clinical Excellence [NICE], 2011; Perry et al., 2010; SegalGidan et al., 2011; Villars et al., 2010; Waldemar et al., 2007a, 2007b).

Although there is insufficient evidence of benefit to justify population screening in primary care (Ashford et al., 2007; Bond, 2010; Boustani et al., 2003; Freyne, 2001; Harvan & Cotter, 2006; Lawrence et al., 2003; Patterson & Gass, 2001; White et al., 2002), most Western

expert position papers recommend “case finding” strategies by PCP to promote early detection of dementia disorders. As a first step in the screening and/or as part of the diagnostic algorithm, PCP are encouraged to use brief cognitive screening tools in symptomatic patients. There are many instruments available for this purpose. However, for various reasons, to date, no single one has been unanimously endorsed for use by PCP (Brodaty et al., 2006; Holsinger et al., 2007; Mitchell & Malladi, 2010a, 2010b). Nevertheless, over years, a number of relatively simple cognitive screening tools have emerged as the most widely accepted and validated instruments for use in this setting: e.g., Mini Mental Status Examination (MMSE), Mini-Cog, Montreal Cognitive Assessment (MoCa), and Memory Impairment Screen (MIS). Several recent review articles and meta-analyses provide a comprehensive review of the psychometric properties, feasibility and applicability of these instruments in primary care (Brodaty et al., 2006; Culverwell et al., 2009; Harven & Cotter, 2006; Holsinger et al., 2007; Milne et al., 2008; Mitchell & Malladi, 2010a, 2010b).

Once the PCP is alerted to the possibility of dementia, the consensus statements recommend a more comprehensive assessment to establish a diagnosis, which typically requires repeated visits over a course of weeks and possible referrals to specialists. The guidelines seem to differ in their position about the need for a specialist consultation for “typical” cases of dementia, with some of the international position papers favoring a confirmation of the diagnosis by a specialist (Cummings et al., 2002a; Delrieu et al., 2009; NICE, 2011; Villars et al., 2010; Waldemar et al., 2007a, 2007b). Of particular interest is the position of the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCD) held in March 2006. While acknowledging the challenges, the CCCD maintains that the typical presentations of the most common types of dementia can be accurately diagnosed by PCP, even in early stages of the disease (Feldman et al., 2008). The diagnosis can be made through clinical evaluation, brief cognitive screening, basic laboratory tests, and structural imaging, as appropriate. It is recognized that the diagnosis of dementia remains mostly clinical and largely based on a thorough medical history, which ideally should be collected by separately interviewing the PWD and family caregiver(s).

According to most CPG, once a diagnosis is established, it should be shared with the PWD/caregiver. In addition to providing information about the diagnosis, it is recommended that the disclosure process include a discussion of prognosis, advance planning, treatment options and support services (Cummings et al., 2002a; Delrieu et al., 2009; Feldman et al., 2008; Fisk et al., 2007; Hogan et al., 2008; Holmes & Adler, 2005; NICE, 2011; Perry et al., 2010; Villars et al., 2010). This typically requires follow-up visits and an on-going management of the evolving psycho-social needs of PWD/caregivers. The follow-up visits also provide opportunities to conduct medical reassessments, manage co-morbid conditions, monitor cognitive evolution of the disease, and evaluate the response to any prescribed treatments. Box 2 presents a list of actions recommended by the CCCD guidelines to assist PCP in providing medical, practical and emotional support to the PWD/caregivers after a dementia diagnosis.

Despite some variations in the recommended practice, Western dementia CPG generally advocate for an early diagnosis for a multitude of ethical, clinical, social and financial reasons (Carpenter & Dave, 2004; Cummings et al., 2002a, 2002b; Hogan et al., 2008; Kissel & Carpenter, 2007; Waldemar et al., 2007a). It is believed that early diagnosis can facilitate a more person-centered and proactive approach to dementia care, which would enable all parties involved (i.e., PWD, family caregivers and professional providers) to respond in a more timely fashion and more effectively to the complex and evolving needs. The goal is to maximize treatment effect and to help PWD/caregivers adjust better, both emotionally and practically, in order to avoid or at least delay complications, even though they may be initially distressed by the diagnostic process.

Box 2. Interventions to Assist Patients with a Mild to Moderate Dementia & their Families after a Diagnosis of Dementia Based on the Recommendations from the CCCD

- Inform the patient and his or her family (if present and appropriate) of the diagnosis (this would include general counseling and responding to specific questions)
- Identify the presence of a family caregiver, what support this person can offer, his or her status (i.e., evidence of strain) and his or her needs (this would include trying to deal with any identified needs) — ongoing activity
- Decide on the need for referrals for further diagnostic and management assistance (e.g., referral to genetic clinic for suspected familial cases) — ongoing activity
- Assess for safety risks (e.g., driving, financial management, medication management, home safety risks that could arise from cooking or smoking, potentially dangerous behaviours such as wandering) — ongoing activity
- Determine presence of any advance planning documents (e.g., will, enduring power of attorney, personal directive). If there are no such documents, advise that they be drafted. Note that this may include assessing the patient's capacity to either draft these documents or whether they should be put into effect.
- Assess the patient's decision-making capacity— ongoing activity
- Refer the patient and family to the local office of the Alzheimer Society of Canada
- Provide information and advice about non-pharmacologic and pharmacologic treatment options and availability of research studies
- Develop and implement a treatment plan with defined goals; continually update plan
- Monitor response to any initiated therapy
- Monitor and manage functional problems as they arise
- Assess and manage behavioural and psychological symptoms of dementia as they arise
- Monitor nutritional status and intervene as needed
- Deal with medical conditions and provide ongoing medical care
- Mobilize community-based and facility-based resources as needed (this includes being knowledgeable about supportive housing and long-term care options and the appropriate timing, and process, for facility placement)

Source: Hogan et. al. (2008). *Diagnosis and treatment of dementia: Approach to management of mild to moderate dementia*. Canadian Medical Association Journal, 179(8), 787-93.

Although, it is beyond the scope of this paper to provide a systematic and detailed description of all published papers discussing the benefits of early dementia diagnosis, we have summarized the key reasons identified in the literature in Table 1. The evidence comes mostly from expert opinion, anecdotal observations, and an emerging body of empirical research (mostly surveys and qualitative studies of PCP, caregivers, and to a much lesser extent that of PWD), as well as a number of review papers (Bamford et al., 2004; De Lepeleire et al., 2008; Foster, 2001; Iliffe et al., 2003; Pinner & Bouman, 2003; Robinson et al., 2008).

All contemporary CPG acknowledge that there may be circumstances in which disclosing a diagnosis of dementia to the person and/or family may not be necessary or advisable, and call for an individualized approach that is tailored to the unique patient/family context and wishes. The typical examples of “unusual circumstances” that may warrant withholding the diagnosis from the PWD are the inability of the person to comprehend and/or retain the diagnosis, and/or the risk of aggravating the person’s depressive symptoms, especially when there is a potential risk for suicide (Cummings et al., 2002a; Delrieu et al., 2009; Hogan et al., 2008; Villars et al., 2010).

In fact, the possibility of an adverse emotional reaction to the dementia diagnosis and concerns about other potentially harmful effects of a highly feared and stigmatizing diagnostic label are the underlying reasons for the more cautious approach of some of the international position papers (Delrieu et al., 2009). Some European experts go as far as suggesting that the term “dementia” may cause sensitivities and that it should be avoided during the disclosure, and/or the prognosis should be withheld (Delrieu et al., 2009). Other CPG leave the decision entirely to the patients, as to whether or not, and to what extent, they wish to be informed about their diagnosis and prognosis (NICE, 2011). Some authors have criticized the consensus guidelines for their apparent inconsistencies, imprecision and insufficient guidance concerning the extent and manner of dementia diagnosis disclosure in different circumstances, contributing to the uncertainty and variability in practice (Bamford et al., 2004; Carpenter & Dave, 2004; De Lepeleire et al., 2008; Kissel & Carpenter, 2007). Future parallel studies of the perspectives and experiences of PWD/caregivers as well as professional providers can

better inform the future revisions of the CPG. Barriers to the disclosure of a dementia diagnosis, the help seeking behaviors of PWD/caregivers, and the help provision practices of PCP will be discussed later.

Table 1. Potential Benefits of Early Dementia Diagnosis

Person with Dementia	Caregiver	Primary Care Physician	Society
Reduced uncertainty (Explanation of symptoms)	Reduced uncertainty (explanation of symptoms)	Reduced uncertainty (explanation of symptoms)	Respect for patient right to autonomy
Enhanced choice & autonomy	Shared management with PWD/physician	Shared management with PWD/caregiver	
Trust building in PWD-caregiver-physician relationship	Trust building in PWD-caregiver-physician relationship	Trust building in PWD-caregiver-physician relationship	
Better understanding of disease & management options	Better understanding of disease & management options	Patient/caregiver education	Improved quality of care
Timely access to specialists/support services	Timely access to specialist/support services	Timely referral/liaison with specialist/support services	
Optimal benefits from early treatment	Optimal benefits from early treatment	Optimal benefits from early treatment	
Advance care planning	Advance care planning	Advance care planning	Advance resource planning
Prevention/delay of complications (e.g., accidents, disability, hospitalization, LTC institutionalization)	Prevention/delay of complications (e.g., caregiver burden)	Prevention/delay of complications (e.g., intensive crisis interventions)	Prevention/delay of complications (e.g., use of emergency, acute care, & ALC hospital services; LTC institutionalization; increased cost of care; risk of driving accidents & other public safety concerns)
Participation in research	Participation in research	Recruitment for research	Advancement of research

Notes: Elements of this table were adapted from several articles in this review, most substantially those by Iliffe et al., 2003; Bamford et al., 2004; Carpenter & Dave, 2004; and De Lepeleire et al., 2008.

3.3 Evidence of Actual Practice

“I usually wait for the problem to be quite severe; I don’t get involved too early” (Bruce et al., 2002, p.188)

International research has consistently shown a lack of concordance between the best practice recommendations and the actual performance of many PCP in all dimensions of dementia diagnosis and management (Iliffe et al., 2005, 2009a, 2009b ; Musicco et al., 2004; Perry et al., 2010; Pimlott et al., 2009a; Van Hout et al., 2006; Waldemar et al., 2007a; Wilcock et al., 2009). There is general consensus that dementia, especially in early stages, remains under-detected, under-diagnosed, under-disclosed and under-treated/managed (Bond et al., 2005; Boise, 2005; Boustani et al., 2003, 2005; Connolly et al., 2011; Hollingworth & Byrne, 2011; Iliffe et al., 2009a, 2009b; Koch & Iliffe, 2010a; Mok et al., 2004; Perry et al., 2010; Sternberg et al., 2000; Valcour et al., 2000; Villars et al., 2010; Waldemar et al., 2007a; Wilkins et al., 2007). The diagnosis seems to occur mostly in moderate to advanced stages of the disease, and it is not always appropriately disclosed to the PWD/caregiver, and/or followed by a timely, responsive and comprehensive therapeutic approach (Bond et al., 2005; Boustani et al., 2003; Connolly et al., 2012; Iliffe 2009; Lopponen et al., 2003; Rait et al., 2010; Rondeau et al., 2008; Valcour et al., 2000; Waldemar et al., 2007a; Wilkins et al., 2007).

As discussed earlier, despite the remarkable progress that has been made in the neurosciences over the past few decades, the diagnosis of dementia disorders remains mostly clinical (Feldman et al., 2008). Although it has been documented that the clinical diagnosis of dementia can approach an accuracy rate of as high as 95%, this is typically achieved in circumstances involving experienced clinicians working with PWD who are monitored over time (Mayeux et al., 2011).

International research has consistently shown that in primary care settings, dementia disorders, in mild to moderate stages of the disease, are on average diagnosed in about 50% of cases (Boustani et al., 2003, 2005; Bradford et al., 2009; Callahan et al., 2009; Connolly et al.,

2011; Delrieu et al, 2009; Feldman et al., 2008; Ganguli et al., 2004; Sternberg et al., 2000; Valcour et al., 2000; Waldemar et al., 2007a; Wilkins et al., 2007). A recent systematic review of European and North American studies measuring sensitivity and specificity of dementia diagnosis in primary care confirmed the high rates of missed, delayed and undocumented diagnosis in this setting (Bradford et al., 2009). The pooled diagnostic sensitivity estimation in the meta-analysis of studies reviewed was 0.49, ranging from 0.26 to 0.69. This variability in the results is not surprising given the heterogeneity of the research methodologies, and the diversity in patient/provider populations studied. As expected, diagnostic sensitivity was strongly associated with the disease severity, with the rates being the lowest among individuals with mild dementia symptoms (0.09 to 0.41), compared to those with severe symptoms (0.60 to 1.0). Diagnostic specificity was assessed in only two studies and it was very high at 0.99.

Consistent with the above findings, a recent large scale prospective observational cohort study of 2000 patients in 138 general practices in Germany showed a high dementia diagnostic specificity rate of 0.96 and a much lower sensitivity rate of 0.51 (Pentzek et al., 2009b). Similarly, a recent British study of 351 general practices showed that just under half of the expected numbers of patients with dementia were recognized in general practice dementia registers (Connolly et al., 2011). These findings reaffirm that it is much more likely that PCP miss or delay a diagnosis of dementia than they falsely mislabel older patients.

Of interest is another large scale European study which showed significantly higher sensitivity rates for the recognition of “memory impairment” in primary care, compared to the rates for an actual diagnosis of dementia (Lopponen et al., 2003). In this Finish cross-sectional population-based study, the sensitivity of the general practitioners’ diagnosis of dementia was 0.48 and the specificity was very high at nearly 1.0. According to the severity of the disease, the documentation of a dementia diagnosis in patients’ medical records was at 73% in severe, 46% in moderate and 33% in mild cases. However, the physicians’ sensitivity to detect cognitive decline, in general, was much higher at 0.77. The documentation rates of “memory impairment” were at 97%, 71% and 66% for severe, moderate and mild dementia patients,

respectively. The effect of a dementia diagnostic label on physicians' diagnostic evaluation and management decisions will be discussed later under "Barriers to Best Practice".

A third study that should be noted here is Boise and colleagues' cross-sectional cohort study (2004) of 553 patients aged 75 or older in three American managed health care systems. In this study, nearly 43% of participants were identified by the research team as having some level of cognitive impairment, with 14% having moderately severe deficits. Among the latter group, in only about one-third (35%) of cases, was there any evidence of dementia investigations detected in the medical records, and only 15% had received a dementia diagnosis. This is despite the fact that three-fourths (75%) of these patients had experienced one or more adverse events which should have raised a suspicion of dementia. In another American study, 13% of 3,340 older patients of seven urban and racially diverse primary care practices screened positive for possible dementia, of which about half agreed to have a formal diagnostic evaluation (Boustani et al, 2005). Among this latter group, nearly half (47%) were diagnosed with dementia and an additional 33% had MCI. However, only 19% of the patients with confirmed dementia diagnosis had documentation of dementia in their medical records.

There is also evidence that delays in diagnostic evaluation may occur even when a suspicion of dementia is raised in older adults with positive cognitive screening results. In a Danish prospective study, 17% of 793 older patients consulting 17 general practices were identified with possible dementia (either because of their MMSE score of <23 and/or their physicians' clinical impression of dementia) (Waldorff et al., 2005). However, less than a quarter of these patients (23%) were later evaluated by their PCP or referred for further evaluation to a memory clinic within the following six months. This likely overestimates performance as the study had prompted the participating physicians to consider dementia at every consultation, and thus, had further sensitized them regarding this issue.

Similarly, in Borson and colleagues' American study (2007) of four university affiliated primary care clinics, physician action (in the form of further diagnostic or therapeutic interventions) occurred only in 17% of patients who failed a Mini-Cog test, administered by a medical assistant. The participating PCP acted mainly on positive screens when cognitive

impairment was severe, and only when patients were 75 years or older. The authors concluded that PCP take a “wait-and-see” approach for the majority of older persons who have some evidence of cognitive decline. A similar lack of follow-up on a positive dementia screen was reported in another recent American study (Boise et al., 2010).

These observations are corroborated by the results of a few qualitative studies of family caregivers’ perspectives and experiences, revealing the frustrations of many caregivers in obtaining adequate and timely evaluation of their relatives’ dementia symptoms (Bruce & Paterson, 2000; Connell et al., 2004; Hinton et al., 2004; Millard et al., 2008; Millard & Baune, 2009; Robinson et al., 2008; Teel & Carson, 2003). In Connell and colleagues’ American study (2004), 52 family caregivers of PWD who participated in focus group interviews reported that they often met with resistance from the PCP when attempting to obtain a dementia assessment and/or a definitive diagnosis. In another American qualitative study, family caregivers maintained that obtaining a dementia diagnosis for their relatives took several years and numerous physician visits, resulting in significant caregiver distress (Teel & Carson, 2003). Similar sentiments were expressed by the caregivers who participated in focus group interviews in an Australian study (Robinson et al., 2008). In this study, the overwhelming majority of family caregivers experienced the diagnostic process as a protracted and jumbled array of occurrences and communications, causing significant personal strain. The authors concluded that when family caregivers consult a PCP, they have already observed over time many changes in their relatives with suspected dementia, and are often ready for a speedy resolution.

A few published articles reporting the results of large scale multinational European and Australian surveys, including the Facing Dementia Survey, shed further light into this problem (Bond et al., 2005; Wilkinson et al., 2004, 2005). The latter is one of the largest surveys conducted on dementia involving over 2500 key stakeholders, including physicians, PWD and caregivers from six European countries. The results confirmed major difficulties experienced by both the physicians and the public in recognizing and responding to early dementia symptoms, and significant delays in the provision of a dementia diagnosis, even

after a suspicion is raised. Approximately 600 physicians participated in this survey, of which about half were PCP. Most physicians agreed that a dementia diagnosis is too often delayed because of factors affecting both physicians and caregivers. These factors will be explored in the next section.

According to the survey, from the initial presentation of symptoms, the confirmation of a dementia diagnosis in Europe takes an average of 20 months, with a wide disparity among countries, from 10 months in Germany to 32 months in the UK. The first delay occurs during the time between family recognition of symptoms and consultation with a physician. Caregivers typically waited several months before bringing the symptoms to the attention of a physician, and about one-fourth waited over a year to do so. The majority consulted a PCP first (74%). Although, in most cases (87%) the diagnosis was ultimately provided by a specialist, with neurologists being the main providers of dementia diagnosis (52%), followed by geriatricians (18%) and psychiatrists/psycho-geriatricians (12%). In this survey, about one-third of caregivers expressed dissatisfaction with the time taken from first seeking help to receiving a diagnosis. Physicians, on the other hand, reported that by the time PWD were first brought to their attention, most exhibited moderate symptoms, with about half having a MMSE score of between 10 and 20 at the first visit. Similar MMSE scores were noted among the newly diagnosed older patients of 681 PCP in a recent large scale French study (Rondeau et al., 2008).

Other Canadian and international studies have reported delays of one to two years between the first observation of symptoms and consultation with a physician (ASC, 2012; Knopman et al., 2000; Cattell et al., 2000; Teel, 2004; Speechly et al., 2008; Wilkinson et al., 2004). An Australian survey of 209 family caregivers showed a delay of close to two years between symptom recognition and professional consultation, and about three years before a firm diagnosis of dementia was provided (Speechly et al., 2008). Again, in the vast majority of cases (84%), a PCP was the first health professional consulted, with most patients being referred to a specialist after the first visit (59%). Finally, a recent national on-line survey of 958 family caregivers of PWD commissioned by the ASC (2012) revealed that almost half (44%) waited a year, with 16% of them waiting two years or longer, before seeking medical

help. Consistent with the international research, the vast majority (83%) visited their PCP first, but only about half (49%) were diagnosed by their PCP.

These large scale Canadian and international surveys point to the high rates of referrals of suspected cases of dementia from PCP to medical specialists. Similarly, Wilkinson and colleagues' multinational survey (2004) of 741 caregivers from Australia and four European nations showed that half of the patients with Alzheimer's Disease were managed by a specialist, about one-third jointly by a specialist and a PCP, and only in less than 20% of cases by a PCP alone. It has been reported that in France, nine out of 10 patients suspected of dementia are referred to a specialist (Cantegreil-Kallen et al., 2006). The review of medical records of 450 patients with dementia in 35 primary care practices in the UK showed that 58% of the patients who consulted their PCP for suspected dementia symptoms were referred to a medical specialist at the index consultation and often without conducting basic assessments (a practice that can further delay diagnosis and treatment) (Wilcock et al., 2009). In three quarters of patients in this study, a formal dementia diagnosis was ultimately made by a specialist.

Lopponen and colleagues' cross sectional population-based Finish study (2003) showed a slightly lower rate of referral to a specialist. A retrospective chart review revealed that 49% of patients with a documented dementia diagnosis, and 31% of those with memory impairment were referred to a specialist. Interestingly, the referral rates fell from 78% among patients aged 64-74 to only 14% among those over age 85. Patient characteristics influencing dementia diagnostic decisions will be discussed later. Stoppe and colleagues' German study (2007) showed that the potential referral rate from family practices to neuropsychiatrists is considerably high. Using case vignettes, 78% of the 122 participating PCP indicated that they would refer a suspected patient with moderate vascular dementia to a neuropsychiatrist. The rates were higher at 84% in the case vignette for a patient with symptoms of moderate Alzheimer's Disease. Similarly, in Chotirmall and colleagues' survey (2008) of 200 Irish PCP, 89% of respondents indicated that they routinely referred to a hospital geriatrician in their catchment area, and all maintained that they would refer to a memory clinic, if available.

The referrals to medical specialists may be made for various reasons, such as further diagnostic investigation, diagnosis provision/verification, or even treatment initiation. In many European countries, PCP are encouraged to consult with a specialist even for a diagnosis of a typical dementia, and in some countries they are not authorized to prescribe anti-dementia medications. Therefore, one might question the applicability of the international studies to the Canadian context given the cultural, geographic and health system policy differences. However, Pimlott and colleagues' Canadian study (2006) of 160 patients of three university affiliated family medicine clinics confirms the high rates of specialist referrals in Canada as well. In this study, a total of 82% of the patients with a confirmed diagnosis of dementia were referred to a specialist according to their medical records. Twenty-three percent of these patients were referred to geriatricians, 20.6% to geriatric psychiatrists, 30.7% to neurologists, and 7.5% to clinical psychologists.

Some authors have argued that these high rates of utilization of specialist services are not sustainable, given the growing prevalence of dementia and the shortage of medical specialist in most countries (Iliffe et al., 2005). This is particularly a concern when the referrals are not appropriate. In a Norwegian study, geriatricians rated referrals by PCP as being appropriate only in about 55% of cases, compared to 63% of referrals made by PWD/caregivers and other providers (Kada et al., 2007). In the same study, in about one-third of referrals from PCP, geriatricians evaluated the quality of information contained as poor.

There is also evidence that some PCP may not conduct adequate diagnostic investigations prior to making a referral. In Wilcock and colleagues' British study (2009), a review of medical records of 450 patients with dementia in 35 primary care practices indicated that nearly two-thirds were referred to a specialist at the index consultation. However, blood tests were ordered in only about one-third and cognitive function testing was performed in about one-fourth of these cases. In Stoppe and colleagues' German study (2007) described earlier, 15% of PCP maintained that they would conduct neuropsychological tests and 33% would order brain imaging in the case of moderate vascular dementia, and less than one-fourth

would apply the same tests in the case of Alzheimer's Disease (25% and 20%, respectively). The corresponding proportions for the 64 participating neuropsychiatrists in the same study were 60% in both cases for testing, and more than 80% for brain imaging. The neuropsychiatrists in this study were also more likely to identify the need for an informant report, physical examination, and screening for depression compared to the PCP.

In an American study, among over 1500 patients aged 65 years and older in the four primary care rural practices, 31 cases of dementia were identified from computerized office databases (Camicioli et al., 2000). Even among these documented dementia cases, laboratory studies (33%) and neuroimaging tests (18%) were recorded in only a minority, and the use of a standardized cognitive test was documented in only one chart. Pimlott and colleagues' Canadian study (2006) provides a more positive picture of diagnostic investigation practices of university affiliated PCP in family health teams. A retrospective medical chart review of 160 patients showed generally good concordance between the laboratory tests ordered by PCP and the CCCD guideline recommendations in most cases. Most physicians ordered appropriate basic blood tests as part of their assessment and for most patients, a primary caregiver was identified (79%) and a collateral history was obtained (70%). Most patients with dementia (81%) received at least one cognitive test, and 40% had computed tomographic examinations within 3 months of reporting symptoms of cognitive difficulties to their PCP (in some cases, the scans were ordered by the specialist consultants to whom the patients had been referred).

In Waldroff and Moller's large scale survey (2001) of 2539 PCP in Denmark, nearly half of the sample (47%) was classified as conducting good basic diagnostic evaluations of dementia. A substantial proportion of survey respondents self-reported that they always supplemented their suspicion of dementia by contacting family (45%), performing physical examination (62%), and ordering blood tests (60%). The authors acknowledged that the participating PCP may have over-rated their performance given the inherent biases associated with self-reports. Nevertheless, 44% of respondents indicated that they "seldom" or "never" performed a validated cognitive test as part of their assessment.

Overall, the international studies reviewed indicate that in about half to over three-quarters of cases, PCP either report and/or document conducting basic blood tests as part of their dementia investigation (Baloch et al. 2010; Cahill et al., 2006; Cherry et al., 2004; Chodosh et al., 2004; Cody et al., 2002; Downs et al., 2000; Lopponen et al., 2003). However, it appears that most do not routinely use validated cognitive instruments as part of their evaluations (Iliffe et al., 2005; Millard et al., 2011).

In Van Hout and colleagues' observational study (2006), general practitioners were instructed to use the Dutch dementia guidelines on all their older patients suspected of dementia. The use of a cognitive assessment tool (in this case, the MMSE), which is optional in the Dutch guidelines, was noted in only 18% of these patients. Similar results were obtained in two other European studies. In an Italian study examining PCPs' adherence with Italian guidelines, 70%-80% of a sample of 1549 patients with suspected dementia had no formal evaluation of their cognitive function, as evidenced by the use of a validated tool (Musicco et al., 2004). Similarly, Lopponen and colleagues' large scale population-based Finish study (2003) reviewed earlier showed that only 28% of patients with dementia had any evidence of cognitive testing in their medical records. In another study, physicians documented cognitive testing in only one-third of those whom they had recorded as being symptomatic, and in 42% of those whom they diagnosed with dementia (Ganguli et al., 2004). Interestingly, physicians largely tested patients whose MMSE scores ranged from 24 to 28. The authors concluded that there is a tendency for PCP to use a cognitive test in those in whom there is some clinical uncertainty as to the presence of impairment, whereas for those at the either end of the spectrum, there may be less motivation (and/or indication) to do so.

Wilcock and colleagues' British study (2009) of 35 PCP practices showed that at index visit, about one-fourth of 450 patients with a diagnosis of dementia had a documented cognitive function testing. It was unclear whether these patients were further tested at consecutive visits. In another prospective British study, Fisher and Lerner (2007) reviewed referral letters for 231 patients seen at a specialized memory clinic over a two-year period. Half of these patients

were directly referred by their PCP, about one-third of whom ultimately received a dementia diagnosis at the clinic. The evidence of cognitive test use in primary care was found in only 20% of patients referred (about 30% of patients diagnosed with dementia and 15% of those without dementia). It was found that those primary care patients who had received a cognitive test prior to the referral were more likely to receive a diagnosis of dementia, compared to those who had not been tested (56% vs 32%). The authors concluded that the use of simple cognitive instruments in primary care can reduce the rate of inappropriate referrals (which is an important outcome given the limited specialist resources in many countries).

The results of the above documentation review and observation studies are in contrast to the findings of a number of international surveys reporting PCPs' self-evaluations of their practice. In these studies, the majority of participating PCP indicated that they typically would perform a cognitive test in patients suspected of dementia (Baloch et al., 2010; Briages-Well 2006; Cody et al., 2002; Thyrian & Hoffmann, 2011; Iracleous et al., 2009). The possibility of response bias, especially in self-reported studies in which a checklist is used, should be considered.

Even when dementia is detected and documented in medical charts, across studies, PCP seem to withhold the diagnosis in a significant number of cases, and they may fail to follow-up with the PWD/caregivers. Furthermore, the manner and content of the diagnosis disclosure are often incongruent with the CPG recommendations and/or the expectations of PWD/caregivers.

Diagnosis disclosure has been a key focus of dementia research over the past decade. A number of British and North American review papers and a Canadian dissertation have identified over 70 studies written in English on this topic (Bamford et al., 2004; Carpenter & Dave, 2004; Crofton, 2005; Fisk et al., 2007; Pinner & Bouman, 2002; Wilkinson & Milne, 2003). These papers report wide variability in all dimensions of dementia diagnosis disclosure practices among physicians (both generalists and specialists) based on the physicians' self-reports, the accounts of other health care professionals, and the evaluation of PWD/caregivers.

Internationally, this seems to be one of the areas where there is significant discrepancy between current practices of many physicians and expert advice (Bamford et al., 2004; Carpenter & Dave, 2004; Crofton, 2005; Fisk et al., 2007; Perry et al., 2010; Wilkinson & Milne, 2003). A review paper summarizing studies published prior to 2002 estimated that about 50% of physicians routinely withheld a dementia diagnosis (Carpenter & Dave, 2004). Although, as shown below, more recent studies report relatively higher rates of disclosure, possibly an indication of a practice change in recent years.

For a variety of reasons which will be explored later, many PCP admit having difficulty disclosing a diagnosis of dementia, particularly to the patient (Baloch et al., 2010; Bamford et al., 2004; Pinner & Bouman, 2002; Carpenter & Dave, 2004; Crofton, 2005; Cody et al., 2002; Downs et al., 2000, 2002; Iliffe et al., 2003; Karnieli-Miller et al., 2007; Van Hout et al., 2001a). This is reflected in the higher self-reported and documented rates of disclosure to caregivers compared to the PWD. Across studies, only a minority of PCP seem to routinely discuss the dementia diagnosis and prognosis directly with the patient. In a Flemish survey of 1000 PCP, only about one-third (37%) reported that they “usually” or “always” informed PWD of their diagnosis, and a similar proportion indicated that they “rarely” or “never” did so (De Lepeleire et al., 2004). Other European studies found patient disclosure rates of between 20% and 50% (Down et al., 2002; Cahill et al., 2006; Olafsdottir et al., 2001).

As expected, the rates of disclosure to family caregivers are typically higher. In Van Hout and colleagues’ Dutch study (2006), a review of medical records of 64 PCP indicated that 42% of patients diagnosed with dementia, and almost twice as many as caregivers (82%) were informed of the diagnosis. In a Canadian survey of 312 PCP working in British Columbia (Crofton, 2005), a fairly high proportion of participants (59%) reported disclosing a dementia diagnosis to patients/caregivers most of the time, with physicians being more likely to disclose the diagnosis to the family than to the patients (the exact differential proportions were not reported). Finally, an American study of PCPs’ self-reports of their practices, also reported high rates of over 70% disclosure to patients and over 90% to caregivers (Cody et al., 2002).

In contrast, in a British study, only 15% of the medical records of 450 patients with dementia in 35 PCP practices indicated that the diagnosis was formally discussed with the patients and/or caregivers (Wilcock et al., 2009). Once again, the discrepancy may be at least partly related to the limitations inherent in each type of methodology, with medical records under-estimating and physicians' self-reports over-estimating their actual practices. Of note is also a large scale French survey of 616 general practitioners (Cantegreil-Kallen et al., 2005) which revealed interesting discrepancies between physicians' values and their actual reported practices. Nine out of 10 respondents considered it their role to explain the dementia illness, its symptoms and consequences to the patient. However, only one in four reported actually tackling the issue.

In a recent systematic review of studies examining the attitudes and perspectives of the PCP towards caregivers, the authors concluded that physicians seem to generally acknowledge the importance of an adequate diagnostic process, but they feel uncomfortable disclosing the diagnosis to patients and caregivers (Schoenmakers et al., 2009). This discomfort is reflected in the common use of euphemistic terms (e.g., "confusion" and "memory problems"), as opposed to sharing the proper medical diagnosis during the disclosure. Many physicians admit that they tend to avoid the use of explicit terms, such as "dementia" or "Alzheimer's Disease", and express a preference for the use of more subtle terms, especially when sharing the diagnosis with the patient (Bamford et al., 2004; Cody et al., 2002; Connell et al., 2004; Downs et al., 2002; Karnieli-Miller et al., 2007). The underlying reasons for this practice will be further discussed later under "Physician Factors").

In focus group interviews with 39 PCP, participants acknowledged the challenges of sharing a diagnosis of dementia, and reported using a variety of terms during the disclosure, including vague expressions such as "memory loss" (Connell et al., 2004). Some admitted that they deliberately avoided the use of specific medical terms, such as dementia and Alzheimer's Disease. Similarly, in the American survey of 142 PCP, participants admitted using a variety of terms when sharing a dementia diagnosis, including "confusion" (63%) and "memory problems" (35%) (Cody et al., 2002). In Downs and colleagues' British survey (2002), more

than a third of the respondents who reported that they tell the patient the diagnosis of dementia, admitted using only euphemistic terms to describe the illness and withholding considerable amount of information about the likely prognosis from the patients. Respondents maintained that they were more likely to discuss the factual medical information and the disease progression with the family caregivers.

An emerging body of literature shows important discrepancies between physicians' and family caregivers' views about the diagnosis and disclosure process. While there is a scarcity of research on the perspectives and experiences of PWD, several surveys and qualitative studies of family caregivers reveal some level of dissatisfaction with the manner of disclosure, the transference of critical information, and post-diagnosis guidance and follow-up support provided by PCP (Boise & Connell, 2005; Bruce & Paterson, 2000; Bruce et al., 2002; Connell et al., 2004; Hinton et al., 2004; Millard & Baune, 2009; Teel & Carson, 2003). In Bamford and colleagues' review article (2004), the main criticisms of family caregivers about the disclosure process focused on: a) the physicians' reticence to make a precise diagnosis and/or to explain the diagnosis and prognosis, b) the insensitive and abrupt manner of disclosure, and c) the limited opportunities to address the emotional aspects of dealing with the diagnosis. Similar conclusions were made by Wilkinson and Milne (2003) in their review article examining the expectations of older people and their families about dementia disclosure practices.

In Connell and colleagues' parallel survey of PCP and caregivers (2004), although physicians often believed that the diagnosis and disclosure process had gone well, many family caregivers reported challenges they faced in obtaining a diagnosis, criticized the manner of disclosure, and felt that they did not receive adequate information about the illness and/or available support services. Some caregivers were disappointed with the lack of post-diagnosis follow-up and maintained that the physicians had not suggested a return visit to monitor their relatives' conditions and/or referred them to appropriate support services. In the same study, some participating physicians also admitted that they typically did not schedule a return visit for patients with dementia.

In another review article, it was noted that although PCP mostly believe that they are highly involved in the community care of PWD, many caregivers rate their involvement to be insufficient (Schoenmakers et al., 2009). Caregivers seem to have mixed feelings about the attitudes and behaviors of PCP. On the one hand, they describe the PCP as being indispensable and helpful. On the other hand, they regret the physicians' apparent lack of time, empathy, communication skills and response to their psycho-social needs. Two other review articles confirmed the unmet needs of family caregivers with regards to various aspects of medical care during and after dementia diagnosis (Boise & Connell, 2005; Fortinsky, 2001). These papers concluded that the interactions in medical encounters when dementia care is discussed are far from optimal from the perspectives of family caregivers, with the main concerns centering on: (1) obtaining a diagnosis; (2) learning how to manage current or expected symptoms; (3) locating and using support services in the community; and (4) receiving emotional support.

The caregivers' feedback is validated by a small number of observational studies which reveal many shortcomings during the medical encounters. These studies confirm inadequate discussion of treatment and management options, including guidance on symptom management, safety and legal issues, and caregiver stress; as well as the lack of targeted interventions, including referrals to support services (Bridges-Webb et al., 2006; Cantegreil-Kallen et al., 2005; Chodosh et al., 2004; Downs et al., 2002; Millard & Baune, 2009; Olafsdottir et al., 2001; Pimlott et al., 2006; Teel & Carson, 2003; Yaffe et al., 2008; Van Hout et al., 2006; Wilcock et al., 2009). For instance, in Van Hout and colleagues' prospective observational study (2006) of 64 PCP who were instructed to use Dutch national dementia guidelines, less than half of the PWD/caregivers were advised on typical behavioral changes, communication, and safety issues in dementia.

Similarly, in Wilcock and colleagues' British study (2009), a review of medical records from 35 primary care practices revealed that follow-up and coaching on non-pharmacological ways of coping with behavioral disturbances and referral to support groups were the areas in which clinical practice diverged most from the guidelines. These findings may be in part a reflection

of the inadequate documentation of the interventions undertaken and may underestimate the actual performance of PCP.

Across studies, referral rates of below 50% have been reported for counseling, educational and support services, such as Alzheimer societies (Bond et al., 2005; Bridges-Webb et al., 2003; Cantegreil-Kallen et al., 2005; Cherry et al., 2004; Fortinsky et al., 2010; Reuben et al., 2009; Robinson et al., 2010b). In the large scale European Facing Dementia survey (Bond et al., 2005), very few PWD/caregivers were aware of their national or local Alzheimer societies/associations. However, those who were in contact with these organizations found them valuable for providing support and education. In Bruce and colleagues' Australian study (2002), several family caregivers of PWD maintained that PCP were not sufficiently aware of support services and some commented that they needed to prompt the physicians for a referral. In an American survey, only about half of the participating PCP agreed with the statement that the Alzheimer's association provides accessible education and support services to dementia patients and their families (Meuser et al., 2004).

Two Canadian studies have reported similar results. In Pimlott and colleagues' study (2006), a review of medical records of 160 Canadian patients diagnosed with dementia in three university affiliated family medicine clinics indicated that only 13% of caregivers were referred for counseling or support. In Yaffe and colleagues' study (2008) of 25 PCP in Quebec, participants were generally unaware of resources within their communities that were specifically oriented to the needs of caregivers of PWD. Most did not maintain any substantive or up-to-date lists of community resources, handouts, or pamphlets for patients or families. Although some were aware of the organizations such as Alzheimer societies, they were less aware of what these societies do, and they rarely referred to them. Instead, they used a "blanket" approach of undifferentiated, nonspecific referrals to local community service centers, known as CLSCs (centre local de services communautaires), potentially resulting in serious gaps in the care of their patients.

As shown above, despite a general consensus on what more or less constitutes an ideal primary care practice in dementia, there continues to be wide variability in the actual day to day realities of physicians' practices. The multitude of obstacles to optimal *primary dementia care* have been widely debated and studied internationally over the past decade. These will be discussed in the next section.

3.4 Barriers to Best Practice

The obstacles to an effective dementia diagnosis and management in primary care are multifold and highly inter-related. The common barriers identified in the international literature appear to be the result of complex interactions of a multitude of factors related to the disease, PWD/caregiver, physician, and health/social systems. This section provides a detailed description of the main factors identified in the literature. Insights provided are based on a variety of sources, including: a) several empirical studies examining the perspectives and experiences of PCP, family caregivers, and to a lesser extent those of PWD; b) review articles synthesizing the existing evidence on various dimensions of dementia diagnosis and clinical management in primary care; and finally, c) expert opinion papers debating these issues.

3.4.1 Disease-Related Factors

“...the very nature of the illness is that it can be impacted by all kinds of different things, so one of the barriers for me is just trying to sort out really the complexity of their cognitive function.” (Pimlott et al., 2009b)

There is a general consensus that the diagnosis and management of dementia in the primary care practice, especially at early stages of the illness, can be difficult. The timely diagnosis and continuing care of PWD is a complex and time intensive process characterized by multiple biomedical, psychosocial and ethical challenges (Adams et al., 2005; Bond et al., 2005; Bradford et al., 2009; Feldman et al., 2008; Hogan et al., 2008; Iliffe et al., 2006, 2009b; Mayeux et al., 2011; Pimlott et al., 2009b)

As discussed earlier, the investigation process can be lengthy and convoluted, often requiring longitudinal observations, a detailed assessment of cognitive function, and a thorough clinical evaluation (Delrieu et al., 2009; Feldman et al., 2008; Hansen et al., 2008; Hogan et al., 2008; Iliffe et al., 2006; Villars et al., 2010; Waldemar et al., 2007b). Early signs may be subtle and fluctuating, and the clinical manifestations may be diverse and often overlapping with other co-morbidities, further complicating the diagnostic process (Bradford et al., 2009; Bridges-Webb, 2002; Cahill et al., 2006; Cerejeira et al. 2007; Fortinsky et al., 2010; Ganguli et al., 2004; Iliffe et al., 2006, 2009b; Mok et al., 2004; Pimlott et al., 2009b; Van Hout et al., 2000; Yaffe et al., 2008). The presence of co-morbid conditions can also act as a distraction, reducing the likelihood that the less acute dementia symptoms receive adequate medical attention during brief medical encounters (Bradford et al., 2009; Cahill et al., 2006; Chodosh et al., 2004; Ganguli et al., 2004; Iliffe et al., 2006). Dementia itself can have a “domino effect”, negatively influencing the management of other chronic conditions, thereby destabilizing these conditions and further complicating the medical care of PWD.

The lack of definitive cognitive assessment, diagnostic imaging and laboratory tests adds to the diagnostic uncertainty, raising concerns about mislabeling the patient with a potentially devastating diagnosis for which therapeutic options remain limited and symptomatic (Chertkow, 2008; Maslow et al., 2002; Mayeux et al., 2011; Waldemar et al., 2007b). The absence of a definitive diagnostic test also means that physicians have to largely rely on medical history, which may not be always easy to obtain, given that it comes from a cognitively impaired older person and/or collateral sources with varying degrees of insight and/or involvement (Foster, 2001; Ganguli et al., 2006; Mayeux et al., 2011). As we will see later, the proxy and/or self-reported estimates of health and function in dementia patients may be unreliable (Adams et al., 2005; Arlt et al., 2007; Ganguli et al., 2006; Hunsaker et al., 2010). Finally, the presence of family caregivers, although often very helpful, can further add to the complexity and time requirements of the medical appointments (Adams et al., 2005; Foster, 2001; Schoemakers et al., 2009; Yaffe et al., 2008).

In addition to the difficulties related to the diagnosis provision, the actual management of dementia presents on-going complexities and evolving challenges as well (Hogan et al., 2008). Practicing physicians often find themselves in uncertain territories (which may well be outside the area of their clinical knowledge and expertise), when dealing with sensitive issues, such as diagnosis disclosure, drug treatment, caregiver support, and housing and driving decisions (Foster, 2001; Hogan et al., 2008; Snellgrove & Hecker, 2002; Yaffe et al., 2008). Good dementia care often requires multi-component interventions, involving a variety of practitioners and services. Complex alliances need to be developed with the PWD, family caregivers, and other service providers in order to meet the multifaceted needs of PWD/caregiver (Hinton et al., 2007). Coordinating various specialty and community services can further add to the challenges of working with PWD and increase the workload and paperwork demands for the PCP (Hinton et al. 2007; Hogan, 2008; Yaffe et al., 2008).

3.4.2 PWD/Caregiver Factors

“I think it’s easier sometimes to miss it, especially if the family member is part of the whole conspiracy, almost where they either take over or they help the person, so they’re like a team, so no one really wants to see the problem.”
(Pimlott et al., 2009b)

Several manuscripts reviewed in this paper have identified multiple barriers related to PWD/caregiver that can contribute to the delays in dementia diagnosis and its effective management in primary care. The PWD/caregivers’ lack of recognition and/or acknowledgment of dementia symptoms, their delays in seeking help, their lack of acceptance of the diagnosis, and their refusal to follow the recommended interventions are important barriers to timely dementia management in primary care (Adams et al., 2005; ASC, 2012; Austrom et al., 2006; Bamford et al., 2004; Bradford et al., 2009; Bruce & Paterson, 2000; Bruce et al., 2002; Boustani et al., 2006; Bridges-Webb et al., 2006; Helmer et al., 2008; Iliffe et al., 2002; Koch & Iliffe, 2010a; Koehn et al., 2012; Rondeau et al., 2008; Reuben et al., 2009; Teel, 2004).

As discussed earlier, research evidence points to significant delays in help seeking from the onset of dementia symptoms to the first physician consultation (Adams et al., 2005; ASC, 2012; Bond et al., 2005; Iliffe et al., 2002; Koehn et al., 2012; Teel, 2004; Teel & Carson, 2003; Wilkinson et al., 2004, 2005). Informed and involved family caregivers can play a critical role in early recognition and the proactive management of dementia in primary care. Their role can range from reporting symptoms promptly and accurately, leading to a timely diagnosis, to facilitating the actual implementation of recommended interventions. In several studies, PCP have identified many ways in which PWD and their families can either help or hinder effective diagnosis and management of dementia. For instance, in two Canadian studies, PCP recognized the importance of their relationship with both patients and their family caregivers as a strong determinant of the success of community-based dementia care (Pimlott et al., 2009b; Yaffe et al. 2008). Working with informed, involved and supportive PWD/caregivers was perceived by PCP as being an important enabling factor in dementia care.

In a number of Canadian and international studies, PCP admitted that family members' complaints about their relatives' memory loss, was one of the main triggers for a dementia investigation (Adams et al., 2005; Crofton, 2005; Olafsdottir et al., 2001; Pimlott et al., 2009b). On the other hand, inaccurate or selective reporting of symptoms, denying or downplaying the concerns, or even covering up the person's deficits were viewed as being a major barrier to timely and accurate dementia diagnosis and management (Adams et al., 2005; Boise et al., 2004; Boustani et al., 2006; Cantegreil-Kallen et al., 2006; Franz et al., 2007, 2010; Helmer et al., 2008; Hunsaker et al., 2010; Pimlott et al., 2009b; Wilkinson et al., 2004, 2005). So were their ambivalence and refusal to be referred for further assessment and supportive interventions (Boustani et al., 2005, 2006; Bruce et al., 2002; Cantegreil-Kallen et al., 2006; Cohen, 2000; Franz et al., 2010; Rondeau et al., 2008; Reuben et al., 2009; Van Hout et al., 2000; Yaffe et al., 2008).

A careful examination of the underlying reasons for this apparent lack of constructive participation of some PWD/caregivers reveals three overarching and interrelated barriers: a) gaps in knowledge/awareness, b) belief/attitudinal concerns, and c) lack of support/resources. Interestingly, as we will see later, the same themes also capture the main physician-related barriers to optimal diagnosis and management of dementia in primary care.

Knowledge/Awareness

The lack of awareness of the early signs and symptoms of dementia among older persons and their families, and the uncertainty about the boundary between normal ageing and cognitive impairment are important obstacles to timely dementia recognition. Research points to some underlying reasons for this gap in knowledge, including: a) the public's limited conceptual framework of dementia which reflects only its more advanced symptomatology, b) different cultural beliefs about normal aging, and c) the misattribution of the symptoms to other medical conditions (Adams et al., 2005; ASC, 2012; Baloch et al., 2010; Bond et al., 2005; Bradford et al., 2009; Bruce & Paterson, 2000; Franz et al., 2010; Koehn et al., 2012; Iliffe et al., 2005; Lee et al., 2011; Leung et al., 2011; Teel & Carson, 2003; Valcour et al., 2000; Vernooij-Dassen et al., 2005; Wilkinson et al., 2005). The lack of insight of some PWD, and/or their active denial of the symptoms, can further hinder a proactive approach to their care (ASC, 2012; Helmer et al., 2008; Iliffe et al., 2005; Pimlott et al., 2009b).

Beliefs/Attitudes

As argued by Iliffe (2005), in increasingly informed Western societies, the attribution of dementia symptoms to normal ageing may at times be related to conscious or unconscious choices, rather than simply reflecting a lack of awareness. The journey of PWD/caregivers continues to be punctuated by three closely intertwined concepts of ageism, stigma and nihilism. Ageism results in a negative perception of ageing, which is regarded as being a degenerative or disabling process, in which losses in memory and function are viewed as being normal changes of relative low priority (Iliffe et al., 2005). Therefore, the early symptoms of dementia may be attributed to "normal" ageing, and assimilated into everyday

life by the PWD/caregivers. This coping strategy can lead to problem minimization, inappropriate normalization, or even denial of dementia symptoms.

The fear of being labeled as having a stigmatizing mental illness, such as dementia, and the many potential negative consequences of such a powerful diagnostic label (e.g., the loss of autonomy, dignity, relationships, and social privileges) are real concerns for many PWD/caregivers (Aminzadeh et al., 2007; Bond et al., 2005; Bradford et al., 2009; Goodwin, 2002; Iliffe et al., 2002; Iliffe et al., 2005; Justiss et al., 2009; Kaduszkiewicz et al., 2008; Koehn et al., 2012; Lee et al., 2011; Reuben et al., 2009). Indeed, numerous studies have shown that the fear of stigma attached to dementia disorders, and the negative emotional reactions that the diagnosis may invoke in PWD/caregivers and their broader social networks, can act as powerful obstacles in seeking help (Aminzadeh et al., 2007; Bamford et al., 2004; Bond et al., 2005; Bradford et al., 2009; Bruce et al., 2002; Connell et al., 2004; Iliffe et al., 2003, 2005; Justiss et al., 2009; Kaduszkiewicz et al., 2008; Koehn et al., 2012; Lee et al., 2011; Reuben et al., 2009; Robinson et al., 2008).

As we will see later, PCP seem to be very conscious of the anxieties that some PWD/caregivers may experience and their potential negative response to dementia investigations and diagnosis disclosure, which may in turn, negatively influence their own approach to dementia care (Bradford et al, 2009; Cantegreil-Kallen et al., 2005; Reuben et al., 2009; Robinson et al., 2008; Teel, 2004; Van Hout et al., 2000). The fear of losses associated with a dementia diagnosis is closely linked to nihilism, and the lack of belief in the existence of helpful therapeutic and supportive interventions (Downs et al., 2006). As discussed later, the taboo of dementia illness and the negative perception of its prognosis are frequently reinforced by the attitudes of physicians and other care providers as well. Among other concerns cited in the literature are the over-reliance of some PWD/caregivers on physicians to broach the topic of cognitive impairment during medical encounters, and their failure to challenge the physician's authority when their concerns are not dealt with adequately (Adelman et al., 2004; Koehn et al., 2012).

Support/Resources

One of the most important resources shaping the outcomes of dementia care in the community is the patient's support network. In particular, research has shown that the presence of a family caregiver who is willing to work constructively with the PWD, PCP and other providers is an important facilitator of dementia care. In two large scale German and American studies, dementia was more likely to be missed in primary care among older adults who lived alone (Pentzek et al., 2009b; Wilkins et al., 2007). In Yaffe and colleagues' Canadian survey (2008), a sample of PCP practicing in Quebec felt that it was more challenging to coordinate patient care in the absence of a family spokesperson who was "supportive, understanding, or accepting". In a French survey of over 600 PCP, participants were more reluctant to discuss the nature of Alzheimer's Disease when the patient had no family caregiver (Cantegreil-Kallen et al., 2005). Finally, financial constraints, residency in rural areas, and the lack of transportation have also been identified as barriers to timely access to dementia services (Bradford et al., 2009; Franz et al., 2010).

Patient Characteristics

In addition to the person's living arrangement and social network, research has identified other socio-demographic and health-related patient characteristics that may influence the processes and outcomes of dementia diagnosis and management in primary care. These variables seem to interact in complex ways which are not yet well understood. Borson and colleagues' American study (2006) of 3710 predominantly ethnic minority elderly persons illustrates some of these complexities. In this study, the results of bivariate analyses of the impact of demographic factors on physician's recognition of cognitive impairment indicated positive associations between the low levels of education and low income with the lower rates of recognition. However, in the multivariate analysis, the non-English speaking status of older participants emerged as the only statistically significant demographic variable influencing physician recognition (as the bivariate effects of education was eliminated by shared variance with language and the effect of income was outweighed by illness related attributes). Interestingly, in the same study, the results of the Mini-Cog were relatively free of bias by demographic variations.

In an American study, interviews with 39 ethnically diverse family caregivers of PWD revealed important cross ethnic differences (Hinton et al., 2004). While most of Anglo and black caregivers maintained that the family initiated help seeking, half of the Chinese-American families reported that health care providers initiated care for dementia symptoms. In the same study, the lack of a final diagnosis was much more commonly reported by Chinese-American caregivers (43%), followed by blacks (20%), and Anglos (7%). It appears that the cumulative effect of lower socio-economic status and ethno-cultural minority background places some PWD/caregivers in a particularly disadvantaged position. The lack of familiarity with the mainstream biomedical model of disease, linguistic barriers, low income, and low literacy may have a compounding effect resulting in under-recognition and under-treatment of these patients in primary care settings (Austrom et al., 2006; Baloch et al., 2010; Borson et al., 2006; Bradford et al., 2009; Lee et al., 2011; Hinton et al., 2004; Iliffe et al., 2005; Koehn et al., 2012).

Age is another demographic factor that seems to have an important influence on dementia diagnosis and care decisions. As we saw earlier, in Lopponen and colleagues' Finnish observational study (2003) of 1260 older persons, the percentages of participants whose dementia was not detected by their PCP rose from 17% in patients aged 64–74 years to 28% among those over age 85. In a multinational European and Australian large scale survey of nearly 750 caregivers of persons with dementia, older persons under 80 years old were more likely to receive a recommendation for anti-dementia treatments compared to their counterparts who were over age 85 (Wilkinson et al., 2004). In Boustani and colleagues' American study (2006) of 434 older patients in seven primary care practice centers, older age was associated with a higher probability of refusing dementia assessment in bivariate analyses. In the multivariate analysis, there was an interesting interaction between age and race. African-American patients aged 80 and older were more likely to refuse the diagnostic assessment than younger African-American participants, while there was no significant age association for white patients. Other studies have shown a negative relationship between age

and dementia diagnosis, drug treatment and specialist consultation (Helmer et al., 2008; Sternberg et al., 2000; Wilkins et al., 2007).

It is possible that in addition to its independent effect, age exercises its influence through its associations with the person's, overall health status and social support. For instance, older persons may have more complex and pressing health concerns and fewer resources to meet their needs. The presence of multiple co-morbid conditions can complicate the diagnosis and management of dementia in many ways. As discussed earlier, the symptomatology of these conditions may overlap with early dementia symptoms resulting in missed or delayed diagnosis (Bradford et al., 2009; Bridges-Webb, 2002; Cahill et al., 2006; Cerejeira et al. 2007; Fortinsky et al., 2010; Ganguli et al., 2004; Iliffe et al., 2006, 2009b; Pimlott et al., 2009b; Van Hout et al., 2000; Yaffe et al., 2008). The presence of co-morbidities can also act as a distraction, reducing the likelihood that the less acute dementia symptoms receive adequate medical attention during brief medical encounters (Bradford et al., 2009; Cahill et al., 2006; Chodosh et al., 2004; Ganguli et al., 2004; Iliffe et al., 2006).

On the other hand, some physical, mental and functional disabilities may actually increase the likelihood that a person is diagnosed with dementia. In Pentzek and colleagues' German study (2009b) of over 3000 patients of 138 general practices, frail older persons with co-morbidities, hearing loss, and mobility disabilities were more likely to be rated as "cognitively impaired" by their PCP. Finally, a number of studies have shown that the presence of depression may also increase the likelihood of case detection for dementia (Chodosh et al., 2004; Crane et al., 2006; b et al., 2009). While, in other studies, it is associated with a greater likelihood of missed diagnosis (Lopponen et al., 2003).

As far as the severity of dementia illness is concerned, individuals at both ends of the continuum seem to be at higher risk of not receiving a diagnosis and/or treatment. Mild symptoms are more difficult to recognize (Boise et al., 2004; Bradford et al., 2009; Lopponen et al., 2003; Pentzek et al. 2009b; Valcour et al., 2000; Sternberg et al., 2000) and patients with mild symptoms may be more likely to refuse diagnostic investigations and referrals

(Boustani et al., 2006). In contrast, PCP seem to be more reluctant to provide a formal diagnosis to older persons with more advanced dementia, which may be at least partly a reflection of their perceived lack of therapeutic benefit (Downs et al., 2002; Bamford et al., 2004). This issue will be further explored in the next section.

3.4.3 Physician Factors

Knowledge/Skills/Confidence

“[Dementia is] something that’s not necessarily like chest pain, and it can progress, so where is that spectrum, like sometimes it can be very obvious, but early dementia... can be difficult to sort, even have the clinical acumen to even ask about it.” (Pimlott et al., 2009b)

Much of the material generated in this section is based on the studies of self-evaluations of PCP of their knowledge, skills, and confidence in making a diagnosis of dementia, disclosing the bad news, and managing behavioral and psychosocial needs of PWD/caregivers. These self-reports are punctuated with a sense of uncertainty with regard to all of the aforementioned aspects of *primary dementia care*.

For instance, many PCP express low confidence in making a diagnosis of dementia, particularly in the early stages of the disease (Baloch et al., 2010; Cahill et al., 2006; Cody et al., 2002; Downs et al., 2002; Iliffe et al., 2006; Iliffe & Wilcock, 2005; Millard et al., 2011; Valcour et al., 2000; Van Hout et al., 2002); feel that their training has been insufficient to prepare them for this task (Fortinsky et al., 2007; Iliffe et al., 2003, 2005; Overcoming Barriers, 2008; Renshaw et al., 2001); and, express a strong desire for a specialist consultation (Iliffe et al., 2003, 2005, 2006; Pimlott et al., 2009b; Turner et al., 2004; Yaffe et al., 2008).

There is evidence that many PCP view the diagnosis and management of dementia disorders as being more complex than other chronic conditions. In Harris and colleagues' American study (2009) of PCP working at 18 outpatient clinics, more than three-fourth of participants felt that older patients with dementia were difficult to manage, whereas fewer than half shared the same view with respect to the management of heart diseases. Similarly, in Pimlott and colleagues' Canadian study (2009b), 18 PCP working in academic family practice clinics in various regions of Canada expressed substantial uncertainty about making the diagnosis of dementia, and viewed dementia as being more complicated, both biologically and psychosocially, than other chronic conditions they managed. The perception of the complexity of diagnosis and early management of dementia disorders has been reported in other Canadian and international research papers (Harris et al., 2009; Hinton et al., 2007; Millard et al., 2011; Pimlott et al., 2009b; Teel, 2004; Turner et al., 2004; Van Hout et al., 2002). It appears that across studies, between one-third to three-quarters of PCP question their ability to address various aspects of dementia diagnosis, such as recognizing the significance of early symptoms, identifying dementia sub-types, and making an accurate diagnosis (Cody et al., 2002; Downs et al., 2002; Franz et al., 2007; Millard et al., 2011; Olafsdottir et al., 2001; Turner et al., 2004; Van Hout et al., 2002; Wilkinson et al., 2005).

As discussed previously, one area of physicians' difficulty repeatedly cited in the literature is the recognition of the early indicators of dementia in order to begin the diagnostic process (see "Evidence of Actual Practice"). Similar to PWD/caregivers, many PCP seem to have a limited conceptual framework of dementia which includes only its more advanced symptomatology. Therefore, the early dementia symptoms are often misattributed to the frailties of old age, fatigue, and mood disturbances (Bradford et al., 2009; Cahill et al., 2006; Delrieu et al., 2009; Iliffe et al., 2005; Iliffe & Wilcock, 2005; Mok et al., 2004; Snellgrove & Hecker, 2002). In the Dementia Face Survey involving over 2500 participants in six European nations (Bond et al., 2005), over two-thirds of caregiver and physician respondents agreed or strongly agreed that many PCP are unaware of the early symptoms of Alzheimer's Disease, and consequently, fail to diagnose it. Earlier we also talked about the impact of multiple pathologies commonly present among frail older adults, and how they may overshadow, and

indeed in some cases even mask, the dementia symptoms (See “Disease-Related Factors”). In the complexities of differentiating dementia from the signs and symptoms of ageing (and its associated co-morbidities), this added challenge should also be noted.

Several studies have shown that many PCP have limited dementia specific training and they identify the need for relevant education (Baloch et al., 2010; Cahill et al., 2006; Fortinsky et al., 2007; Franz et al., 2007; Iliffe et al., 2003, 2005; Overcoming Barriers, 2008; Renshaw et al., 2001; Robinson et al., 2001; Turner et al., 2003). In Cahill and colleagues’ national postal survey (2006) of 600 Irish PCP, the majority (90%) had no dementia specific training and expressed a desire for it (83%). In Baloch and colleagues’ American survey (2010), about two-thirds of the responding PCP believed they did not receive sufficient training in dementia evaluation and management during their residency. Similarly, in two European surveys, between half and two-thirds of the participating PCP felt that they had not received sufficient training in the diagnosis and management of dementia (Overcoming Barriers, 2008; Renshaw et al., 2001). Similar sentiments were expressed by most workshop participants in Iliffe and Manthorpe’s British study (2004). In another published paper from the same study, many participants argued that dementia diagnosis belonged to specialists (Iliffe et al., 2003), a perception that has been reported by PCP in other studies as well (Turner et al., 2004; Iliffe & Wilcock, 2005). Another group of studies have shown the strong desire of PCP for specialist consultation and verification of dementia diagnoses (Iliffe et al., 2005, 2006; Pimlott et al., 2009b; Manthorpe et al., 2003; Yaffe et al., 2008). Further evidence in support of this finding was provided earlier in this paper, when discussing the high rates of referral of patients with dementia to specialists in various international studies (see “Evidence of Actual Practice”).

Some authors suggest that PCP may be more competent in making a dementia diagnosis than they acknowledge. In Olafsdottir and colleagues’ survey (2001) of 228 PCP in Sweden, although the participants demonstrated a good knowledge of the clinical features of dementia, a majority regarded their knowledge as insufficient and asked for more education in this field. In this study, only 20% of participants agreed that their knowledge and experience was adequate to detect patients with dementia, to identify dementia sub-types and to make a

differential diagnosis. Similarly, in Pimlott and colleagues' Canadian study (2009b), the 18 participating PCP from academic family practice clinics had overall good knowledge of dementia diagnosis and management. Nevertheless, they expressed a strong desire for a specialist to either make or verify the diagnosis. Moreover, the studies that have used quizzes and case vignettes have shown moderately good textbook knowledge of PCP in identifying dementia symptoms (Iliffe et al., 2009b; Pentzek et al., 2009a; Turner et al., 2004; Wijeratne & Harris, 2009). This apparent lack of translation of the textbook knowledge into everyday clinical practice of PCP is related to several confounding factors which will be further explored later in this paper (for a discussion of the actual dementia detection rates in primary care refer to "Evidence of Actual Practice").

As mentioned earlier, it is believed that the use of CPG can improve physicians' confidence and their actual performance vis-à-vis dementia diagnostic practices (Downs et al., 2006; Pimlott et al., 2009a; Waldorff et al., 2003). In a cross sectional comparison of the diagnostic accuracy of 64 Dutch PCP who were instructed to use their national dementia guidelines and a memory clinic, there was an agreement of dementia diagnosis in 76% of 93 cases (Van Hout et al., 2000). The accuracy of PCP diagnoses fell to 53% in differentiating between dementia sub-types. However, most PCP were able to assess the firmness of their own diagnoses, suggesting that they were able to determine which patients were most appropriate for a specialty referral. Overall, the PCP reported diagnostic confidence in 59% of cases, which was associated with the level of diagnostic agreement with the memory clinic. Once again, their diagnostic confidence fell for specific dementia sub-types.

However, it appears that many PCP are unaware of the existing CPG (Pimlott et al., 2009a; Waldorff et al., 2003). It has been reported that in France only one-third of family physicians know of their national guidelines (De Lepeleire et al., 2008). In Pimlott's multisite Canadian study (2009a) of a sample of PCP in academic family practice clinics, most participants were not aware of having received the Canadian consensus guidelines (CCCD), and those who did remember receiving them did not have much knowledge of the specific content. As we will see later, the knowledge of the guidelines does not necessarily guarantee their endorsement.

There is a continued perception among many PCP that they do not have adequate methods to make a diagnosis of dementia. As discussed earlier, in recent years many clinically useful screening tools and assessment protocols have been developed for use in primary care. However, according to many international studies, the perception of the lack of validated and feasible tools and assessment methods persists among many PCP (Bradford et al., 2009; Downs et al., 2000; Waldorff & Moller, 2001). This perspective may be, at least in part, due to their unawareness of the existing tools/protocols and their lack of comfort and confidence in using them. This especially applies to the newer tests of cognitive function, such as the Mini-Cog, the General Practitioner Assessment of Cognition (GPCOG), and the Memory Impairment Screen (MIS), which may be more suitable for use in primary care, due to their brevity and ease of administration (Brodaty et al., 2006; Iracleous et al., 2010; Koch & Iliffe, 2009; Milne et al., 2008; Mitchell & Malladi, 2010a, 2010b).

Milne and colleagues (2008) conducted a survey of three primary care trusts in the UK to examine their use of cognitive screening tools. Over half of the responding practices (53%) indicated that they used at least one dementia screening tool, with MMSE being the most commonly employed instrument (80%). Survey respondents raised concerns about the limited availability of measures other than MMSE, expressed the need for information about the full range of screening instruments, and asked for greater access to training and advice on cognitive screening. MMSE was also the most commonly used cognitive assessment tool in a recent Canadian study of a random sample of 249 members of the College of Family Physicians (Iracleous et al., 2010). In this survey, the majority of respondents agreed that cognitive impairment assessment is important in primary care (89%). However, 35% expressed ambivalence about whether it actually leads to better patient outcomes. A relatively high proportion of respondents in this study (67%) reported using MMSE “often” or “routinely”, followed by Clock Drawing Test (52%) and Delayed Word Recall Test (52%). However, the vast majority had ‘never used’ or were ‘not familiar with’ the Mini-Cog (94%), MoCA (82%), GPCOG (96%); and 3MS (68%). This is despite the fact that the majority of those who responded to the survey (52% of the target population) had been in practice for

over five years, typically in a group practice setting, and devoted between 40-60% of their practice to the care of elderly. For a more detailed discussion on the evidence on the use of cognitive assessment tools refer to the “Best Practice Recommendations” and “Evidence of Actual Practice” discussed earlier.

Some experts have argued that the main concerns vis-à-vis the training needs of PCP is their lack of skills in patient/caregiver education, and in their management of their patient’s broader quality of life and psychosocial needs (Iliffe et al., 2005, 2009b; Iliffe & Manthorpe, 2004). The term management is broadly used here to include the anticipation and recognition of needs, as well as referral to available services, as appropriate. In support of this argument is the emerging body of research on physicians’ self-evaluations of their performance in this area, as well as the PWD/caregivers’ feedback on physicians’ practices. Several studies reviewed in this paper have shown that PCP express greater confidence in their diagnostic competence compared to their communication and management skills, especially with regard to the psychosocial needs of PWD/caregivers. In Olafsdottir and colleagues’ Swedish study (2001), PCP identified the assessment of social circumstances and social care of patients with dementia as the most difficult aspect of dementia management. In Turner and colleagues’ British study (2004), while about two-thirds of PCP expressed some level of confidence in their diagnostic skills, only about one-third expressed similar sentiments with regard to their ability to give advice on the management of behavioral problems. In the same study, fewer than half of the participants reported being aware of a support group for PWD/caregivers in their area, and only about one-third could name and locate one.

In a survey of 631 French PCP, 56% of the sample thought they were insufficiently informed about the existing services, compared to only 5% who reported a lack of knowledge of Alzheimer’s Disease (Cantegreil-Kallen et al., 2006). In another British study, over two-thirds of a sample of 278 PCP attending training seminars on dementia reported difficulty responding to patients’ behavioral problems, and slightly over half admitted having difficulty obtaining information about support services and coordinating such services for their patients with dementia (Downs et al., 2000). Although, in a recent American study of 600 PCP, a

relatively smaller proportion of participants (20%-40%) identified unfamiliarity with symptom management approaches (other than the use of medications), and the lack of knowledge of available community resources as important barriers to optimal dementia care (Fortinsky et al., 2010).

Other international studies have consistently shown that many PCP readily admit that they are insufficiently informed about the available support services for PWD/caregiver (Downs et al., 2000; Hinton et al., 2007; Fortinsky et al., 2010; Pentzek et al., 2011; Reuben et al., 2009; Turner et al., 2003; Yaffe et al., 2008). This has been identified as a major obstacle to a more comprehensive approach to dementia care (Hansen et al., 2008; Holmes & Adher, 2005; Iliffe et al., 2000; Yaffe et al., 2008). Of interest is a study of PCP practicing in Quebec which reaffirms the low levels of awareness of community resources for PWD/caregivers among some Canadian PCP as well (Yaffe et al., 2008). In this study, although the PCP were somewhat aware of the organizations such as Alzheimer societies, they were less informed about what these societies actually do, and they rarely referred their patients to them. Instead, physicians used a “blanket” approach of undifferentiated, nonspecific referrals to CLSCs. As we saw earlier, these findings are corroborated by the studies of family caregivers, many of whom have reported being insufficiently informed about and/or referred to such services. For a detailed discussion of the caregivers’ feedback on the PCPs’ actual referral practices to community support services see “Evidence of Actual Practice”.

One specific aspect of dementia diagnosis that many PCP seem to have difficulties with is the actual disclosure of the bad news. As mentioned earlier, numerous studies have identified multiple challenges PCP face in effectively communicating the diagnosis and adequately responding to the immediate emotional and educational needs of PWD/caregivers (see “Evidence of Actual Practice”). In a number of studies, PCP have identified communication about dementia diagnosis as one of the most difficult aspects of dementia care (Fisk et al., 2007; Bamford et al., 2004; Bradford et al., 2009; Connell et al., 2004; Crofton, 2005; Downs et al., 2000; Iliffe & Wilcock, 2005; Turner et al., 2003). There is evidence that these perceived difficulties may be underpinned by the physician’s lack of confidence in their

diagnostic accuracy, as well as deficits in their disclosure skills (Iliffe et al., 2002; Cody et al., 2002; Crofton, 2005; Foster, 2001; Fisk et al., 2007; Wilkinson & Milne, 2003). There are indications that those physicians who report lower confidence in their skills to establish a diagnosis of dementia and to communicate the results, are also more likely to express reservations about sharing the diagnosis with patients/family (Cody et al., 2002; Crofton, 2005; Fisk et al., 2007). In the next section we will discuss in more detail the beliefs and attitudes of PCP that may affect their approach to dementia diagnosis and management.

Attitudes/Beliefs

“Early diagnosis will lead to wasteful plans and miseries” (Renshaw et al., 2001, p.37)

Over the past decade, there has been a growing awareness of the importance of physicians’ beliefs and attitudes in shaping their overall response to PWD/caregivers. A growing body of research shows that the diagnostic and management practices of PCP are profoundly influenced by their underlying beliefs and attitudes. The findings of several studies indicate that those PCP who believe in the importance of early dementia diagnosis are more likely to practice it (Bamford et al., 2004; Downs et al., 2002; Milne et al., 2000, 2005; Perry et al., 2010; Renshaw et al., 2001; Van Hout et al., 2000). As Renshaw and colleagues (2001) have pointed out, attitudes may represent a barometer of commitment to proactive dementia diagnosis and early management. In turn, physicians’ attitudes seem to be shaped by specific beliefs and values. As per PWD/caregivers, the three intertwined concepts of ageism, stigma, and therapeutic nihilism appear to be the main underpinning beliefs that may negatively influence physicians’ responses to patients with dementia. This section examines the evidence related to these barriers.

For the PCP to have a proactive approach towards dementia diagnosis, they first need to believe that this is within the domain of their practice, and that the diagnostic tools and therapeutic interventions are available to improve the clinical outcomes. The perception of inability to make an accurate diagnosis, and a sense of futility, or even the fear of potential harmful effects of diagnosis and interventions can seriously undermine the timely response to

dementia symptoms (Bradford et al., 2009; Iliffe et al., 2005; Iliffe & Wilcock, 2005; Lee et al., 2011; Milne et al., 2000; Wilkinson & Milne, 2003).

Some specialists believe that under-diagnosis and under-management of dementia in primary care may be more a reflection of the lack of commitment of PCP to undertake these tasks than their actual lack of clinical competence (Iliffe et al., 2006). In Iliffe and colleagues British qualitative study (2006), a sample of 30 specialists maintained that negative attitudes characterized by an overtone of therapeutic nihilism, risk avoidance and ageism may hold back some PCP from recognizing early symptoms, and undermine their motivation to educate themselves about the available resources. As discussed earlier, many PCP feel that the diagnosis and management of dementia patients may be beyond their role and outside their area of expertise. Furthermore, there are reports that some PCP believe that the treatment and management of physical problems may be a more pressing need than providing dementia care within the normal consultation process (Hansen et al., 2008).

There is on-going evidence that some negative beliefs surrounding early dementia diagnosis (e.g., the risks of misdiagnosis, the lack of real therapeutic benefits, the potential harmful effects due to the stigma of dementia, the possibility that the care of PWD could strain the already stretched system of care, etc.) continue to threaten the commitment of a significant proportion of PCP (Fortinsky et al., 2010; Iliffe & Wilcock, 2005; Lee et al., 2011; Milne et al., 2000, 2005; Ollafsdottir et al., 2000; Wilkinson & Milne, 2003). A detailed discussion of these beliefs will follow.

a) Therapeutic Nihilism

“Dementia is untreatable so why diagnose” (Renshaw et al., 2001, p.37)

Therapeutic nihilism, refers to the perception that early detection of dementia, as a severe progressive mental disability with no cure, is futile or even possibly harmful to the patient, family and the society at large. Evidence suggests that therapeutic nihilism is widespread among many professional groups, including PCP. In a multinational sample of multi-professional experts, a striking similarity across all nations was the therapeutic nihilism expressed by many participants, a general belief that there is little to offer to PWD since dementia is a degenerative and progressive disease (Vernooij-Dassen et al., 2005). This belief, in turn, was associated with reluctance to pursue an early diagnosis and pessimism about the disease prognosis.

Believing that little or nothing could be done to assist PWD/family in their journey, is indeed a major impediment to the provision of a timely dementia diagnosis. Numerous studies conducted over the past decade point to the continued skepticism of many PCP about the benefits of early dementia detection, and the on-going perception of limited therapeutic options and benefits (Ahmad et al., 2010; Boise et al., 2004, 2010; Bond et al., 2010; Bradford et al., 2009; Hansen et al., 2008; Iliffe & Manthorpe, 2004; Kaduszkiewicz et al., 2008; Lee et al., 2011; Meuser et al., 2004; Milne et al., 2000; Olafsdottir et al., 2001; Overcoming Barriers, 2008; Renshaw et al., 2001; Teel, 2004; Vernooij-Dassen et al., 2005; Wijeratne & Harris, 2009; Wilkinson et al., 2004; Wilkinson & Milne, 2000, 2003, 2008).

It is beyond the scope of this paper to provide a detailed discussion of dementia drug treatments. However, it should be noted that there is substantial international empirical evidence that although most PCP are aware of their availability, many remain skeptical about their cost-effectiveness (Boise et al., 2004; Chodosh et al., 2004; Franz et al., 2007; Hansen et al., 2008; Hillmer et al., 2006; Hollingworth & Byrne, 2011; Iliffe et al., 2003; Maeck et al.,

2008; Milne et al., 2000; Oremus et al., 2007; Ruof et al., 2002; Teel, 2004; Vernooij-Dassen et al., 2005; Wilcock et al., 2009; Wilkinson et al., 2004, 2005). This is partly a reflection of the controversies surrounding these medications: a) the benefits remain modest and are not sustained, b) the gains are experienced only in a minority of individuals with certain dementia sub-types, and c) they are very costly (Assal & Meulen, 2009; Boustani et al., 2003; Franz et al., 2007; Iliffe et al., 2009b; Qaseem et al., 2008). Furthermore the clinical guidelines for the use of these drugs have been at times conflicting, and some have changed over time, creating further ambiguities for practicing PCP (Franz et al., 2007).

Of interest are two Canadian studies examining the attitudes and practices of PCP with regard to the use of anti-dementia medications. In a survey of a stratified random sample of 1000 Canadian family physicians from various regions (Hillmer et al., 2006), slightly over half of the respondents indicated that they routinely recommended cholinesterase inhibitors to their patients with Alzheimer's Disease. Over 25% considered them ineffective and prescribed them to less than 10% of their patients. The results of another Canadian study suggest that physicians may have more stringent requirements for cost-effectiveness of anti-dementia drugs than are currently met by the existing medications. Oremus and colleagues' Canadian survey (2007) of 233 PCP and medical specialists in Quebec showed that in addition to stabilizing the progression of cognitive impairment, physicians also required that a new anti-dementia medication reduces the problematic behaviors and moods in their patients. Moreover, their minimum requirement for the prolongation of time in the mild to moderate disease states was over one year, which again exceeds the performance of the current drugs.

b) Stigma/risk avoidance

“If I reply that my forgetful octogenarian patient has early Alzheimer's, I transform her from a great grandmother who repeats herself into something less than human, an object to be talked about, about whom decisions must be made. I have also made her the likely cause of a similar end for the daughter and her

children. A dark force has been introduced into the family....” (Goodwin, 2002, p.295).

The physicians’ ambiguity and skepticism of the therapeutic options for their patients with dementia is compounded by their concerns about the potential harmful effects of providing a diagnosis. Several studies show that many PCP are concerned that early dementia diagnosis may actually be harmful to their patients (Bamford et al., 2004; De Lepeleire et al., 2004; Downs et al., 2002; Hansen et al., 2008; Iliffe et al., 2003; Iliffe & Wilcock, 2005; Kaduszkiewicz et al., 2008; Meuser et al., 2004; Milne et al., 2000; Vernooij-Dassen et al., 2005; Wilkinson et al., 2005). Thus, the fears and denial experienced by PWD/caregivers discussed earlier, may mirror their provider’s hesitancy to proceed with a diagnostic investigation. As Bradford and colleagues (2009) have pointed out, in many instances, patients and providers may be implicit partners in avoiding a timely response to dementia symptoms.

There is empirical evidence that a major fear of all parties involved is that of stigmatizing the person. In numerous international studies, PCP remarked on the potential stigma associated with a dementia diagnosis, their own reluctance to use the exact medical diagnostic labels in conversations with their patients with dementia and their families, and their tendency to somewhat “normalize” the experience for their patients (Bradford et al., 2009; Cahill et al., 2006; Carpenter & Dave, 2004; Downs et al., 2002; Goodwin, 2002; Iliffe et al., 2002; Iliffe & Wilcock, 2005; Justiss et al., 2009; Kaduszkiewicz et al., 2008; Lopponen et al., 2003; Milne et al., 2000, 2005; Morgan et al., 2011; Teel, 2004; Vernooij-Dassen et al., 2005; Wilkinson et al., 2005). These concerns are compounded by the prospect of mislabeling an older person with a wrong diagnosis, especially when there are uncertainties about the diagnostic accuracy in individuals exhibiting early dementia symptoms (Bradford et al., 2009; Iliffe et al., 2005, 2006; Iliffe & Wilcock, 2005; Kaduszkiewicz et al., 2008; Milne et al., 2000, 2005; Wilkinson et al., 2005).

As we saw earlier, physicians' reluctance and discomfort in diagnosing dementia is apparent in their disclosure practices. The hesitations and embarrassment of PCP in openly sharing the diagnosis and prognosis of dementia (especially with the patients compared to their family caregivers) are partly a reflection of physicians' own discomfort in broaching the topic. Kaduszkiewicz and colleagues (2008) use the concept of "double taboo" to describe the emotional aversion of both PWD/caregivers' and PCP in discussing the perceived taboo subject of dementia diagnosis.

Furthermore, the disclosure of a diagnosis of dementia often necessitates a discussion of other potentially uncertain, sensitive and anxiety provoking issues such as the patient's driving competency, decision making capacity and home safety (Lipski, 2002; Pimlott et al. 2006; Snellgrove & Hecker, 2002; Wilson & Kirby, 2008). In addition to the desire to protect their patients/families from undue distress, the hesitation of some PCP is also partly due to their concerns about the risk of damaging the longstanding doctor-patient-family relationship as a result of a full disclosure of a dementia diagnosis and its' implications (Foster, 2001; Kaduszkiewicz et al., 2008). Given the importance of PCPs' on-going relationships with their patients/families, some authors have suggested this concern may be a major reason for PCPs' tendency to delegate the diagnosis provision to a medical specialist (Ilfie et al., 2005; Pimlott et al., 2009b).

c) Ageism

"I took her to the family physician to do a mini-mental. I didn't feel I got a lot of support there. He basically just brushed it off saying: 'she's not material for nursing home yet'. Things were deteriorating and again back to the family physician... again: 'No, she's fine. What can you expect at her age?'... I wanted him to refer her to geriatric program, he said 'no, they're busy'...." (Aminzadeh et al., 2009b)

There are also indications that the diagnostic practices of PCP may be shaped by their beliefs about aging, mental disability and dementia, which are in turn, deeply rooted in the broader societal ageist attitudes. There is emerging evidence that different types of ageism may be involved in under-diagnosis and under-treatment of PWD, including: a) the tendency of some physicians to attach negative attributes to ageing, viewed as a degenerative or disabling process, in which memory and functional losses may be seen as “normal” changes; b) trivializing and giving lower priority to the health concerns of older people and their chronic conditions; c) the lack of interest in working with frail older adults with multiple comorbidities and disabilities, manifested in a desire to delegate their care to other professionals, and finally; d) a perception that older people may drain the already stretched health care resources (Ahmad et al., 2010; Bradford et al., 2009; Fortinsky, 2001; Hansen et al., 2008; Iliffe et al., 2003, 2005, 2009; Milne et al., 2000; Vernooij-Dassen et al., 2005; Yaffe et al., 2008).

Much of the literature reviewed here shines a spotlight on some PCPs’ negative perceptions and attitudes, describing their sense of uncertainty, ambiguity, discomfort, and pessimism as impediments to a proactive dementia diagnosis and management. In contrast, there are authors who portray a more benevolent and positive view of physicians’ decision making processes. For instance, some argue that giving lower priority to dementia diagnosis, rather than reflecting an ageist attitude, may actually be related to the holistic nature of general practice. Hansen and colleagues (2008) maintain that PCP have a tendency to make diagnostic decisions in the context of their patients’ overall health and quality of life. When dealing with older patients with multiple coexisting conditions, PCP and their patients/family may give a relatively lower priority to the diagnosis and management of dementia symptoms compared to other potentially more immediately pressing and troublesome conditions they may have to face every day.

Others have suggested that the diagnostic logic of PCP may differ from the medical specialists and/or CPG, reflecting a more holistic, individualized and complex problem solving process which is often influenced by non-medical factors, including moral/ethical

considerations, the patient/family wishes and unique circumstances, as well as the physician's own values and past experiences (Crofton , 2005; Iliffe & Wilcock, 2005; Kissel & Carpenter, 2007; Pimlott et al., 2009b; Waldorff et al., 2005). In Crofton's Canadian study (2005), the participating PCP maintained that their choice to disclose a diagnosis of dementia was largely influenced by the ethical principles of beneficence and non-maleficence, patient/caregiver wishes, and their personal experiences. It was notable that many physicians who made fewer disclosures to patients gave high rankings to the importance of their non-professional experience as a basis to decide to disclose less often. The authors concluded that PCP may feel that they are required to use their expertise to determine if it is in the patient's best interest to disclose a diagnosis of dementia. Other researchers have reported that PCP give considerations to family wishes and ethical principles, when making diagnostic and treatment decisions for PWD (Franz et al., 2007).

Some have argued that this protectionist approach is paternalistic and it does not take into account the emerging evidence on the positive impact of diagnosis provision, and the needs and expectations of an increasingly informed PWD/caregiver population (Fisk et al., 2007; Pinner & Bouman, 2002; Wilkinson et al., 2005). Moreover, the nihilistic attitudes of some PCP have been criticized as reflecting a narrow paradigm that is largely constrained by the traditional bio-medical definitions of "treatment", ignoring a host of therapeutic supportive interventions that may benefit PWD/caregivers (Fisk et al., 2007; Iliffe et al., 2006; Milne et al., 2000; Wilkinson & Milne, 2003). Examples of such interventions to enhance the quality of life of PWD/caregivers and to minimize the risk of adverse clinical outcomes are: a) assessment and management of safety risks (e.g., driving accidents, medication errors, falls and injuries, etc.); b) evaluation of patient's decision capacity and support with advance planning; c) assessment and optimal management of co-morbidities; d) advice about pharmacological and non-pharmacological therapeutic options to manage psychological, behavioral and functional symptoms of dementia; and e) mobilizing support for the caregiver, including referral to a local Alzheimer Society. These interventions can potentially avoid crisis; the use of costly emergency, acute care, and ALC hospital services; and premature LTC institutionalization; which have far reaching individual and societal implications.

As noted in Wilkinson and Milne's study (2003), the PCP committed to early diagnosis seem to be more aware of the practical and therapeutic opportunities that timely diagnosis may offer. Furthermore, they tend to define their role more broadly to include patient/family education, joint problem solving, partnership in future planning, and advice on support services. For a more detailed discussion of the potential benefits of early diagnosis and PWD/caregivers' expectations, refer to the evidence presented earlier under "Best Practice Recommendations" and the "Evidence of Actual Practice" (also see Box 2 and Table 1). It is unclear to what extent the PCP may be aware of this growing line of research.

On a final note, physicians' attitudes should be examined in the context of the broader societal values and resources. The ambivalence of some PCP towards an early dementia diagnosis may be a reflection of a period of transition, redefinition of dementia, and the overall changing societal attitudes. Hansen and colleagues (2008) have noted this transition by describing the uncertainty of the PCP in their accounts of describing dementia, shifting between viewing dementia as part of a natural process of ageing and defining it as a discrete disease entity that requires diagnosis and management. This transition is also evident in the studies reporting a slow and gradual improvement in the attitudes of PCP in many Western countries (Iliffe et al., 2000; Maeck et al., 2008; Milne et al., 2005; Woods et al., 2003). Indeed, the findings of Franz and colleagues' American study (2007) are very encouraging. In this study, a significant minority of PCP reported that they enjoyed the complexity of treating PWD and they experienced a sense of fulfillment in working with these patients. Similar positive views, characterized by dedication and contentment with the tasks of caring for dementia patients and a commitment to early detection and therapeutic interventions, were found in a survey of nearly 389 PCP in Germany (Kaduszkiewicz et al., 2008).

In recent years, the key question in dementia diagnosis provision has shifted from whether or not to make a diagnosis and to tell the truth to patient/caregiver (which was one of the main focuses of research in 1990s and early part of the past decade) to how to best detect early symptoms, make a differential diagnosis, disclose the news in a sensitive and responsive

manner, and meet the educational and support needs PWD/caregivers (Aminzadeh et al., 2007; Byszewski et al., 2007; Delrieu et al. 2009; Fisk et al., 2007; Pratt & Wilkinson, 2001; Wilkinson & Milne, 2003).

Resources/Support

This section mostly focuses on the views of PCP on their support needs. The broader underlying structural and systemic factors influencing the resources available to PCP will be discussed later.

a) Time and Financial Constraints

“Personally, I find it difficult to really recognize it in a 15-minute interview or, you know, appointment every 2 or 3 months.” (Adams et al., 2005, p.234)

Across studies, the lack of time has been identified by PCP in different nations as the single most important barrier to comprehensive dementia diagnosis and management in primary care. In Turner and colleagues’ British study (2004), PCP ranked the lack of time as number one barrier to good dementia care practice. In Olafsdottir and colleagues’ Swedish study (2001), over two thirds of the participating PCP indicated that more time for each patient was the most important enabling factor to improve dementia management in their practice. In Pimlott and colleagues’ Canadian study (2009b) when asked to describe a substantial barrier to dementia care, PCP simply replied, “Time, time, time”. In another Canadian study, PCP described dementia as a very time-consuming and “involved illness” (Yaffe et al., 2008). In Connell and colleagues’ American parallel surveys (2004) of family caregivers and PCP, several physicians echoed the sentiments of caregivers, expressing frustrations with the limited amount of time they were able to spend with their patients with dementia and their family. The lack of time was also cited as an important barrier to dementia diagnosis and care in a large scale American study of over 1600 PCPs (Fortinsky et al., 2010). In several other international studies, PCP have remarked about the challenges of assessing and responding to

the complex needs of PWD/caregivers during a typical short office visit (Adams et al., 2005; Bradford et al., 2009; Bruce et al., 2002; Fortinsky et al., 2010; Hansen et al., 2008; Hinton et al., 2007; Iliffe et al., 2003; Pimlott et al., 2009b; Robinson et al., 2010a, 2010b; Van Hout et al., 2000; Woods et al., 2003).

Another barrier commonly identified by many PCP, which is closely linked to their perception of time constraints, is the inadequacy of financial remuneration systems in primary care. Again, in several studies, PCP have pointed out the negative impact of current reimbursement systems, especially in fee-for-service practices (Bruce et al., 2002; Fortinsky et al., 2010; Hinton et al., 2007; Iliffe et al., 2009b; Stoppe et al., 2007a; Turner et al., 2004).

b) Shared Care

“I mean shared care, I think is very much the way we should be moving. It’s about creating a comfortable working relationship between specialists and general practitioners, so there’s trust and confidence...the comfortable interface that allows patients to move backwards and forwards very smoothly....” (Iliffe et al., 2006, p.359)

Many PCP seem to be aware of the complex and multidimensional needs of PWD/caregivers and express a desire to share the responsibilities with medical specialists, specialized programs and other community support services. As we will see later, a collaborative relationship between PCP and these services has shown to have a positive and constructive impact on the quality of *primary dementia care*.

As discussed earlier, most PCP value consultations with medical specialists for a more accurate diagnosis and effective treatment of dementia, especially in early stages (see “Physician factors: Knowledge/Skills/Confidence”). The expert advice and sharing of risks and responsibilities seem to reduce the anxieties of PCP, while maintaining the desired continuity of care with PWD/caregivers (Iliffe et al., 2005). However, this highly valued

resource is not always readily available to PCP and/or deemed to be satisfactory. Several international studies have shown that PCP view the long waiting times and the lack of specialist support as an important barrier to optimal dementia diagnosis and treatment (Cody et al., 2002; Fortinsky et al., 2010; Franz et al., 2010; Iliffe & Manthorpe, 2002; Manthorpe et al., 2003; Teel, 2004; Iliffe et al., 2003, 2006; Bradford et al., 2009; Hunsaker et al., 2010). Other studies have identified various sources of dissatisfaction with the specialist consultations, including the lack of timely and effective communication and care coordination. In Franz and colleagues' American study (2010), PCP reported poor communication and coordination with mental health specialist services, resulting in complications in the patient care. Participants complained that they seldom received timely written or verbal feedback from the specialists, making the referrals largely unhelpful for managing the ongoing patient care. Similar remarks about the lack of timely and useful recommendations (especially as it pertains to the management of psychosocial needs) have been noted by a group of PCP participating in other studies (Gardner et al., 2004; Hinton et al., 2007; Van Hout et al., 2001b). The overall satisfaction rates for these specialized services vary greatly across international studies, with rates being as low as 50% or less in some settings (Ahmad et al., 2010; Olafsdottir et al., 2001; Renshaw et al., 2001) and as high as over 65% in others (Gardner et al., 2004; Van Hout et al., 2001b).

In two Canadian studies, PCP expressed a strong need for medical experts to either make or verify dementia diagnoses (Pimlott et al., 2009b; Yaffe et al., 2008) and reported difficulties in the assessment of PWD when access to specialists was limited. In Yaffe and colleagues' study of 25 PCP in Quebec (2008), most participants perceived their role as being only a small part of what the PWD/caregivers needed. They expressed concerns about the limited or slow access to specialist consultations; and they sought greater collaboration from specialists, specialized programs and other community support services. Physicians recommended easier referral systems, and more accessible and efficient pathways to dementia care services.

In a number of studies, PCP have identified the need for specialized memory disorder clinics and interdisciplinary geriatric teams to provide more comprehensive biomedical,

psychosocial, and practical dementia care to their patients (Austrom et al, 2005; Gardner et al., 2004; Hinton et al., 2007; Williams, 2000). Indeed, there is growing evidence that collaboration between such services and PCP can have a positive impact on the perspectives/practices of PCP and a variety of patient/caregiver outcomes (Aupperle et al., 2003; Banerjee et al., 2007; Chotirmall et al., 2008; Gardner et al., 2004; Renshaw et al., 2001; Szymczynska et al., 2011). A more thorough discussion of this issue will follow later in this paper.

In contrast, a perception of the lack of adequate support and resources in the on-going care of PWD can have a negative impact on the commitment of PCP to early diagnosis (Bradford et al., 2009; Iliffe et al., 2003; Iliffe & Wilcock, 2005; Milne et al., 2000). Many PCP view dementia support services as being inaccessible and insufficient (Bradford et al., 2009; Cantegreil-Kallen et al., 2006; Iliffe et al., 2003, 2005, 2009b; Turner et al., 2004; Yaffe et al., 2008). As we saw earlier, the perception of the lack of resources is at times due to the physician's unfamiliarity with the existing local services. Some PCP acknowledge that they do not have the time, interest and expertise in this matter and express the need for a support staff to link PWD/caregivers to adequate community services and to coordinate the person's on-going care as part of a PCP's practice (Cody et al., 2002; Downs et al., 2000; Fortinsky et al., 2010; Hinton et al., 2007; Iliffe et al., 2006; Olafsdottir et al., 2001; Van Hout et al., 2000).

c) Guidelines

“This is real-world stuff and it's all airy-fairy written about and then we have to take all of this stuff and apply it and it doesn't work. It needs people who are on the ground doing the work to say, ‘you expect me to do that! In the context of office visits, you've got to be out of your mind!’” (Pimlott et al., 2009a)

In addition to providing consultations, expert input in supporting dementia diagnosis and management in primary care can take other forms as well. For instance, recommendations of

best practice guidelines and consensus statements can provide valuable guidance to PCP. However, despite their proliferation over the past decade, many PCP continue to identify the lack of clear, practical and credible guidelines as an important obstacle in their practice (Bridges-Webb et al., 2003; Pimlott et al., 2006, 2009a; Waldorff et al., 2003; Yaffe et al., 2008). As discussed earlier, many PCP are unaware of the existence of these resources and/or lack the knowledge of the specific content (see “Physician Factors: Knowledge/Skills/Confidence”). Furthermore, among those physicians who are familiar with the guidelines, many do not view them as being useful tools in their practice and question their credibility, applicability and feasibility (Bridges-Webb et al., 2003; Pimlott et al., 2009a; Waldorff et al., 2003).

In a Canadian study of a sample of PCP in academic family practice clinics in several provinces, many participants expressed doubts about the credibility of the industry sponsored guidelines and questioned the applicability of the trial data to their practice (Pimlott et al., 2009a). Some were ambiguous about the extent to which the recommendations were evidence-based, others felt that guidelines did not accurately reflect the day-to-day practice experiences of PCP, questioning their relevance. A retrospective review of medical records of 160 patients diagnosed with dementia in three family medicine clinics conducted by the same authors (Pimlott et al., 2006) revealed various levels of compliance with the 1999 CCCD recommendations on the assessment and management of dementia, depending on the aspect of care evaluated. For A-level maneuvers for which there was “good” evidence (defined by the authors as the availability of at least one properly randomized controlled trial), the compliance was generally good. However, given the limited empirical evidence, most recommendations were considered B-level, many of which were based on expert opinion, creating further doubts about their credibility.

Franz and colleagues (2007) argue that physicians’ ambivalent attitudes toward dementia diagnosis and treatment can be in part attributed to the ambiguity in the guidelines, which is in turn, a reflection of the limitations of research evidence in this field. Others have questioned the applicability of the guidelines to individual cases in a routine clinical practice (Cerejeira &

Mukaetova-Ladinska, 2007). The guideline developers seem to be aware of these concerns and admit that in many instances clear unambiguous recommendations could not be made due to the limited empirical evidence, and “unrecognized” barriers to the implementation of best practice recommendations (Chertkow, 2008). It should be noted that many of the limitations of dementia CPG discussed here are common barriers to the implementation of CPG, and they are not unique to dementia guidelines (Cabana et al., 1999). Table 2 summarizes some of the barriers to the implementation of CPG discussed here.

Table 2. Barriers to implementation of Dementia Clinical Practice Guidelines

<p>Physician Factors</p> <ul style="list-style-type: none"> Lack of awareness of guidelines Lack of familiarity with content Lack of agreement with content Lack of motivation Lack of self-efficacy Lack of outcome expectancy
<p>Guideline Factors</p> <ul style="list-style-type: none"> Applicability to patient/practice Feasibility Credibility User-Friendliness
<p>System factors</p> <ul style="list-style-type: none"> Time and resource constraints Accessibility of guideline Training requirements

Notes: Several elements of this table were adopted from the framework developed by Cabana et al., 1999

d) Training

Another way experts can support PCP in the care of PWD/caregivers is through training. As discussed earlier, PCP often self-identify the need for more dementia specific training (see “Physician Factors: Knowledge/Skills/Confidence”), especially applied, problem-based, and solution-focused education. In Yaffe and colleagues’ Canadian study (2008), some PCP expressed a desire for more problem-based and case-based education on Alzheimer’s Disease led by psycho-geriatricians and social workers, as opposed to “the endless talk about medication that is repeated by pharma companies”. A more thorough discussion of the training needs of PCP and the effectiveness of various educational intervention strategies will be covered later under “System/Societal Factors”.

Physician Characteristics

A few studies have explored the associations between physicians’ socio-demographic characteristics and their perspectives and practices. For instance, a limited number of studies have examined gender difference in physicians’ dementia diagnostic practices. Their findings suggest that female PCP are: a) more likely to express positive attitudes towards cognitive testing (Iracleous 2010); b) have higher levels of knowledge about dementia (Cahill et al., 2006; Turner et al., 2004); c) are less likely to believe that dementia care is the responsibility of a specialist (Turner et al., 2004); and d) are more interested in obtaining information about community resources to support PWD/caregivers (Downs et al., 2000) compared to their male counterparts. At the same time, they are less confident in diagnosing dementia (Ahmad et al., 2010; Cahill et al., 2006), disclosing the diagnosis (Cody et al., 2002; Downs et al., 2000; Kaduszkiewicz et al., 2008) and giving advice about the management of dementia-related symptoms (Ahmed et al., 2010).

There is also emerging evidence that the age and experience of PCP may influence their approach to dementia care. Younger physicians seem to: a) have greater knowledge of dementia (Cahill et al., 2006; Maeck et al., 2007; Turner et al., 2004); b) employ superior diagnostic practices (Cody et al., 2002; Downs et al., 2000); and c) have more positive

attitudes towards early dementia diagnosis and management (Kaduszkiewicz et al., 2008; Turner et al., 2004). They are more likely to disclose the diagnosis (Crofton, 2005; Downs et al., 2000; Van Hout et al., 2000) and to believe in the benefits of early detection of dementia (Ahmad et al., 2010). They are also less likely to believe that dementia is the responsibility of a specialist (Turner et al., 2004) and to express the need for specialist consultation (Yaffe et al., 2008). They also seem to be more open to use information technology to assist with the care of PWD (Fortinsky et al., 2010; Meuser et al., 2004). At the same time, they report lower confidence in their diagnostic and management skills (Ahmad et al., 2010; Cahill et al., 2006), and report greater difficulty obtaining information about community support services for PWD (Downs et al., 2000).

Paradoxically, in a few studies, although the more experienced PCP expressed greater confidence in their skills in diagnosing and managing patients with dementia, they were more likely to desire specialist input (Ahmad et al., 2010; Crofton, 2005; Iliffe & Wilcock, 2005; Kaduszkiewicz et al., 2008; Yaffe et al., 2008). In these studies, the more seasoned PCP seemed to be less convinced of the benefits of early diagnosis and expressed greater reservations about disclosing the diagnosis to the patient. While these findings may partly be related to a cohort effect, reflecting the diversity in knowledge, training and values of different physicians' age groups, the results may also reflect the complexity of dementia care and the impact of physicians' personal and professional experiences on their views and practices. Crofton's study (2005) of practicing PCP in British Columbia showed the possible interplay of age, experience, training, cultural and attitudinal factors. In this study, PCP who were in practice for more than 20 years, those who gave higher rankings of the impact of their non-professional experience on their disclosure practices, and physicians trained in British medical schools were less likely to disclose a dementia diagnosis. In a British study of 144 general practitioners, participants attributed the enthusiasm of younger professionals for early dementia diagnosis to their inexperience (Iliffe & Wilcock, 2005). Using case experiences, participants challenged the notion that early diagnosis and disclosure are desirable, emphasizing the potential harmful effects.

The unique challenges faced by the PCP in rural practices should also be noted. The findings of two recent systematic reviews of the dementia diagnostic and management practices of PWD in rural areas confirm the key role of PCP in these communities, where access to specialist and support services is substantially more limited (Morgan et al., 2011; Szymczyńska et al., 2011). As expected, the evidence shows that rural PCP are more likely to report the lack of access to various diagnostic, patient education and support services. Thus, they are expected to function more autonomously, often having to diagnose, disclose and manage the care of PWD entirely on their own, compared to their counterparts practicing in larger urban centers. Finally, there is a lack of solid evidence on the impact of a number of potentially important practice related attributes, such as the type of practice (solo vs group practice) and the proportion of older patients seen. So far, the results of a few studies that have explored these associations have been inconclusive (Cahill et al., 2006; Connolly et al., 2011; Kaduszkiewicz et al., 2008; Perry et al., 2010).

3.4.4 System/Societal Factors

Much of the difficulties in detecting and managing dementia in primary care settings are rooted in the broader societal and health systems challenges. The realities of primary care can indeed constrain the ability of PCP to provide quality care to PWD/caregiver. For instance, insufficient time, which many PCP have identified as being the single most important barrier to optimal dementia care, is closely linked to the inadequate payment models adopted in most health care systems in Western nations. Reimbursement structures that inaccurately reflect the time required to effectively respond to the needs of older persons in general, and those with dementia in particular, may discourage some PCP from committing to the care of these complex patients. As noted by others, the reactive, time limited care systems that reward brief physician consultations and focus primarily on physical complaints present significant barriers to timely dementia diagnosis and management (Foster, 2001; Bradford et al., 2009; Iliffe et al., 2005, 2009b). Although within the constraints of the system, with commitment and collaboration, PCP can find ways to maximize the opportunities for their patients. For

instance, it has been proposed that even within the limitations of short clinic visits, the needs of PWD/caregivers can be sequentially addressed if regular follow-up visits are scheduled (Hogan et al., 2008). A discussion of supportive interventions to facilitate the work of PCP will follow.

PCP clearly need substantial support to meet the multifaceted needs of PWD/caregivers. As noted earlier, many are willing to share the risks and responsibilities of dementia diagnosis and the on-going care of their patients with other care providers. However, it has been argued that the current state of affairs, in which practice is skewed towards brief office-based assessments with referral to specialists for diagnosis and early management, and blanket referrals to community organizations, that may or may not be appropriate, and that are not linked in time or place to the primary care practices, is not efficient and/or sustainable (Iliffe et al., 2009b; Pimlott et al., 2009b).

This awareness has led to a growing international interest in the development and evaluation of more integrated models of community-based dementia care, with the PCP being at the center of such initiatives (Hogan et al., 2008; Iliffe et al., 2009b; Pimlott et al., 2009b). Over the past decade, a wide spectrum of approaches and intervention designs has been implemented in various international experimental studies to improve the quality of dementia care in the primary care settings. Overall, it appears that the more comprehensive and coordinated care management approaches that provide intensive dementia specific services in primary care produce the most promising results (Austrom et al., 2006; Callahan et al., 2006, 2011; Chodosh et al., 2006; Cherry et al., 2004, 2009; Reuben et al., 2010; Venohr et al., 2001; Vichrey et al., 2006).

The common features of these more intensive interventions are that they incorporate a combination of the following key strategies: a) the use of multidisciplinary teams of clinicians with relevant expertise (as opposed to the traditional models of primary medical care in which PCP take the full responsibility for patient care); b) on-going care management, typically coordinated by a nurse working closely with the PWD/caregiver, attending PCP, and other

care providers; c) the provision of formal dementia training for PCP (and other clinic staff), as well as interactive case-centered experiential learning opportunities, including access to an advanced practice geriatric nurse and/or medical specialists for educational detailing and consultation; d) the use of standard tools, protocols and guidelines to ensure active case finding and consistent care processes; e) access to various types of information technology resources, such as electronic patient records, medical record prompts, decision support tools, and internet-based care management systems; f) the provision of education and support for PWD/caregivers, in collaboration with community agencies, such as local Alzheimer Societies; and finally, g) regular patient follow-ups to monitor care processes and outcomes.

Among the positive outcomes of these interventions, which have not been consistently shown across studies, are significant improvements in: a) quality of dementia care, as measured by greater adherence to guidelines, enhanced patient/caregiver satisfaction with care, higher patient/caregiver ratings of physicians' performances, and successful engagement with disadvantaged ethnic minority groups; b) aspects of patient/caregiver quality of life, such as enhanced sense of self-efficacy in managing dementia and improved social support; c) knowledge and attitudes of primary care providers; and, d) clinical outcomes, such as fewer behavioral symptoms, and even a delay in LTC placement.

More research is needed to evaluate cost-effectiveness, feasibility and long term sustainability of these experimental programs, and to test their replicability in the Canadian primary care practices. Although, it is expected that the additional upfront cost of developing these innovative comprehensive services will be later offset by the savings made through the reduced use of high-cost specialists, emergency departments, acute care hospitals and LTC institutional services, more research is needed to provide the evidence of such cost savings (Callahan et al., 2011). Moreover, the low participation rates of PCP in the educational sessions provided in some of these studies, and the stronger perception that managing dementia in primary care is difficult among those in the intervention groups, are potentially important barriers that need to be addressed (Cherry et al., 2009; Chodosh et al., 2006).

Another recent innovation in this field is the creation of interdisciplinary memory clinics within primary care settings. The emerging evidence from a Canadian and two British studies point to the potential benefits of these programs in building capacity in primary care, while improving the efficacy of the use of specialist expertise (Greaves & Jolley, 2010; Greening et al., 2009; Lee et al., 2010). Of particular interest is Lee and colleagues' Canadian study (2010) involving a primary care memory clinic in Ontario. The program aimed at providing timely access to comprehensive dementia assessment and management, while improving physicians' knowledge and confidence in managing their patients with cognitive impairment through collaborative care, practice-based education, and mentorship by a designated geriatrician. Management interventions included social worker outreach, long-term care planning, home and driving safety assessments, referral to community resources, and periodic follow-ups and monitoring. The results of a full evaluation of this program have not been published. However, a preliminary survey of patients and caregivers points to the high levels of satisfaction with the care provided at the clinic. Moreover, a chart audit conducted by two independent geriatricians has shown agreement with the PCPs' diagnosis and management decisions. The two British papers describing the evaluation of a similar clinic provide further support for the potential benefits of these types of programs in: a) diagnosing dementia earlier, b) implementing comprehensive evidence-based care, and c) using specialist services more efficiently (Greaves & Jolley, 2010; Greening et al., 2009). The authors argue that these programs can provide a viable alternative to the current practice of referring the patients with cognitive impairments to the more expensive and potentially stigmatized secondary specialist dementia care services (Greaves & Jolley, 2010).

The above intervention studies all require the use of additional resources, and practice/system redesign. Another group of studies have examined the impact of a more efficient use of the existing resources, through stronger collaborations between PCP and the available community services specialized in dementia education and support, including the local Alzheimer societies (Fortinsky et al., 2002, 2009; Mittleman et al., 2006; Callahan et al., 2009; McAiney et al., 2008). It is believed that the lack of involvement of PCP in psycho-educational interventions for PWD/caregivers helps perpetuate their low awareness and low use of such

resources in the care of community living PWD (Fortinsky et al., 2009). Thus, collaborative models promoting stronger linkages between PCP and these supportive services seem to be a logical first step in providing more coordinated and comprehensive dementia care.

Typically, these programs involve outreach educational interventions to enhance physicians' awareness of the available services and to encourage their referrals to a trained service coordinator based at a local Alzheimer's Association chapter. The referred PWD/caregivers then receive individualized consultations, and are invited to participate in support groups and/or access other appropriate community resources. The favorable outcomes reported so far include: a) greater physicians' awareness of community resources, their higher levels of satisfaction with the care processes, and their enhanced confidence in discussing dementia care with their patients; b) improvements in caregiver satisfaction and self-confidence; and c) in some cases, even a delay in LTC admission. An example of such programs in Canada is the First Link initiative in Ontario (McAiney et al., 2008). An earlier evaluation of this program showed the low rates of direct referrals from PCP. However, there is optimism that the recent primary care reforms in Ontario (i.e., the introduction of Family Health Teams and the Chronic Disease Prevention and Management model) will provide an impetus for greater success of such collaborative initiatives.

In the communities where the aforementioned innovations may not be currently available, the development and dissemination of shared care protocols and referral pathways that clearly outline the roles and responsibilities of various providers and organizations have been advocated in order to facilitate timely and efficient access to the existing local resources (Feldman, 2009; Iliffe et al., 2004b, 2009b; Koch & Iliffe, 2010a).

Finally, as mentioned earlier, some PCP and leaders have identified the benefits of having a support staff, such as a nurse, posted within the primary care clinic to act as a dementia care facilitator and manager (Fortinsky et al., 2010; Cherry et al., 2004; Chodosh et al., 2004; Hunsaker et al., 2010; Iliffe et al., 2009b; Jedenius et al., 2008; O'Brien et al., 2001; Waldorff et al., 2001). This staff person can provide support in different forms, such as screening for

dementia symptoms, providing patient education, scheduling regular follow-ups, and coordinating on-going community care of PWD/caregivers. In a study of PCP in thirteen group general practices in the Netherlands, the PCP who had access to support nurses showed higher adherence to a set of quality indicators for *primary dementia care* compared to those who did not (Perry et al., 2010). In a Swedish study, the addition of a dementia nurse to assist the PCP with the diagnostic investigations and supportive follow-up interventions, resulted in significant improvements in case finding efforts, doubling the proportion of identified dementia cases after the program implementation (Jedenius et al., 2008).

Aupperle and colleagues, in an American study (2003), showed significant differences at two-year follow-up between the outcomes of care for the patients with dementia who were treated by their PCP only, and those who were also followed at a university-based clinic run by a geriatric psychiatrist in collaboration with a geriatric nurse/social worker case manager. The latter provided a range of educational and support interventions to PWD/caregivers, including information on behavioral management, community resources, long-term care planning, and legal/financial planning. The study showed a significantly lower rate of hospitalization and cognitive decline in the intervention group.

The issue of specialist-to-primary care support, whether in the form of clinical consultation, continuing education, or guideline development, needs further attention. Earlier, we talked about the new and more integrated shared models of care that may provide opportunities for a more efficient working relationship between PCP and medical specialists in the community care of PWD. What follows is a discussion of the skills training and decision support that specialists can provide to strengthen *primary dementia care*.

Over the past decade, various educational interventions have been developed and tested with variable success. Consistent with other continuing medical education (CME), in dementia training, traditional passive strategies (e.g., lecture style educational meetings, guidelines and other printed materials, and passive media), especially if used alone, have generally proved to be less effective compared to the combined intervention strategies utilizing more interactive

approaches (e.g., audit and feedback, small group interactive scenario-discussion workshops, educational outreach visits, and decision support systems) (Chesney, 2010; Grimshaw et al., 2005; Lemelin et al., 2001; Travers et al., 2009).

In recent years, the use of case studies in dementia education has received renewed attention (Harvey et al., 2005; Iliffe et al., 2000, 2003, 2005). It has been argued that although the use of case studies has been overshadowed by the preoccupation of evidence-based experimental medicine, they may be the key to promote best dementia practices in primary care (Iliffe et al., 2000). Using interactive approaches, case studies have been successfully used in multidisciplinary working groups, attracting large numbers of PCP and other clinicians in Europe (Iliffe et al., 2000, 2003, 2005; Iliffe & Manthorpe, 2004). In addition to face to face approaches, case studies can be used electronically as interactive training modules or in web-based chat rooms as well. This approach is also consistent with the problem-based and solution-focused dementia training that was proposed by the Canadian PCP in Yaffe and colleagues study (2008).

Among other dementia knowledge transfer approaches that have received some research interest is the on-site outreach academic detailing (by other physicians and/or interdisciplinary clinicians). This approach has been used as a stand-alone intervention (Carmen et al., 2010; Dalsgaard et al., 2007) or in combination with other strategies (Chesney, 2010; Chesney et al., 2011; Waldorff et al., 2003). The goal is to provide a more contextualized dementia training to PCP, facilitate the adaptation of guidelines, and/or promote the use of local resources. The positive outcomes reported so far include: a) increased referral to local community agencies; b) self-reported positive effects on knowledge, confidence, skills, and motivation to work with PWD; and c) improved adherence to guidelines. The main barriers were perceived time constraints and the reluctance of some PCP to receive education from non-physician clinicians (Cameron et al., 2010).

Among this group of studies, Chesney's Canadian research stands out (2010). In his dissertation study, Chesney developed a Mild Dementia Knowledge Transfer pilot program,

which incorporated some novel contemporary knowledge translation concepts in order to overcome some of the barriers perceived by primary care providers (e.g., missing early indicators, diagnostic uncertainty, and unfamiliarity with assessment tools). Twenty three PCP and 15 primary care nurses from 14 practices in Ontario participated in this performance-oriented, specialist-supported, and clinic-based outreach program. As a Neuroscience Master's student, the author trained the participants on-site on the use of cognitive assessment protocols (this was based on the CCCD recommendations and the application of the MoCa test). The procedures were discussed between assessments to enhance learning. Study participants also had the opportunity to share the assessment results with a dementia specialist, and to formulate the diagnosis and initial care plans collaboratively. After the program, participants reported improved self-rated knowledge and confidence in the detection, assessment and care of mild dementia. This improvement remained stable three-months after the program was completed. The participants who assessed more patients and those who received more demonstrations showed greater increase in their knowledge and confidence, reinforcing the importance of experiential learning. Interestingly, there were no differences in the outcomes between the medical and nursing staff, suggesting that the program can potentially be effective for primary care providers in various professional roles and with varying levels of prior knowledge. Once again, most participants provided positive evaluations of the program, while identifying time demands as the worst aspect of their experience.

In recent years, a variety of computer-based learning methods (e.g., computer-assisted learning packages, computer decision-support systems, and computer-based audit and feedback tools) have been developed. Such products have the advantages of low cost and adaptability for individual learning and practice styles, thus making them potentially attractive alternatives to the traditional medical training (Turner et al., 2003). However, emerging international research on their feasibility and effectiveness for dementia training in various primary care settings reveals continued pragmatic challenges and only modest results so far.

Waldorff and colleagues (2009) provided all Danish general practitioners with access to an e-learning program offering training on Danish dementia guidelines. However, very few practitioners (4.7%) actually logged-on to the program. This is despite the fact that the researchers had actively promoted the uptake of the program by mailing three reminder letters. A British study investigated the potential usefulness of a computer decision support system to assist practitioners in diagnosing and managing dementia (Turner et al., 2003). Nearly 100 primary-care practitioners (53 physicians and 44 nurses) participated in this study. The results showed that the decision support program was perceived as being relevant to the practitioners. However, there were practical constraints that limited its efficacy (e.g., time demands and limited familiarity with the computer systems). Other researchers have identified the challenges involved in developing computer decision support systems for complex conditions such as dementia (Degryse et al., 2009).

An Australian team developed a computer-based data extraction tool to track the use of cognitive tests and the documentation of dementia diagnoses (Millard et al., 2008). The tool was evaluated in combination with an educational module in a clinical trial. The study showed that the combined physician education on the CPG and the application of the data extraction tool improved the documentation of the newly diagnosed cases of dementia and the cognitive assessment tools performed, compared to the education alone. Using web-based technologies, Boise and colleagues (2010) evaluated the feasibility of distance learning in training PCP and medical assistants on dementia screening and diagnosis protocols in six American rural primary care practices. The results showed a substantial increase in screening for dementia and improved clinician confidence in diagnosing dementia, but only a modest gain in the actual proportion of patients who were diagnosed. This was largely due to the reluctance of clinicians to follow-up on a positive dementia screen. It was noted that physicians often determined that the symptoms did not warrant a dementia work-up. Although participants found the protocols easy to implement, there was substantial variability in their adherence to the protocols. The authors identified a number of barriers, including the logistic challenges in implementing practice change, and the clinicians' nihilistic attitudes toward dementia assessment and diagnosis.

A descriptive Canadian pilot study (2008) investigated the use of an online CME program on early Alzheimer's Disease among eight rural PCP in Quebec (Luconi, 2008). A problem-based collaborative approach was implemented, with the participating physicians working in pairs, and a family physician with relevant expertise moderating the online discussions over a period of nine months. Objective measures demonstrated a significant increase in declarative knowledge and improvements in problem solving of clinical cases, while self-reported measures indicated positive changes in clinical practice. Participants expressed satisfaction with the program, mainly for its innovative design, interactivity and convenience of access. Among the least effective features noted were an unfriendly platform (WebCT) and limited facilitation during online discussions.

A British unblinded cluster randomized controlled trial compared the effectiveness of three educational interventions in improving the detection rates and management of dementia in 36 primary care practices: i.e., an electronic tutorial, a decision-support software package and practice-based workshops (Downs et al., 2006). It was found that both decision support systems built into electronic medical records and workshops providing case scenario discussions improved dementia detection rates. However, neither of these interventions improved concordance with the dementia guidelines, nor did the electronic tutorial. Building on earlier research, Iliffe and colleagues (2010) developed a customized educational intervention for general practice, which combines practice-based workshops and electronic support material with the goal of promoting both early diagnosis and concordance with the dementia management guidelines. The results of the clinical trial testing the effectiveness of this intervention has not been published yet.

Although the emerging evidence on the use of information technologies suggest potential benefits, these are not currently accessible to many PCP in Canada and other Western countries, particularly to those in solo practices (Bradford et al., 2009; Fortinsky et al., 2010; Turner et al., 2003; Yaffe et al., 2008). In Yaffe and colleagues' Canadian study (2008) of 25 PCP in Quebec, only about half of the sample had office computers, and consistent with Turner and colleagues' British study (2003), many reported the lack of time and skills in

effectively using them. The recent promotion of electronic records systems on the one hand, and the development of large primary care group practices, integrated networks, and community health groups on the other hand, will likely facilitate the use of information technology in the future in various primary care settings in Canada. This is another example of the impact of the wider milieu of dementia care, and the macro-level policies and resources on the day to day practices of PCP. Clearly, more research and development is required to elucidate the best approaches to improve dementia care within the confines of the realities of the current and future primary care practices.

SECTION FOUR

DISCUSSION

The proportion of older persons in Canada and globally has been growing fast over the past decade, and the trend will continue into the future. As this demographic shift occurs, the chronic health problems affecting older adults in general, and dementia in particular, will take a center stage. With the projected rise in the prevalence of dementia disorders, the provision of dementia care will increasingly come under scrutiny, with the PCP being at the center of such attention. Over the past decade, several Western position papers, including the “Rising Tide” report of the ASC (2010), have documented the pressing need for more systematic, coordinated and proactive approaches to the early detection and community-based management of dementia, and have called for immediate governmental action to tackle this global public health challenge.

This renewed international interest in the community care of PWD, centered around the practices of PCP, has led to an unprecedented volume of published manuscripts investigating and debating the existing challenges and the potential solutions. This scoping interpretive review provides a comprehensive repository of these international and Canadian papers published over the past decade, which can be used to inform clinical, research, educational and policy interventions.

This review reaffirms the importance of timely and responsive dementia care which begins with a recognition of early signs and symptoms, followed by a thorough multidimensional evaluation, sensitive diagnosis disclosure, collaborative and person-centered care planning, and on-going monitoring and management of complex and evolving needs of PWD/caregivers. However, evidence suggests that the current primary care systems in many Western countries, including Canada, face many challenges in providing responsive, comprehensive, safe and cost-effective dementia care, in accordance with the best practice recommendations. Primary care has been identified as the *Achilles’ heel of dementia services*, with experts repeatedly calling for systematic approaches to strengthen it (Callahan et al.,

2009; Greaves & Jolley, 2010; Hogan et al., 2008; Iliffe et al., 2009b; Waldemar et al., 2007a).

This paper has identified a multitude of highly inter-related obstacles to optimal *primary dementia care*, including challenges related to: a) the complex biomedical, psychosocial, and ethical nature of the condition; b) the gaps in knowledge, skills, attitudes and resources of PWD/caregivers and their primary care providers; and perhaps most importantly, c) the broader systemic and structural barriers negatively affecting the context of dementia care. In order to reduce the current levels of under-recognition, under-diagnosis, under-disclosure, and under-treatment/management of dementia disorders in primary care; to prevent escalating negative impact on community, acute care hospital and LTC services; and to adequately respond to the growing future care needs of PWD/caregivers, due attention should be devoted to all of these barriers.

To date, most Canadian and international efforts to improve dementia care have been isolated and limited in scope, typically addressing only a subset of these barriers, and often with only modest intensity and very limited coordination (ASC, 2010; Callahan et al., 2009; Hogan et al., 2008; Iliffe et al., 2009b; Mittman, 2005). As noted by Mittman (2005), “Further progress will require a coordinated campaign of inter-related efforts by a broad spectrum of leaders and stakeholders in dementia research, practice, and policy... requiring significantly increased levels of commitment, energy, and effort” (p. 66). Many experts in Western countries have reached the conclusion that the myriad of efforts that are required at multiple levels in order to achieve sustained and meaningful improvements should ideally be orchestrated by national and international dementia strategies.

Over the past decade, many Western governments have made dementia a national priority and have developed national frameworks for action on dementia in order to provide an overarching vision and structure to inform systematic and consistent policy, planning, service delivery and research initiatives (Australian Health Ministers’ Conference, 2006; France Alzheimer Plan, 2008; Norwegian Ministry of Health and Care Services, 2008; UK

Department of Health, 2009). At present, there is no national strategy for dementia in Canada. This is despite the continued advocacy of the ASC to catalyze one, including the recently published “Rising Tide” report’s call for action (ASC, 2010). Although, some provinces, including Ontario and Quebec, have developed their own comprehensive provincial action plans for dementia, which are indeed important first steps towards a national strategy (Rockwood & Keren, 2010).

As mentioned, the ASC has repeatedly pleaded for a national dementia action plan to match those already in place for cancer, cardiovascular diseases and mental health problems, arguing that unless a cure is found, dementia may have the highest economic, social and health cost burden of all diseases in Canada (Picard, 2010). Through a national strategy, a pan-Canadian coalition of experts and stakeholders can collaboratively: a) create a shared national vision for action on dementia, b) review the existing services and initiatives, c) identify the key priority areas for research and development, d) formulate minimal national quality standards, e) address health inequalities across the country, and f) provide a framework within which local services could deliver quality programs.

In this section, we will use the three core elements of the existing Western national dementia frameworks in order to organize the discussion of the key findings of this review paper: a) improving access to timely diagnosis and high quality dementia care, b) raising professional and public awareness and understanding of dementia disorders, and c) investing in dementia research and development. The focus will remain on the community-based primary care services and the perspectives and practices of the PCP.

4.1 Timely Diagnosis and Quality Dementia Care

A common goal of Western national strategies is to ensure that all PWD have access to a pathway of care that delivers accurate and timely diagnosis, sensitively communicates it to the PWD/caregivers, and provides them with adequate treatment, care, advice and support. The evidence reviewed in this paper suggests that this is currently more an exception than a rule in

many parts of Canada and other Western nations. International research has consistently shown that dementia diagnosis typically occurs in later stages of the disease, often made at a time of breakdown or crisis (likely leading to emergency department use, hospitalization with ALC designation, and premature institutionalization), which could have been potentially prevented, if proper diagnosis and interventions had been in place. Furthermore, the diagnosis is not always followed by responsive interventions.

There is general consensus that, because of their close and on-going relationships with patients, PCP are often in an ideal position to detect the early signs and symptoms of dementia, and to initiate the necessary investigations to establish a diagnosis (Koch & Illife, 2010b). However, as we saw earlier, there is evidence that many PCP fail to recognize the early symptoms of dementia and/or tend to overlook their importance. Many feel that they have not received sufficient training in diagnosing and managing this complex chronic illness; express a preference to delegate and/or share the care of PWD with medical specialists (and/or interdisciplinary teams); and identify the need for clear, credible and feasible guidelines and tools to facilitate their work. Some remain skeptical about the benefits of early dementia diagnosis, and express concerns about the potential hazards to the person/caregiver and/or the health care system. These concerns are compounded by the broader system level barriers (e.g., the lack of time, resources, and financial rewards for PCP), further impeding timely dementia diagnosis and interventions in primary care.

Given the complexities of dementia disorders and the constraining realities of primary care settings, consistent with the views expressed by many PCP, some experts also believe that the diagnosis and treatment of dementia requires the expertise and resources of specialists and specialized clinics (Iliffe et al., 2004b; Powell, 2002; Waldemar et al., 2007). Different models of “shared care” have been proposed. Perhaps the most commonly recommended protocol is the two-tiered or two-step triage and diagnostic evaluation pathway, proposed by the European Dementia Consensus Network (Waldemar et al., 2007). In the first step, PCP are expected to maintain a high index of suspicion and carry out the initial investigations, including the use of simple cognitive tests, to accurately identify persons with cognitive

impairment. These individuals are then referred to secondary medical and/or specialized centers for a more thorough evaluation of their underlying pathologies, potentially reversible conditions, co-morbidities, functional performance, and other care needs. Once the dementia sub-type has been established and the initial pharmacological and psychosocial interventions have been initiated, the PCP then take responsibility for the on-going care and monitoring.

This approach seems to be an obvious choice in many European countries where the right to make a dementia diagnosis, initiate more sophisticated diagnostic tests such as neuroimaging, and/or prescribe cognition-enhancing medications, is reserved to specialists. However, some experts question the long term sustainability and cost-effectiveness of this approach. They argue that in order to improve timely access to dementia care, it is crucial to develop the diagnosis and care capacity within the primary care, albeit with the collaboration of medical specialists and other health and social service providers (Callahan et al., 2009; Feldman, 2009; Iliffe et al., 2009b; Jedenius et al., 2010; Morgan et al., 2011).

In many countries, including Canada, there is currently a shortage of specialists with relevant expertise, such as geriatricians, geriatric psychiatrists, care of the elderly physicians and neurologists. Given the projections for a rapid increase in the prevalence of dementia disorders in the near future, this shortage will further tax (and eventually overwhelm) the already saturated specialist services, resulting in even greater delays in time to access dementia diagnosis and treatment (especially in the rural, remote and other under-served communities). As noted earlier, the long waiting times and the problems associated with communicating and coordinating care across multiple providers can negatively affect the quality of dementia care and the satisfaction with the process for all involved. Some argue that PCP may be better prepared than specialty physicians in managing multiple chronic co-morbidities often present in dementia patients, and they may be able to make more person-centered dementia care decisions based on the long term knowledge of the patients' overall health and social conditions (Callahan et al., 2009; Kock & Iliffe, 2010b).

Furthermore, the cost of specialist dementia care should be considered. Jedenius and colleagues (2010) in a Swedish prospective, time and resource utilization study compared the

total cost associated with diagnosing dementia between the specialist and primary care practices. They found that the cost of dementia investigations in order to establish a dementia diagnosis (per true diagnosed patient) was on average 849 € at the primary care level, compared to 1334 € at the specialist level (this includes the sum of the initial cost of 656 € for the PCP, with the additional cost of 657 € for the specialist care). Other multicenter, longitudinal randomized clinical trials have evaluated the cost-effectiveness of post-diagnosis dementia treatment in specialized memory clinics compared to the care coordinated by PCP (Meeuwsen et al., 2009). The results, which have not been published yet, will further inform the debate about the cost-effectiveness of various dementia care approaches. The findings of these comparative cost-analysis investigations should be interpreted in the light of the evidence on the more positive clinical outcomes of specialist care, especially in the context of interdisciplinary team collaboration, and the promising research findings on the more integrated models of dementia care. It is possible that the initial higher cost of these services will be later offset by the savings made through improved clinical outcomes and reduced use of more expensive institutional acute and long term care. Clearly, more research is needed to facilitate a more meaningful discussion and planning regarding this critical issue.

While controversies about the specific roles and responsibilities of primary and specialist/specialized care providers for the diagnosis and management of dementia continue (Robinson et al., 2010b), there is a general consensus that PCP alone cannot adequately meet the multidimensional needs of PWD/caregivers. Primary care, as the front line and the hub of care, not only needs to more effectively integrate the primary and secondary medical care, but also the broader health and social care systems in order to provide high quality dementia care (Feldman, 2009; Iliffe et al., 2004b; Callahan et al., 2009). This review reaffirms the importance of instilling a culture of multidisciplinary and multi-agency collaboration in order to improve detection and management of dementia in primary care (Callahan et al., 2009; Hogan et al., 2008; Koch & Iliffe, 2010; Waldemar et al., 2007a). As we saw earlier, collaborative approaches may not only have a positive impact on the quality and outcomes of care, but they may also enrich the care experiences of both PWD/caregivers as well as their care providers. Physicians with geriatric training have long recognized the need for including

other professionals in the care of older people. Perhaps the time has come that PCP also benefit from such collaboration in their practice (Cody et al., 2002).

Experts in health care delivery have acknowledged the importance of linking medical and community-based services through the development of integrated models of chronic care management (Reuben et al., 2009; Russell et al., 2008, 2010). Given that dementia is one of the most complex chronic illnesses, it has been suggested that the community care of PWD would also benefit from the use of chronic care models (Borson et al., 2007; Robinson et al., 2010a). In fact, the most promising innovative models of dementia diagnosis and management reviewed earlier in this paper contain one or more elements of the models of chronic care management: a) collaborative case management approaches, coordinating and integrating primary and specialty health and social services; b) education and support for PWD/caregiver to promote self-management, including the use of self-management tools; and c) the utilization of various forms of clinical information technology systems (Callahan et al., 2009; Robinson et al., 2010a).

Both the “Rising Tide” report of ASC (2010) and the “Goodness of Fit” report of the Alzheimer Society of Ontario [ASO] (2007) have endorsed the use of an integrated chronic care model for a better management of dementia disorders. However, the penetration of the chronic care model into primary care practices has proven to be difficult, particularly among solo physicians and those in small group practices, where the majority of primary care is currently provided (Callahan et al., 2009; Reuben et al., 2009; Russell et al., 2008). In Canada, there is a movement under way to create new organizational structures in primary care, such as family health teams and community health centers, integrating other disciplines and even some medical specialists into family practice clinics. Such models of care delivery have the potential to better meet the comprehensive support needs of PCP in the care of their frail older patients in general, and those with dementia in particular (ASO, 2007; Pimlott et al., 2009b; Walker, 2011). Nevertheless, given the limited coverage of these innovative primary care initiatives, due consideration should be given to the integrated care model’s application in the traditional primary care settings (ASO, 2007).

Finally, any discussion of the access and equality issues in dementia care should pay special attention to the needs of the more disadvantaged groups (i.e., individuals with low education and income; ethno-cultural minority groups; older persons living alone without caregivers; and people living in remote and rural communities). While there is emerging evidence on the models of care that may be successful in targeting these at risk populations, much more work needs to be completed in order to better inform the interventions that can overcome the unique barriers these individuals and/or communities face in accessing information, care and support.

To summarize, while constructive debates about the most effective dementia strategies in the context of the Canadian health care system need to continue into the future (ideally as part of a national dementia strategy), in the meantime, based on the evidence reviewed here, the following approaches to support the Canadian PCP are worth considering. First, given the critical role of medical specialists (e.g., physicians with expertise in geriatric medicine, geriatric psychiatry, and care of elderly) and specialized interdisciplinary teams (e.g., comprehensive geriatric and psycho-geriatric programs), it is paramount to improve access to and efficient use of these services (especially for the more complicated cases). At the same time, it is important to explore innovative ways of using specialist resources through mentorship and experiential training opportunities for PCP; the development of protocols, guidelines, and other forms of decision support tools specifically designed for this setting (including the use of electronic and web-based technologies); and cost-effective and functional specialist-primary care shared care approaches. In particular, the development and testing of the new models of memory clinics within the primary care settings, with on-site access to a designated specialist and a case manager deserves further attention.

In addition to strengthening the diagnostic capacity of physicians, primary care also needs to adopt a more active management role in dementia care. This would require the use of more adequate reimbursement systems in primary care that would encourage PCP to take the time needed to effectively assess, monitor and manage dementia and other co-morbidities among their frail older patients. Furthermore, the importance of coordinated case management

approaches in enhancing the quality of *primary dementia care* should not be under-estimated. Several studies reviewed in this paper have shown the added value of a case manager in the assessment and on-going community care of PWD, and their role in linking health and social services and maximizing the use of the existing local resources. In primary care practices where the additional resources to finance an on-site case manager may not be available, the use of local programs (such as the First Link initiative and Community Care Access Centers [CCAC] in Ontario, or other community/home care services with designated dementia programs), can be very beneficial in coordinating the psychosocial interventions to complement the work of PCP.

Finally, it is important that each community undertakes a careful review of its own local resources in order to identify the missing links in the web of services, and to develop clear shared care protocols and referral pathways to maximize communication, service coordination and the use of local resources. Active dissemination of this information, including the use of electronic prompts in medical records and patient self-management tools, could be useful in enhancing the utilization of these resources in primary care. A promising initiative in Ontario is the formation of local volunteer-driven dementia networks (e.g., www.champlainedmentianetwork.org), which among other goals, aim at streamlining and coordinating service provision among various providers.

4.2 Professional and Public Education

Another core aim of Western national dementia strategies is to improve public and professional awareness of the disease in order to positively affect both help seeking and help provision behaviors. These frameworks and other papers, including the “Rising Tide” report of ASC, call for greater government investments in promoting access to effective basic education, continuous training, and information on dementia for all levels of health care professionals, the broader networks of providers, informal caregivers, and the general public at large (ASC, 2010; Australian Health Ministers’ Conference, 2006; France Alzheimer Plan, 2008; Norwegian Ministry of Health and Care Services, 2008; Tsolaki et al., 2010; UK

Department of Health, 2009; Waldemar et al., 2007). The need for greater investments in public and professional education is supported by the findings of this review showing continued gaps in knowledge, skills and attitudes among PCP and PWD/caregivers alike. We begin our discussion by focusing on the educational interventions for PCP.

To date, much of the efforts to enhance the knowledge and behaviors of PCP have focused on improving their ability to recognize dementia symptoms; conduct medical investigations, including the use of screening instruments; make a diagnosis; and prescribe drug treatments. Although these are indeed important components of any medical training, they have been criticized as being limited in scope (Ilfie et al., 2003, 2004a, 2009b; Turner et al., 2004). Educational agendas assuming that the core problem in the medical care of patients with dementia is the lack of formal knowledge of the disease pathophysiology and pharmacology fail to take into account the evidence on the multiplicity of factors that influence the physician's recognition of and response to dementia, as outlined in this paper.

Educational interventions need to address the gaps in knowledge, skills, attitudes, and behaviors simultaneously (Ilfie et al., 2003; 2004a). The term "knowledge" should be used broadly to include pattern recognition, conceptual framework, and therapeutic solutions. As we saw earlier, the low awareness of the early indicators of dementia and the delayed response of some PCP may be at least partly due to: a) their limited framework and understanding of the dementia experience; b) problematic attitudes associated with therapeutic nihilism, stigma and ageism; and c) deficits in their communication, disclosure and management skills. Thus, medical education about dementia should evolve in form and content from its largely disease-focused emphasis towards a broader view of dementia as a complex, progressive and chronic condition that is responsive to timely, individualized and comprehensive treatment and management plans.

Therefore, it is important to support PCP in developing capacity not only around diagnostic skills, but also in the following core competencies previously identified by experts in the field, recommended by the ASC, and further validated by the findings of this review: a)

effective communication skills, especially vis-à-vis diagnosis disclosure practices and patient/family education; b) awareness of PWD/caregivers' broader psychosocial needs and experiences; c) practical knowledge of community resources; d) ability to collaborate with other professionals and agencies (Bamford et al., 2004; Cohen et al., 2001; Iliffe et al., 2004a, 2009b; Iliffe & Manthorpe, 2004; Koch & Illife, 2010b). A commitment to effective communication, empathic interactions, supportive interventions, and partnership is consistent with the core principles of effective chronic disease management. This would require a paradigm shift, acquisition of new and diverse skill sets, and structural changes to support PCP in their practice. Change has to happen both at the level of medical training and practice, as well as the society at large.

As evidenced by the results of a recent Canadian study, there are challenges associated with this paradigm shift. Russell and colleagues (2008) examined the impact of a holistic, patient-centered, and pragmatic approach to improve the management of chronic diseases in Ontario family practices. A purposive sample of 13 family physicians working in either Primary Care Networks or Family Health Networks, and 20 patients participated in this evaluation study. The authors found important individual-level barriers to chronic illness management that transcended the existing structural and resource constraints in this setting. With few exceptions, the participating PCP viewed chronic illness management from a predominantly biomedical perspective. The patient-centered principles of the intervention seemed inconsistent with many physicians' perceptions of their roles and of their patients' capacities to be partners in care. Many felt that shared and proactive care was not their "job" and perceived the individual care planning as being time consuming and impractical.

As we saw earlier in this paper, some physicians' narrow conceptualization of dementia and their traditional bio-medical definitions of "treatment" can seriously undermine their commitment to early diagnosis and proactive response to this condition. It is important to raise physicians' awareness of the lived experiences, the expectations and perspectives of PWD/caregivers, and the host of therapeutic supportive interventions that can positively shape these experiences. This can, in turn, help broaden their conception of dementia care and

redefine their role and responsibilities, accordingly. Obviously, physicians' perspectives on dementia care should be examined in the context of the broader societal values towards this illness. Medical training should be part of large scale systematic awareness raising and educational interventions to reframe dementia more accurately, and to enhance the public's understanding of an appropriate response to it. This issue will be addressed in more detail later in this section.

As far as medical education is concerned, many believe that the current medical training (of medical students, residents in training, and practicing physicians) in many regions of Canada, and other Western nations, does not adequately prepare physicians for their roles and responsibilities with regard to the complex and collaborative care of older patients with multiple chronic conditions generally, and those with dementia disorders more specifically (Robinson et al., 2001; Russell et al., 2008; Tsolaki et al., 2010). Education on dementia, especially the priority topics identified earlier, should be included in the training and curricula for physicians (and other professional providers). The need for continued efforts to improve dementia training in medical schools is supported by the findings that younger PCP are not confident in their diagnostic and management skills, and express a desire to learn more about the resources available. The emerging evidence on their more positive attitudes towards early diagnosis and management of dementia compared to their more experienced counterparts is indeed very promising.

It should be noted that in many regions of Canada the issue of medical training has received growing attention over the past decade. For instance, the Ontario College of Family Physicians has received government funding to develop a comprehensive multi-faceted educational program for medical students, family medicine residents and practicing family physicians (McAiney, 2006). The program covers a number of dementia related topics for inclusion in the initial curriculum of undergraduate and postgraduate medical schools, as well as CME programs, including: a) the diagnosis and treatment of dementia, b) the impact of the disease on the person and family, c) directions on the optimal use of available resources, and d) the psychosocial management of PWD/caregivers. In accordance with the evidence

presented in this review, the program has a number of novel components, such as the development of: a) an educational mentoring model for changing physician practice in community settings by identifying community-based family physicians acknowledged by their peers to be informal opinion leaders in the area of dementia and by providing them with easy access to specialist support; b) peer presenter and family medicine preceptor programs; and c) web-based training modules.

This physician training initiative in Ontario is part of a larger government dementia strategy that has been under way for the past decade (ASO, 2011; Ontario Ministry of Health and Long Term Care, 2002). This initiative is one of the most comprehensive provincial strategies in Canada, which among others, focuses on education for health care providers, caregivers and the public, as well as research and knowledge exchange activities. Through its Alzheimer Knowledge Exchange program, it offers an online resource center, various educational opportunities, including on-line participation in so-called ‘communities of practice’ which bring together professional providers with various backgrounds to exchange information about the innovations on various topics related to dementia.

These initiatives are consistent with the evidence on the latest international CME interventions. As we saw earlier, in recent years, different knowledge translation strategies have been developed and tested with mixed results. Generally, multifaceted interventions, which include two or more strategies, and incorporate more flexible and innovative approaches, seem to be more effective than the traditional single interventions that use more passive strategies. Among various educational interventions, the following have received growing attention and have great potential for future research and development: a) small group interactive scenario-discussion workshops (especially in the context of interdisciplinary working groups); b) outreach academic detailing for a more contextualized and applied on-site training; and c) various low cost and adaptable technological facilitative tools (i.e., decision support systems; interactive web-based training modules, chat rooms, virtual communities, and Wiki forums; and, computer-based reminder, tracking, audit and feedback tools).

Clearly more work is needed to overcome some of the pragmatic barriers associated with the implementation of these interventions, in order to enhance their feasibility and effectiveness. An important obstacle related to the use of information technology that needs to be addressed for its more widespread and routine use is the lack of access of many PCP in solo practices to this technology and their limited skills in effectively using it. The evidence showing that younger physicians are more comfortable with and willing to utilize information technology in their education and practice is an indication of its future potential.

Finally, the use of technology can also help with the active dissemination and up-take of CPG, which are clearly a worthwhile educational tool in supporting PCP in the management of complex problems, such as dementia. However, as we have seen in this review, currently, there are important barriers to their use: i.e., the lack of awareness of their existence or specific content, and a continued perception of their lack of clarity, applicability, feasibility and even credibility. Given the multifaceted nature of these obstacles, combined strategies are needed to overcome them. The following approaches are worth considering: a) adopting multiple and more active dissemination strategies; b) making the guidelines available in user-friendly, concise and varied formats; c) including PCP in the development process; d) seeking input of PWD/caregivers to capture their perspectives and experiences; e) minimizing the influence of pharmaceutical companies' funding which can undermine the objectivity and credibility of the guidelines; f) conducting more targeted research to better inform guideline recommendations; g) making attempts to “synchronize” related guidelines to minimize “guideline fatigue”; h) implementing strategies to support their local adaptation; and i) using information technology, including electronic decision supports and health records with integrated reminders for guideline implementation (Bradford et al., 2009; Pimlott et al., 2009a; Travers et al., 2009; Waldorff et al., 2003, 2009).

Here, we have mostly focused on the learning needs of PCP, but in the light of the many barriers related to the gaps in knowledge and attitudes of PWD/caregivers presented earlier, the importance of public education should also be highlighted. As per physicians' training, public information campaigns should: a) address the low levels of awareness of the various

ways in which dementia manifests itself at the early stages; b) emphasize the importance of timely help seeking; and c) encourage access to a range of therapeutic options available to support the PWD/caregivers. Once again, the goal is to reframe dementia by providing a more accurate and comprehensive understanding of the illness experience, and to minimize the misconceptions rooted in ageism, stigma, and nihilism surrounding this condition.

A common strategy among various Western national dementia frameworks is the use of public awareness campaigns. Ideally, a combination of general educational campaigns (at national, regional and local levels), and more targeted campaigns for the disadvantaged groups with special needs (i.e., individuals with low education and income; ethno-cultural minority groups; and people living in remote and rural communities), as well as for the broader service workers that may interact with PWD/caregivers (such as police and transportation workers) should be undertaken to raise public awareness. Some European studies have shown that these campaigns can be effective in promoting more positive attitudes towards dementia (Koch & Iliffe, 2010a; Vernooij-Dassen et al., 2005).

Special attention should be devoted to the needs of family caregivers. As acknowledged by many PCP, caregivers are important partners in the care of PWD living in the community and they significantly influence the success of the interventions. Therefore, it is important to provide them with adequate information throughout the course of illness. In addition to various educational programs and resources developed and delivered by Alzheimer's associations and societies, some academics and researchers in recent years have shown interest in developing and testing practical toolkits and guidelines for PWD/caregivers in accordance with the principles of chronic care self-management. In fact, as reviewed earlier, training and education of PWD/caregivers has been an important component of most new international integrated models of dementia care. Of interest are the interventions that educate and empower PWD/caregivers on how to "partner" with their PCP in order to optimize the processes and outcomes of dementia care (Callahan et al., 2009).

4.3 Research and Development

The growing recognition of the magnitude and the impact of dementia disorders has led to an unprecedented research interest in this field over the past decade. The knowledge gained so far has helped identify the gaps in our understanding of the existing problems and the need for a more systematic examination of the potential solutions. Western dementia strategies and the Canadian “Rising Tide” report call for greatly increased research spending to develop national dementia research agendas to tackle these issues (ASC, 2010; Australian Health Ministers’ Conference, 2006; France Alzheimer Plan, 2008; Norwegian Ministry of Health and Care Services, 2008; UK Department of Health, 2009).

In particular, there is a need for substantially increased investments in Canadian health services research to capture our unique geographic, cultural, policy and practice challenges and opportunities. The need for a Canadian perspective on *primary dementia care* is evidenced by the fact that only a small percentage of all reviewed articles in this paper were published in Canada. It has been reported that for every \$100 worth of cancer research, only \$15 is spent on dementia research in Canada (Picard, 2010). Much of this funding is directed towards identifying the cause and cure for dementia, and it does not necessarily address the care issues explored in this paper. Through a national dementia strategy, experts and stakeholders can establish key priority areas for a nationwide dementia care research, provide resources needed to promote the agreed research agenda, and facilitate the translation of the findings into practice.

Future Canadian research should aim at overcoming some of the methodological shortcomings of the past studies, such as the use of small and non-representative samples, retrospective designs, and the exclusive reliance on the review of medical records and physicians’ self-reports for data collection. More representative samples of PCP from various urban, sub-urban and rural regions of Canada, working both in group as well as solo practices, should be included in this research. This strategy would provide opportunities to better identify regional and practice-related differences in physicians’ perspectives and experiences.

Parallel interviews with PCP, PWD/caregivers, and other involved interdisciplinary team members can help develop a more comprehensive understanding of the processes and outcomes of care from the perspectives of all parties (i.e., meanings, expectations, relationships, and lived experiences; and responses to various types and components of interventions). Another useful approach to triangulate data sources is the use of naturalistic observation methods in combination with the more traditional data collection strategies (i.e., chart reviews, surveys and interviews). An example of research that has utilized creative and comprehensive data collection approaches is a recent Canadian study that examined the emotional and educational needs of PWD/caregivers vis-à-vis dementia disclosure practices in a day hospital program in Ottawa (Aminzadeh et al., 2007; Byszewski et al., 2007). In this prospective qualitative study multiple data sources were used, including field observations, audio-taping of the dementia diagnosis disclosure meeting, separate in-depth parallel interviews with PWD and their primary caregivers within a week after the disclosure meeting, and focus group interviews with a sub-set of caregivers a month later.

To our knowledge, the above study is the only Canadian investigation that has examined the views of PWD, which has been largely neglected in research, in response to what is one of the most difficult and controversial aspects of dementia care. As mentioned earlier in this paper, dementia diagnosis disclosure practices in primary care remain very variable and often surrounded by complexities and uncertainties. The CPG have been criticized for their apparent vagueness, insufficient guidance and even inconsistencies concerning this challenging aspect of *primary dementia care*. Given the importance of the cultural, normative and structural context of care on physicians' disclosure practices, more Canadian research is needed to inform evidence based, clear, and practical recommendations related to this important aspect of the medical encounter.

CPG have also been criticized by many PCP as being unrealistic and impractical. This suggests a continuing need for research to better understand the experiences of Canadian PCP, and their perspectives on their learning and support needs to provide quality dementia care.

Related topics of interest include a more thorough examination of the: a) various dimensions of competence required by PCP (i.e., conceptual knowledge of illness and pattern recognition; problem solving capacity; decision making and communication processes, including clinical and ethical considerations that may affect physicians' diagnostic and management approaches; practical knowledge of the resources and service coordination/collaboration skills); b) effective training strategies and educational tools/resources to support PCP in their practice; c) the feasibility and long term cost-effectiveness of new and more integrated models of dementia care; d) the interface between primary and specialist/specialized dementia care services and the ways in which communication, coordination, information, and resource sharing can be maximized; and finally, e) incentives and barriers to PCP participation in the multidisciplinary/interagency dementia care service delivery systems.

With increased emphasis on the self-management of chronic illnesses, advances in biomedical and psychosocial dementia treatment and management strategies, and the heightened public awareness, there will be higher expectations of PCP to provide more person-centered, collaborative, and comprehensive care to PWD/caregivers. There is a growing need to learn about the public and professional expectations of the roles and responsibilities of PCP as well as the PWD/caregivers during their triadic encounters; and the impact of various communication, interaction and decision making approaches on the processes and outcomes of dementia care. Large scale national Canadian surveys of representative samples of public and professional providers, similar to the European Facing Dementia Survey can be very helpful. The ASC's recent "Let's Face It" initiative, including the 2011 on-line survey of caregivers of PWD is an important step in this direction.

The opinions, expectations and lived experiences of PWD, especially as it relates to the primary care practices, continue to be neglected in Canadian research. This is despite the growing evidence that many individuals with mild-moderate dementia can be successfully included in research and they are capable of providing valuable input into their care experiences and needs (Aminzadeh et al., 2007, 2009a; Trigg et al., 2007; Wilkinson & Milne, 2003). Timely diagnosis of dementia can also create a unique opportunity for research to recruit PWD, early in the course of their disease, who are capable of expressing their

subjective experiences and expectations in order to develop more responsive and person-centered approaches in primary care.

Finally, the priorities identified here for future research call for more interdisciplinary, pluralistic, and collaborative investigations in order to provide a more accurate, in-depth and comprehensive view of the dementia primary care practices. In addition to the need for more research to generate new knowledge, there is a pressing need to effectively transfer the knowledge gained, and to translate the evidence into concrete policy and practice interventions. Once again, a recent national initiative, the Canadian Dementia Knowledge Translation Network (2010) which seeks to provide greater resources for knowledge translation in dementia is a good start (<http://geriatricresearch.medicine.dal.ca/cdktn.htm>).

To conclude, “our society now confronts a growing phenomenon – that of a burgeoning aging population of individuals living with frailty, and/or multiple co-morbidities, all of which may be confounded by the challenges of dementia” (Walker, 2011). Primary care, as the hub of elder care, must be strengthened to respond to this new reality. This comprehensive interpretive scoping review has identified some of the key challenges currently faced in this setting, the potential solutions, and the priority directions for future research and development in this field. We hope that this collection informs future constructive debates and decisive actions, ideally as part of a national dementia strategy in Canada.

REFERENCES

- Adams, W. L., McIlvain, H. E., Geske, J. A., & Porter, J. L. (2005). Physicians' perspectives on caring for cognitively impaired elders. *Gerontologist*, 45(2), 231-239.
- Adelman, R. D., Greene, M. G., & Friedmann, E. (2004). Discussions about cognitive impairment in first medical visits: Older patients' perceptions and preferences. *American Journal of Alzheimer's Disease and Other Dementias*, 19 (4), 233-238.
- Ahmad, S., Orrell, M., Iliffe, S., & Gracie, A. (2010). GPs' attitudes, awareness, and practice regarding early diagnosis of dementia. *British Journal of General Practice*, 60(578), e360-5. (Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medl&AN=20849686>)
- Alzheimer Society of Canada. (2012). *Fact Sheet: Benefits of earlier diagnosis survey*. Alzheimer Society of Canada. (Retrieved from: http://www.alzheimerbc.org/getdoc/253f4cd9-11f8-497e-afb7-64340e229601/AW12-Survey-fact-sheet_En-FINAL.aspx)
- Alzheimer's Society of Canada. (2010). *Rising Tide: The Impact of Dementia on Canadian Society. Executive Summary: A study commissioned by the Alzheimer Society*. Alzheimer Society of Canada.
- Alzheimer Society of Ontario (2011). *10 by 20: Ontario action plan for dementia*. Alzheimer Society of Ontario. (available at: www.alzheimerontario.org)
- Alzheimer Society of Ontario. (2007). *Goodness of Fit: Alzheimer's Disease and Related Dementias and the Chronic Disease Management Framework: A discussion paper based on an experts' workshop*. Alzheimer Society of Ontario.
- Aminzadeh, F., Dalziel, W.B., Molnar, F.J., & Garcia, L.J. (2009a). Symbolic meaning of relocation to a residential care facility for persons with dementia. *Aging & Mental Health*. 13(3). 487-496.
- Aminzadeh, F., Dalziel, W.B., Molnar, F.J., Garcia, L.J., & Eisner, M. (2009b) *Exploring meanings, contexts, processes and outcomes of relocation to a residential care environment for persons with dementia and their family caregivers*. Unpublished manuscript, Regional Geriatric Program of Eastern Ontario.

- Aminzadeh, F., Byszewski, A., Molnar, F., & Eisner, M. (2007), Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging & Mental Health*. 11(3). 281-290.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a Methodological framework. *International Journal of social Research Methodology*. 8(1). 19-32.
- Arlt, S., Hornung, J., Eichenlaub, M., Jahn, H., Bullinger, M., & Petersen, C. (2008). Patient with dementia, the caregiver and the doctor: Cognition, depression and quality of life from three perspectives. *International Journal of Geriatric Psychiatry*,
- Ashford, J.W., Borson, S., O'Hara, R., Dash, P., Frank ,L., Robert, P., ...Fillit, H. (2007). Should older adults be screened for dementia? It is important to screen for evidence of dementia! *Alzheimers Dement*, 3(2), 75-80.
- Assal, F., & van der Meulen, M. (2009). Pharmacological interventions in primary care: Hopes and illusions. *Frontiers of Neurology & Neuroscience*, 24, 54-65.
- Aupperle, P. M., MacPhee, E. R., Coyne, A. C., Blume, J., & Sanchez, B. (2003). Health service utilization by Alzheimer's Disease patients: A 2-year follow-up of primary versus subspecialty care. *Journal of Geriatric Psychiatry & Neurology*, 16(1), 15-17.
- Australian Health Minister's Conference. (May 2006) *National Framework for Action on Dementia (2006-2010)*. NSW Department of Health.)Available at: www.health.nsw.gov.au)
- Austrom, M. G., Hartwell, C., Moore, P., Perkins, A. J., Damush, T., Unverzagt, F. W., . . . Callahan, C. M. (2006). Integrated model of comprehensive care for people with Alzheimer's Disease and their caregivers in a primary care setting. *Dementia*, 5(3), 339-352.
- Austrom, M. G., Hartwell, C., Moore, P. S., Boustani, M., Hendrie, H. C., & Callahan, C. M. (2005). Care management model for enhancing physician practice for Alzheimer Disease in primary care. *Clinical Gerontologist*, 29(2), 35-43.
- Baloch, S., Moss, S. B., Nair, R., & Tingle, L. (2010). Practice patterns in the evaluation and management of dementia by primary care residents, primary care physicians, and geriatricians. *Baylor University Medical Center Proceedings*, 23(2), 121-125.
- Bamford, C., Lamont, S., Eccles, M., Robinson, L., May, C., & Bond, J. (2004). Disclosing a diagnosis of dementia: A systematic review. - *International Journal of Geriatric Psychiatry*, 19(2), 151-69.

- Banerjee, S., Willis, R., Matthews, D., Contell, F., Chan, J., & Murray, J. (2007). Improving the quality of care for mild to moderate dementia: An evaluation of the croydon memory service model. *International Journal of Geriatric Psychiatry*, 22(8), 782-788.
- Barth, A., Riedel, O., & Wittchen, H. (2011). The psychopathological burden of outpatients with Alzheimer's dementia and their caregivers - The idea-study. *Neurodegenerative Diseases. 10th International Conference Alzheimer's and Parkinson's Diseases: Advances, Concepts and New Challenges. Barcelona, Spain.*
- Boise, L., Eckstrom, E., Fagnan, L., King, A., Goubaud, M., Buckley, D. I., & Morris, C. (2010). The rural older adult memory (ROAM) study: A practice-based intervention to improve dementia screening and diagnosis. *Journal of the American Board of Family Medicine*, 23(4), 486-498.
- Boise, L. (2005). Improving dementia care through physician education: Some challenges. *Clinical Gerontologist*, 29(2), 3-10.
- Boise, L., & Connell, C. M. (2005). Diagnosing dementia - what to tell the patient and family. *Geriatrics and Aging*, 8(5), 48-51.
- Boise, L., Neal, M. B., & Kaye, J. (2004). Dementia assessment in primary care: Results from a study in three managed care systems. *Journals of Gerontology: Biological Sciences and Medical Sciences*, 59A(6), 621-626.
- Bond, J., Graham, N., Padovani, A., MacKell, J., Knox, S., & Atkinson, J. (2010). Screening for cognitive impairment, Alzheimer's Disease and other dementias: Opinions of European caregivers, payors, physicians and the general public. *Journal of Nutrition, Health and Aging*, 14(7), 558-562.
- Bond, J., Stave, C., Sganga, A., O'Connell, B., & Stanley, R. L. (2005). Inequalities in dementia care across Europe: Key findings of the facing dementia survey. *International Journal of Clinical Practice (Suppl)*, 59, 8-14.
- Borson, S., Scanlan, J., Hummel, J., Gibbs, K., Lessig, M., & Zuhr, E. (2007). Implementing routine cognitive screening of older adults in primary care: Process and impact on physician behavior. *Journal of General Internal Medicine*, 22(6), 811-817.
- Borson, S., Scanlan, J. M., Watanabe, J., Tu, S. P., & Lessig, M. (2006). Improving identification of cognitive impairment in primary care. *International Journal of Geriatric Psychiatry*, 21(4), 349-355.
- Boustani, M., Sachs, G., & Callahan, C. M. (2007b). Can primary care meet the biopsychosocial needs of older adults with dementia?. *Journal of General Internal Medicine*, 22(11), 1625-1627.

- Boustani, M., Schubert, C., & Sennour, Y. (2007a). The challenge of supporting care for dementia in primary care. *Clinical Interventions in Aging*, 2(4), 631-636.
- Boustani, M., Perkins, A. J., Fox, C., Unverzagt, F., Austrom, M. G., Fultz, B., . . . Hendrie, H. C. (2006). Who refuses the diagnostic assessment for dementia in primary care?. *International Journal of Geriatric Psychiatry*, 21(6), 556-563.
- Boustani, M., Callahan, C. M., Unverzagt, F. W., Austrom, M. G., Perkins, A. J., Fultz, B. A., . . . Hendrie, H. C. (2005). Implementing a screening and diagnosis program for dementia in primary care. *Journal of General Internal Medicine*, 20(7), 572-577.
- Boustani, M., Peterson, B., Hanson, L., Harris, R., Lohr, K. N., U.S., & Preventive Services Task, F. (2003). Screening for dementia in primary care: A summary of the evidence for the U.S. preventive services task force. *Annals of Internal Medicine*, 138(11), 927-937.
- Bradford, A., Kunik, M. E., Schulz, P., Williams, S. P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer Disease and Associated Disorders*, 23(4), 306-314.
- Bridges-Webb, C., Giles, B., Speechly, C., Zurynski, Y., & Hiramaneek, N. (2006). Patients with dementia and their carers in general practice. *Australian Family Physician*, 35(11), 923-924.
- Bridges-Webb, C. (2002). Dementia care in general practice: What can the BEACH survey tell us? *Australian Family Physician*, 31(4), 381-383.
- Bridges-Webb, C., Wolk, J., Britt, H., & Pond, D. (2003). The management of dementia in general practice. A field test of guidelines. *Australian Family Physician*, 32(4), 283-285.
- Brodsky, H., Low, L. F., Gibson, L., & Burns, K. (2006). What is the best dementia screening instrument for general practitioners to use? *American Journal of Geriatric Psychiatry*, 14(5), 391-400.
- Bronskill, S.E., Camacho, X., Gruneir, A. & Ho, M.H. (November, 2011). *Health system use by frail Ontario Seniors: An in-depth examination of four vulnerable cohorts*. Institute for Clinical Evaluative Sciences, Toronto. (available at: www.ices.on.ca)
- Bruce, D. G., Paley, G. A., Underwood, P. J., Roberts, D., & Steed, D. (2002). Communication problems between dementia carers and general practitioners: Effect on access to community support services. *Medical Journal of Australia*, 177(4), 186-188.
- Bruce, D. G., & Paterson, A. (2000). Barriers to community support for the dementia carer: A qualitative study. *International Journal of Geriatric Psychiatry*, 15(5), 451-457.

- Byszewski, A.M., Molnar, F., Aminsadeh, F., Eisner, M., Gardezi, F., Bassett, R. (2007), dementia Diagnosis Disclosure: A study of patient and caregiver perspectives. *Alzheimer Disease and Associated Disorders*, 21(2).
- Cabana, M.D., Rand, C., Powe, N., Wu, A.W., Wilson, M.H., et al. (1999), Why don't physicians follow clinical practice guidelines? A framework for improvement. *Journal of the American Medical Association*, 282: 1458-1465.
- Cahill, S., Clark, M., Walsh, C., O'Connell, H., & Lawlor, B. (2006). Dementia in primary care: The first survey of Irish general practitioners. *International Journal of Geriatric Psychiatry*, 21(4), 319-324.
- Callahan, C. M., Boustani, M. A., Weiner, M., Beck, R. A., Livin, L. R., Kellams, J. J., . . . Hendrie, H. C. (2011). Implementing dementia care models in primary care settings: The aging brain care medical home. *Aging & Mental Health*, 15(1), 5-12.
- Callahan, C. M., Boustani, M., Sachs, G. A., & Hendrie, H. C. (2009). Integrating care for older adults with cognitive impairment. *Current Alzheimer Research*, 6(4), 368-374.
- Callahan, C. M., Boustani, M. A., Unverzagt, F. W., Austrom, M. G., Damush, T. M., Perkins, A. J., . . . Hendrie, H. C. (2006). Effectiveness of collaborative care for older adults with Alzheimer Disease in primary care: A randomized controlled trial. *Journal of American Medical Association*, 295(18), 2148-2157.
- Cameron, M. J., Horst, M., Lawhorne, L. W., & Lichtenberg, P. A. (2010). Evaluation of academic detailing for primary care physician dementia education. *American Journal of Alzheimer Disease & Other Dementias*, 25(4), 333-339.
- Camicioli, R., Willert, P., Lear, J., Grossmann, S., Kaye, J., & Butterfield, P. (2000). Dementia in rural primary care practices in lake county, Oregon. *Journal of Geriatric Psychiatry and Neurology*, 13(2), 87-92.
- Canadian Institute for Health Information (2011a) *Analysis in brief: Taking health information further, alternative level of care in Canada*. (Retrieved from: http://secure.cihi.ca/cihiweb/products/alc_aib_january2011_e.pdf.)
- Canadian Institute for Health Information (2011b). *Caring for Seniors with Alzheimer's Disease and other forms of dementia*. (Retrieved from: http://secure.cihi.ca/cihiweb/products/dementia_AIB_2010_eng.pdf.)
- Cantegreil-Kallen, I., Turbelin, C., Angel, P., Flahault, A., & Rigaud, A. (2006). Dementia management in France: Health care and support services in the community. *Dementia*, 5(3), 317-326.

- Cantegreil-Kallen, I., Turbelin, C., Olaya, E., Blanchon, T., Moulin, F., Rigaud, A., & Flahault, A. (2005). Disclosure of diagnosis of Alzheimer's Disease in french general practice. *American Journal of Alzheimer's Disease & Other Dementias*, 20(4), 228-232.
- Carpenter, B., & Dave, J. (2004). Disclosing a dementia diagnosis: A review of opinion and practice, and a proposed research agenda. *Gerontologist*, 44(2), 149-58.
- Cattel, C., Gambassi, G., Sgadi, A., Zuccala, G., Carbonin, P., et al. (2000). Correlates of delayed referral for the diagnosis of dementia in an outpatient population. *Journal of Gerontology: Biological Sciences and Medical Sciences*, 55(2) M98-102.
- Cerejeira, J., & Mukaetova-Ladinska, E. (2007). Treating dementia: Will the NICE guidance 2006 change our clinical practice? *Age and Ageing*, 36, 605-606.
- Cherry, D. L., Hahn, C., & Vickrey, B. G. (2009). Educating primary care physicians in the management of Alzheimer's Disease: Using practice guidelines to set quality benchmarks. *International Psychogeriatrics*, 21(Suppl 1), S44-52.
- Cherry, D. L., Vickrey, B. G., Schwankovsky, L., Heck, E., Plauchm, M., & Yep, R. (2004). Interventions to improve quality of care: The kaiser permanente-alzheimer's association dementia care project. *American Journal of Managed Care*, 10(8), 553-560.
- Chertkow, H. (2008). Diagnosis and treatment of dementia: Introducing a series based on the third Canadian consensus conference on the diagnosis and treatment of dementia. *Canadian Medical Association Journal*, 178(3), 316-21.
- Chertkow, H., Massoud, F., Nasreddine, Z., Belleville, S., Joannette, Y., Bocti, C., . . . Bergman, H. (2008). Diagnosis and treatment of dementia: 3. Mild cognitive impairment and cognitive impairment without dementia. *Canadian Medical Association Journal*, 178(10), 1273-1285.
- Chesney, T. R., Alvarado, B. E., & Garcia, A. (2011). A mild dementia knowledge transfer program to improve knowledge and confidence in primary care. *Journal of the American Geriatrics Society*, 59(5), 942-944.
- Chesney, T. R. (2010). *A mild dementia knowledge transfer program to improve knowledge and confidence in primary care*. Master's Thesis, Queen's University, Canada.
- Chodosh, J., Berry, E., Lee, M., Connor, K., DeMonte, R., Ganiats, T., . . . Vickrey, B. (2006). Effect of a dementia care management intervention on primary care provider knowledge, attitudes, and perceptions of quality of care. *Journal of the American Geriatrics Society*, 54(2), 311-317.

- Chodosh, J., Petitti, D.B., Elliott, M., Hays, R.D., Crooks, V.C., Reuben, D.B., et al. (2004). Physician recognition of cognitive impairment: evaluating the need for improvement. *Journal of the American Geriatrics Society*, 52(7), 1051-1059.
- Chotirmall, S. H., Lee, G., Cosgrave, M., & Moore, A. (2008). Optimisation of dementia management in irish primary care. *International Journal of Geriatric Psychiatry*, 23(8), 880.
- Cody, M., Beck, C., Shue, V. M., & Pope, S. (2002). Reported practices of primary care physicians in the diagnosis and management of dementia. *Aging and Mental Health*, 6(1), 72-76.
- Cohen, C. A., Pringle, D., & LeDuc, L. (2001). Dementia caregiving: The role of the primary care physician. *Canadian Journal of Neurological Sciences*, 28(Suppl 1), S72-6.
- Cohen, C. A. (2000). Caregivers for people with dementia: What is the family physician's role?. *Canadian Family Physician*, 46, 376-380.
- Connell, C. M., Boise, L., Stuckey, J. C., Holmes, S. B., & Hudson, M. L. (2004). Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist*, 44(4), 500-507.
- Connolly, A, Iliffe, S., Gaehl, E., Campbell, S., Drake, R. et al., (2012). Quality of care provided to people with dementia: Utilisation and quality of the annual dementia review in general practice. *British Journal of General Practice*, 62 (595). E91-98 (8) (Retrieved from: <http://www.ingentaconnect.com/content/rcgp/bjgp/2012>)
- Connolly, A., Gaehl, E., Martin, H., Morris, J., & Purandare, N. (2011). Underdiagnosis of dementia in primary care: Variations in the observed prevalence and comparisons to the expected prevalence. *Aging and Mental Health*, 15(8), 978-984.
- Crane, M. K., Bogner, H. R., Rabins, P. V., & Gallo, J. J. (2006). Brief report: Patient cognitive status and the identification and management of depression by primary care physicians. *Journal of General Internal Medicine*, 21(10), 1042-1044.
- Crofton, J. E. (2005). *Dementia diagnosis practices of primary care physicians in british columbia: Who knows?* Master's Thesis, Trinity Western University, Canada.
- Culverwell, A., Milne, A., Guss, R., & Tuppen, J. (2008). Screening for dementia in primary care: How is it measuring up? *Quality in Ageing*, 9(3), 39-44.
- Cummings, J. L., Frank, J. C., Cherry, D., Kohatsu, N. D., Kemp, B., Hewett, L., & Mittman, B. (2002a). Guidelines for managing Alzheimer's Disease: Part I. assessment. *American Family Physician*, 65(11), 2263-2272.

- Cummings, J. L., Frank, J. C., Cherry, D., Kohatsu, N. D., Kemp, B., Hewett, L., & Mittman, B. (2002b). Guidelines for managing Alzheimer's Disease: Part II. treatment. *American Family Physician*, 65(12), 2525-2534.
- Dalsgaard, T., Kallerup, H., & Rosendal, M. (2007). Outreach visits to improve dementia care in general practice: A qualitative study. *International Journal for Quality in Health Care*, 19(5), 267-273.
- Davis, K., Drey, N., & Gould, D (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies*, 45: 1386-1400.
- De Lepeleire, J., Wind, A. W., Iliffe, S., MonizCook, E. D., Wilcock, J., Gonzalez, V. M., et al. (2008). The primary care diagnosis of dementia in Europe: An analysis using multidisciplinary, multinational expert groups. *Aging & Mental Health*, 12(5), 568-576.
- De Lepeleire, J., Buntinx, F., & Aertgeerts, B. (2004). Disclosing the diagnosis of dementia: The performance of flemish general practitioners. *International Psychogeriatrics*, 16(4), 421-428.
- Degryse, J., Lepeleire, J., Southgate, L., VernooijDassen, M., Gay, B., & Heyrman, J. (2009). An evaluation of a computer based education program for the diagnosis and management of dementia in primary care. an international study of the transcultural adaptations necessary for european dissemination. *Medical Teacher*, 31(5), 397-402.
- Delrieu J. et al. (2009). Mild Alzheimer's Disease: a position paper. *The Journal of Nutrition, Health and Aging*, 13 (6), 503-519.
- UK Department of Health (2009). *Living well with Dementia: A national Dementia Strategy*. (Retrieved from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)
- Downs, M., Ariss, S., Grant, E., Keady, J., Turner, S., Bryans, M., . . . Iliffe, S. (2006). Family carers' accounts of general practice contacts for their relatives with early signs of dementia. *Dementia*, 5(3), 353-373.
- Downs, M., Clibbens, R., Rae, C., Cook, A., & Woods, R. (2002). What do general practitioners tell people with dementia and their families about the condition? A survey of experiences in Scotland. *Dementia*, 1(1), 47-58.
- Downs, M., Turner, S., Bryans, M., Wilcock, J., Keady, J., Levin, E., . . . Iliffe, S. (2006). Effectiveness of educational interventions in improving detection and management of dementia in primary care: Cluster randomised controlled study. *British Medical Journal*, 332(7543), 692-696.

- Downs, M., Cook, A., Rae, C., & Collins, K. E. (2000). Caring for patients with dementia: The GP perspective. *Aging & Mental Health*, 4(4), 301-304.
- Eisele, M., van den Bussche, H., Koller, D., Wiese, B., Kaduszkiewicz, H., Maier, W., . . . Schon, G. (2010). Utilization patterns of ambulatory medical care before and after the diagnosis of dementia in germany--results of a case-control study. *Dementia & Geriatric Cognitive Disorders*, 29(6), 475-483.
- Feldman, H. H., Jacova, C., Robillard, A., Garcia, A., Chow, T., Borrie, M., . . . Chertkow, H. (2008). Diagnosis and treatment of dementia: 2. Diagnosis. *Canadian Medical Association Journal*, 178(7), 825-836.
- Fick, D.M., Kolanowski, A.M., Waller, J.L., & Inouye, S.K. (2005). Delirium superimposed on dementia in a community-dwelling managed care population: A 3-year retrospective study of occurrence, costs, and utilization. *Journal of Gerontology: Biological Sciences and Medical Sciences*. 60(6): 748-53.
- Fisher, C. A., & Lerner, A. J. (2007). Frequency and diagnostic utility of cognitive test instrument use by GPs prior to memory clinic referral. *Family Practice*, 24(5), 495-497.
- Fisk, J. D., Beattie, B. L., Donnelly, M., Byszewski, A., & Molnar, F. J. (2007). Disclosure of the diagnosis of dementia. *Alzheimer's and Dementia*, 3(4), 404-410.
- Fortinsky, R. H., Zlateva, I., Delaney, C., & Kleppinger, A. (2010). Primary care physicians' dementia care practices: Evidence of geographic variation. *Gerontologist*, 50(2), 179-191.
- Fortinsky, R. H., Kulldorff, M., Kleppinger, A., & Kenyon-Pesce, L. (2009). Dementia care consultation for family caregivers: Collaborative model linking an Alzheimer's association chapter with primary care physicians. *Aging and Mental Health*, 13(2), 162-170.
- Fortinsky, R. H. (2007). Physicians' views on dementia care and prospects for improved clinical practice. *Aging-Clinical & Experimental Research*, 19(5), 341-343.
- Fortinsky, R. H., Unson, C. G., & Garcia, R. I. (2002). Helping family caregivers by linking primary care physicians with community-based dementia care services: The Alzheimer's service coordination program. *Dementia*, 1(2), 227-240.
- Fortinsky, R. H. (2001). Health care triads and dementia care: Integrative framework and future directions. *Aging & Mental Health*, 5(Suppl1), S35-S48.
- Foster, N. L. (2001). Barriers to treatment: The unique challenges for physicians providing dementia care. *Journal of Geriatric Psychiatry and Neurology*, 14(4), 188-198.

- Franz, C. E., Barker, J. C., Kim, K., Flores, Y., Jenkins, C., Kravitz, R. L., & Hinton, L. (2010). When help becomes a hindrance: Mental health referral systems as barriers to care for primary care physicians treating patients with Alzheimer's Disease. *American Journal of Geriatric Psychiatry, 18*(7), 576-585.
- Franz, C. E., Barker, J. C., Kravitz, R. L., Flores, Y., Krishnan, S., & Hinton, L. (2007). Nonmedical influences on the use of cholinesterase inhibitors in dementia care. *Alzheimer Disease and Associated Disorders, 21*(3), 241-248.
- Freyne, A. (2001). Screening for dementia in primary care--a viable proposition? *Irish Journal of Psychological Medicine, 18*(2), 75-77.
- Froelich, L., Andreasen, N., Tsolaki, M., Foucher, A., Kavanagh, S., Baelen, B. V., & Schwalen, S. (2009). Long-term treatment of patients with Alzheimer's Disease in primary and secondary care: Results from an international survey. *Current Medical Research and Opinion, 25*(12), 3059-3068.
- Ganguli, M., Du, Y., Rodriguez, E. G., Mulsant, B. H., McMichael, K. A., Bilt, J. V., . . . Dodge, H. H. (2006). Discrepancies in information provided to primary care physicians by patients with and without dementia: The steel valley seniors survey. *The American Journal of Geriatric Psychiatry, 14*(5), 446-455.
- Ganguli, M., Rodriguez, E., Mulsant, B., Richards, S., Pandav, R., Vander Bilt, J., . . . Morycz, R. K. (2004). Detection and management of cognitive impairment in primary care: The steel valley seniors survey. *Journal of the American Geriatrics Society, 52*(10), 1668-1675.
- Gardner, I. L., Foreman, P., & Davis, S. (2004). Cognitive dementia and memory service clinics: Opinions of general practitioners. *American Journal of Alzheimer's Disease and Other Dementias, 19*(2), 105-110.
- Goodwin, J. S. (2002). Language and medicine: Thinking and talking about Alzheimer's Disease. *Gerontologist, 42*(3), 293-296.
- Greaves, I., & Jolley, D. (2010). National dementia strategy: Well intentioned - but how well founded and how well directed? *British Journal of General Practice, 60*(572), 193-198.
- Grimshaw, J.M., Martin, P.E., Walker, A.E., & Thomas, R.E. (2005). Changing physicians' behaviour: What works and thoughts on getting more things to work. *Journal of Continuing Education in Health Professions, 22*(4). 237-243.
- Hansen, E. C., Hughes, C., Routley, G., & Robinson, A. L. (2008). General practitioners' experiences and understandings of diagnosing dementia: Factors impacting on early diagnosis. *Social Science and Medicine, 67*(11), 1776-1783.

- Harris, D. P., Chodosh, J., Vassar, S. D., Vickrey, B. G., & Shapiro, M. F. (2009). Primary care providers' views of challenges and rewards of dementia care relative to other conditions. *Journal of the American Geriatrics Society*, 57(12), 2209-2216.
- Harvan, J. R., & Cotter, V. (2006). An evaluation of dementia screening in the primary care setting. *Journal of the American Academy of Nurse Practitioners*, 18(8), 351-360.
- Harvey, R. M., Horvath, K. J., Levine, S. A., & Volicer, L. (2005). Models of physician education for Alzheimer's Disease and dementia: Practical application in an integrated network. *Clinical Gerontologist*, 29(2), 11-23.
- Hébert, R., Dubois, M.F., Wolfson, C., Chambers, L., & Cohen, C. (2001). Factors associated with long-term institutionalization of older people with dementia: Data from the Canadian Study of Health and Aging. *Journal of Gerontology: Medical Sciences*, 56A(11), M693-699.
- Helmer, C., Peres, K., Pariente, A., Pasquier, F., Auriacombe, S., Poncet, M., . . . Dartigues, J. (2008). Primary and secondary care consultations in elderly demented individuals in France: Results from the three-city study. *Dementia and Geriatric Cognitive Disorders*, 26(5), 407-415.
- Hillmer M., Krahn, M., Hillmer, M., Pariser, P., & Naglie, G. (2006). Prescribing patterns for Alzheimer Disease; Survey of Canadian family physicians. *Canadian Family Physician*. 52:208-9. 8.
- Hinton, L., Franz, C. E., Reddy, G., Flores, Y., Kravitz, R. L., & Barker, J. C. (2007). Practice constraints, behavioral problems, and dementia care: Primary care physicians' perspectives. *Journal of General Internal Medicine*, 22(11), 1487-1492.
- Hinton, L., Franz, C., & Friend, J. (2004). Pathways to dementia diagnosis: Evidence for cross-ethnic differences. *Alzheimer's Disease and Associated Disorders*, 18(3), 134-144.
- Hogan, D. B., Bailey, P., Black, S., Carswell, A., Chertkow, H., . . . Thorpe, L (2008). Diagnosis and treatment of dementia: 4. Approach to management of mild to moderate dementia. *Canadian Medical Association Journal*, 179(8)
- Hollingworth, S. A., & Byrne, G. J. (2011). Prescribing trends in cognition enhancing drugs in Australia. *International Psychogeriatrics*, 23(2), 238-245.
- Holmes, S. B., & Adler, D. (2005). Dementia care: Critical interactions among primary care physicians, patients and caregivers. *Primary Care; Clinics in Office Practice*, 32(3), 671-682.
- Holsinger, T., Deveau, J., Boustani, M., & Williams, J. W., Jr. (2007). Does this patient have dementia? *Journal of American Medical Association*, 297(21), 2391-2404.

- Hunsaker, A. E., Schmidt, K., & Lingler, J. H. (2010). Discussing dementia-related behaviors during medical visits for people with Alzheimer's Disease. *American Journal of Alzheimer's Disease and Other Dementias*, 25(3), 248-254.
- Ilfie, S., Wilcock, J., Griffin, M., Jain, P., Thune-Boyle, I., Koch, T., & Lefford, F. (2010). Evidence-based interventions in dementia: A pragmatic cluster-randomised trial of an educational intervention to promote earlier recognition and response to dementia in primary care (EVIDEM-ED). *BMC Trials*, 11, 13 (Retrieved from: www.trialsjournal.com/content/11/1/13)
- Ilfie, S., Robinson, L., Brayne, C., Goodman, C., Rait, G., Manthorpe, J., & Ashley, P. (2009a). Primary care and dementia: 1. diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry*, 24(9), 895-901.
- Ilfie, S., Jain, P., Wong, G., Lefford, F., Warner, A., Gupta, S., . . . Kennedy, H. (2009b). Dementia diagnosis in primary care: Thinking outside the educational box. *Aging and Health*, 5(1), 51-59.
- Ilfie, S., Wilcock, J., & Haworth, D. (2006). Obstacles to shared care for patients with dementia: A qualitative study. *Family Practice*, 23(3), 353-362.
- Ilfie, S., de Lepeleire, J., van Hout, H., Kenny, G., Lewis, A., & Vernooij-Dassen, M. (2005). Understanding obstacles to the recognition of and response to dementia in different European countries: A modified focus group approach using multinational, multi-disciplinary expert groups. *Aging and Mental Health*, 9(1), 1-6.
- Ilfie, S., & Wilcock, J. (2005). The identification of barriers to the recognition of, and response to, dementia in primary care using a modified focus group approach. *Dementia: The International Journal of Social Research and Practice*, 4(1), 73-85.
- Ilfie, S., & Manthorpe, J. (2004). The recognition of and response to dementia in the community: Lessons for professional development. *Learning in Health and Social Care*, 3(1), 5.
- Ilfie, S., Wilcock, J., & Haworth, D. (2004a). A toolbox of skills to share across dementia care. *Journal of Dementia Care*, 12(4), 16-17.
- Ilfie, S., Wilcock, J., & Haworth, D. (2004b). A 'shared care' model for people with dementia. *Journal of Dementia Care*, 12(3), 16-18.
- Ilfie, S., Manthorpe, J., & Eden, A. (2003). Sooner or later? issues in the early diagnosis of dementia in general practice: A qualitative study. *Family Practice*, 20(4), 376-381.
- Ilfie, S., & Manthorpe, J. (2002). Dementia in the community: Challenges for primary care development. *Reviews in Clinical Gerontology*, 12(3), 243-252.

- Illiffe, S., Wilcock, J., Austin, T., Walters, K., Rait, G., Turner, S., . . . Downs, M. (2002). Dementia diagnosis and management in primary care: Developing and testing educational models. *Dementia: The International Journal of Social Research and Practice*, 1(1), 11-23.
- Illiffe, S., Walters, K., & Rait, G. (2000). Shortcomings in the diagnosis and management of dementia in primary care: Towards an educational strategy. *Aging and Mental Health*, 4(4), 286-291.
- Iracleous, P., Nie, J. X., Tracy, C. S., Moineddin, R., Ismail, Z., Shulman, K. I., & Upshur, R. E. (2010). Primary care physicians' attitudes towards cognitive screening: Findings from a national postal survey. *International Journal of Geriatric Psychiatry*, 25(1), 23-29.
- Jedenius, E., Wimo, A., Strömquist, J., Jönsson, L., & Andreasen, N. (2010). The cost of diagnosing dementia in a community setting. *International Journal of Geriatric Psychiatry*, 25(5), 476-482.
- Jedenius, E., Wimo, A., Stromqvist, J., & Andreasen, N. (2008). A swedish programme for dementia diagnostics in primary healthcare. *Scandinavian Journal of Primary Health Care*, 26(4), 235-240.
- Justiss, M. D., Boustani, M., Fox, C., Katona, C., Perkins, A. J., Healey, P. J., et al. (2009). Patients' attitudes of dementia screening across the Atlantic. *International Journal of Geriatric Psychiatry*, 24(6), 632-637.
- Kada, S., Nygaard, H. A., Geitung, J. T., Mukesh, B. N., Naik, M., Wold, G., & Soevik, D. H. (2007). Quality and appropriateness of referrals for dementia patients. *Quality in Primary Care*, 15(1), 53-57.
- Kaduszkiewicz, H., Wiese, B., & van den Bussche, H. (2008). Self-reported competence, attitude and approach of physicians towards patients with dementia in ambulatory care: Results of a postal survey. *BMC Health Services Research*, 8, 54.
- Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., & Eidelman, S. (2007). Dilemmas in the (un)veiling of the diagnosis of Alzheimer's Disease: Walking an ethical and professional tight rope. *Patient Education and Counseling*, 67(3), 307-314.
- Kissel, E. C., & Carpenter, B. D. (2007). It's all in the details: Physician variability in disclosing a dementia diagnosis. *Aging and Mental Health*, 11(3), 273-280.
- Knopman, D., Donohue, J.A., Gutterman, E.M. (2000). Patterns of care in the early stages of Alzheimer's disease: Impediments to timely diagnosis. *Journal of American Geriatric Society*, 48(3): 300-4.

- Koch, T., & Iliffe, S. (2010a). Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: A systematic review. *BMC Family Practice, 11*, 52, 1-8e. (Retrieved from: www.biodmedcentral.com/1471-2296/11/52)
- Koch, T., Iliffe, S., & Evidem, P. (2010b). The role of primary care in the recognition of and response to dementia. *Journal of Nutrition, Health and Aging, 14*(2), 107-109.
- Koch, T., & Iliffe, S. (2009). Implementing the NDS: Case studies from primary care. *Journal of Dementia Care, 17*(6), 26-29.
- Koehn, S., McCleary, L., Garcia, L., Spence, M., Jarvis, P., & Drummond, N. (2012). Understanding Chinese-Canadian pathways to a diagnosis of dementia through a critical-constructionist lens. *Journal of Aging Studies, 26*(1), 44-54.
- Lawrence, J. M., Davidoff, D. A., KattLloyd, D., Connell, A., Berlow, Y. A., & Savoie, J. A. (2003). Is large-scale community memory screening feasible? Experience from a regional memory-screening day. *Journal of the American Geriatrics Society, 51*(8), 1072-1078.
- Lee, S. M., Lin, X., Haralambous, B., Dow, B., Vratsidis, F., Tinney, J., . . . Giudice, D. L. (2011). Factors impacting on early detection of dementia in older people of Asian background in primary healthcare. *Asia-Pacific Psychiatry, 3*(3), 120-127.
- Lee, L., Hillier, L. M., Stolee, P., Heckman, G., Gagnon, M., McAiney, C. A., & Harvey, D. (2010). Enhancing dementia care: A primary care-based memory clinic. *Journal of the American Geriatrics Society, 58*(11), 2197-2204.
- Lemelin, J., Hogg, W., & Baskerville, N., (2001). Evidence to action: a tailored multifaceted approach to changing family physician practice patterns and improving preventive care. *Canadian Medical Association. 164* (6).757-63.
- Leung, K.,K., Finlay, J., Silvius, J.,L., Koehn, S., McCleary, L., Cohen, C.,A., . . . Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a dementia diagnosis among Anglo-Canadians. *Health and Social Care in the Community, 19*(4), 372-81.
- Lipski, P. S. (2002). Survey of general practitioners' attitudes to older drivers on the new South Wales central coast. *Australasian Journal on Ageing, 21*(2), 98-100.
- Lopponen, M., Raiha, I., Isoaho, R., Vahlberg, T., & Kivela, S. L. (2003). Diagnosing cognitive impairment and dementia in primary health care - a more active approach is needed. *Age & Ageing, 32*(6), 606-612.

- Luconi, F. (2010). *Exploring rural family physicians' learning from a web-based continuing medical education program on Alzheimer's Disease: A pilot study*. Master's Thesis, McGill University, Canada.
- Maeck, L., Haak, S., Knoblauch, A., & Stoppe, G. (2008). Primary care physicians' attitudes related to cognition enhancers in early dementia: A representative eight-year follow-up study in lower Saxony, Germany. *International Journal of Geriatric Psychiatry*, 23(4), 415-421.
- Maeck, L., Haak, S., Knoblauch, A., & Stoppe, G. (2007). Early diagnosis of dementia in primary care: A representative eight-year follow-up study in lower Saxony, Germany. *International Journal of Geriatric Psychiatry*, 22(1), 23-31.
- Manthorpe, J., Iliffe, S., & Eden, A. (2003). The implications of the early recognition of dementia for multiprofessional teamworking: Conflicts and contradictions in practitioner perspectives. *Dementia*, 2(2), 163-179.
- Maslow, K., Selstad, J., Denman S.J. (2002). Guidelines and care management issues for people with Alzheimer's Disease and other disorders. *Disease Management Health Outcomes*.10(11). 6930-706.
- Mayeux, R., Reitz, C., Brickman, A., Haan, M., Manly, J., Glymour, M. M., . . . Morris JC. (2011). Operationalizing diagnostic criteria for Alzheimer's Disease and other age-related cognitive impairment—Part 1. *Alzheimer's & Dementia*, 7, 15-34.
- McAiney, C.A. (February, 2006). Initiative #2: Physician Training Final Evaluation Report 2006. Ontario's Strategy for Alzheimer's Disease and Related Dementias. (Retrieved from: <http://www.ocfp.on.ca/docs/cme/init-2---final-evaluation-report.pdf>)
- Meeuwssen, E. J., German, P., Melis, R. J., Adang, E. M., Goluke-Willemse, G. A., Krabbe, P. F., . . . Rikkert, M. G. (2009). Cost-effectiveness of post-diagnosis treatment in dementia coordinated by multidisciplinary memory clinics in comparison to treatment coordinated by general practitioners: An example of a pragmatic trial. *Journal of Nutrition, Health and Aging*, 13(3), 242-248.
- Meuser, T. M., Boise, L., & Morris, J. C. (2004). Clinician beliefs and practices in dementia care: Implications for health educators. *Educational Gerontology*, 30(6), 491-516.
- Millard, F. B., Kennedy, R. L., & Baune, B. T. (2011). Dementia: Opportunities for risk reduction and early detection in general practice. *Australian Journal of Primary Health*, 17(1), 89-94.
- Millard, F., & Baune, B. (2009). Dementia - who cares? A comparison of community needs and primary care services. *Australian Family Physician*, 38(8), 642-649.

- Millard, F. B., Thistlethwaite, J., Spagnolo, C., Kennedy, R. L., & Baune, B. T. (2008). Dementia diagnosis: A pilot randomised controlled trial of education and IT audit to assess change in GP dementia documentation. *Australian Journal of Primary Health*, 14(3), 141-149.
- Milne, A., Culverwell, A., Guss, R., Tuppen, J., & WheIton, R. (2008). Screening for dementia in primary care: A review of the use, efficacy and quality of measures. *International Psychogeriatrics*, 20(5), 911-926.
- Milne, A. J., Hamilton-West, K., & Hatzidimitriadou, E. (2005). GP attitudes to early diagnosis of dementia: Evidence of improvement. *Aging and Mental Health*, 9(5), 449-455.
- Milne, A. J., Woolford, H. H., Mason, J., & Hatzidimitriadou, E. (2000). Early diagnosis of dementia by GPs: An exploratory study of attitudes. *Aging and Mental Health*, 4(4), 292-300.
- Mitchell, A. J., & Malladi, S. (2010a). Screening and case finding tools for the detection of dementia. part I: Evidence-based meta-analysis of multidomain tests. *American Journal of Geriatric Psychiatry*, 18(9), 759-782.
- Mitchell, A. J., & Malladi, S. (2010b). Screening and case-finding tools for the detection of dementia. part II: Evidence-based meta-analysis of single-domain tests. *American Journal of Geriatric Psychiatry*, 18(9), 783-800.
- Mittleman, M.S., Haley, W.E. Clay, O.J., Roth, D.L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer Disease. *Neurology*. 67:1592-1599
- Mok, W., Chow, T. W., Zheng, L., Mack, W. J., & Miller, C. (2004). Clinicopathological concordance of dementia diagnoses by community versus tertiary care clinicians. *American Journal of Alzheimer's Disease and Other Dementias*, 19(3), 161-165.
- Morgan, D., Innes, A., & Kosteniuk, J. (2011). Dementia care in rural and remote settings: A systematic review of formal or paid care. *Maturitas*, 68(1), 17-33.
- Musicco, M., Sorbi, S., Bonavita, V., Caltagirone, C., et al. (2004). Validation of the guidelines for the diagnosis of dementia and Alzheimer's Disease of the Italian neurological society. *Neurological Sciences*, 25(5), 289-295.
- National Institute for health and clinical Excellence (2011). *Dementia: Supporting People with dementia and their carers in health and social care*. Social Care institute for excellence. (available at: www.nice.org.uk)

- Norwegian Ministry of Health and Care Services. (2008). *Dementia Plan 2015*. Norwegian Ministry of Health and Care Services (Retrieved from: <http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf>)
- O'Brien, J., Robinson, L., & Fairbairn, A. (2001). Proposed shared care protocol between primary and secondary care for the ongoing management of those on anti-dementia medication. *Primary Care Psychiatry*, 7(3), 111-113.
- Olafsdottir, M., Foldevi, M., & Marcusson, J. (2001). Dementia in primary care: Why the low detection rate? *Scandinavian Journal of Primary Health Care*, 19(3), 194-198.
- Olafsdottir, M., Skoog, I., & Marcusson, J. (2000). Detection of dementia in primary care: The linköping study. *Dementia and Geriatric Cognitive Disorders*, 11(4), 223-229.
- Oremus, M., Wolfson, C., Bergman, H., & Vandal, A. C. (2007). Physicians' efficacy requirements for prescribing medications to persons with Alzheimer's Disease. *Canadian Journal on Aging*, 26(2), 139-148.
- Overcoming barriers to early dementia diagnosis. (2008). *Lancet*, 371 (9628), 1888.
- Patterson, C., Gauthier, S., Bergman, H., Cohen, C., Feightner, J. W., Feldman, H., . . . Hogan, D. B. (2001). The recognition, assessment and management of dementing disorders: Conclusions from the Canadian consensus conference on dementia. *Canadian Journal of Neurological Sciences*, 28(Suppl 1), S3-16.
- Pedone, C., Ercolani, S., Cantani, M., Maggio, D., Ruggiero, C., et al., (2005). Elderly patients cognitive impairment have a high risk for functional decline during hospitalization.: The GIFA study. *Journal of Gerontology: Biological Sciences and Medical Sciences*, 60 (12), 1576-1580.
- Pentzek, M., Fuchs, A., Abholz, H. -, & Wollny, A. (2011). Awareness of local dementia services among general practitioners with academic affiliation. *Aging - Clinical and Experimental Research*, 23(3), 241-243.
- Pentzek, M., Abholz, H. H., Ostapczuk, M., Altiner, A., Wollny, A., & Fuchs, A. (2009a). Dementia knowledge among general practitioners: First results and psychometric properties of a new instrument. *International Psychogeriatrics*, 21(6), 1105-1115.
- Pentzek, M., Wollny, A., Wiese, B., Jessen, F., Haller, F., Maier, W. et al. (2009b). Apart from nihilism and stigma: What influences general practitioners' accuracy in identifying incident dementia? *American Journal of Geriatric Psychiatry*, 17(11), 965-975.

- Perry, M., Draskovic, I., Lucassen, P., VernooijDassen, M., van Achterberg, T., & Rikkert, M. O. (2011). Effects of educational interventions on primary dementia care: A systematic review. *International Journal of Geriatric Psychiatry*, 26(1), 1-11.
- Perry, M., Draskovic, I., van Achterberg, T., van Eijken, M., Lucassen, P., Vernooij-Dassen, M., & Olde Rikkert, M. (2010). Development and validation of quality indicators for dementia diagnosis and management in a primary care setting. *Journal of the American Geriatrics Society*, 58(3), 557-563.
- Picard, A. (2010, September 18). Why Canada needs a national strategy on dementia, *Globe & Mail* (Retrieved from: <http://www.theglobeandmail.com/life/health/dementia/why-canada-needs-a-national-strategy-on-dementia/article1712700>)
- Pimlott, N. J., Persaud, M., Drummond, N., Cohen, C. A., Silvius, J. L., Seigel, K., . . . Dalziel, W. B. (2009a). Family physicians and dementia in Canada: Part 2. understanding the challenges of dementia care. *Canadian Family Physician*, 55(5), 508-9.e1-7. (Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medl&AN=19439708>)
- Pimlott, N. J., Persaud, M., Drummond, N., Cohen, C. A., Silvius, J. L., Seigel, K., . . . Dalziel, W. B. (2009b). Family physicians and dementia in Canada: Part 1. clinical practice guidelines: Awareness, attitudes, and opinions. *Canadian Family Physician*, 55(5), 506-7.e1-5. (Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medl&AN=19439707>)
- Pimlott, N. J., Siegel, K., Persaud, M., Slaughter, S., Cohen, C., Hollingworth, G., . . . Eliasziw, T. (2006). Management of dementia by family physicians in academic settings. *Canadian Family Physician*, 52(9), 1108-1109.
- Pinner, G., & Bouman, W. P. (2002). To tell or not to tell: On disclosing the diagnosis of dementia. *International Psychogeriatrics*, 14(2), 127-137.
- Powell, A. L. (2002). On issues pertinent to Alzheimer Disease and cultural diversity. *Alzheimer's Disease and Associated Disorders*, 16(Suppl 2), S43-5.
- Pratt, R., & Wilkinson, H. (2001). A Psychosocial Model of Understanding the Experience of Receiving a Diagnosis of Dementia. *Dementia*, 2 (2): 181-199.
- Qaseem A. Snow V. Cross JT Jr. Forcica MA. Hopkins R Jr. Shekelle P. Adelman A. . . . Owens DK. (2008). Current pharmacologic treatment of dementia: A clinical practice guideline from the American college of physicians and the American academy of family physicians. *Annals of Internal Medicine*, 148(5), 370-378.

- Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S., & Nazareth, I. (2010). Survival of people with clinical diagnosis of dementia in primary care: Cohort study. *British Medical Journal*, *341*, c3584.
- Renshaw, J., Scurfield, P., Cloke, L., & Orrell, M. (2001). General practitioners' views on the early diagnosis of dementia. *British Journal of General Practice*, *51*(462), 37-38.
- Reuben, D. B., Roth, C. P., Frank, J. C., Hirsch, S. H., Katz, D., McCreath, H., . . . Wenger, N. S. (2010). Assessing care of vulnerable elders-Alzheimer's Disease: A pilot study of a practice redesign intervention to improve the quality of dementia care. *Journal of the American Geriatrics Society*, *58*(2), 324-329.
- Reuben, D., Levin, J., Frank, J., Hirsch, S., McCreath, H., Roth, C., & Wenger, N. (2009). Closing the dementia care gap: Can referral to Alzheimer's association chapters help? *Alzheimer's & Dementia*, *5*(6), 498-502.
- Reuben, D. B., Roth, C., Kamberg, C., & Wenger, N. S. (2003). Restructuring primary care practices to manage geriatric syndromes: The ACOVE-2 intervention. *Journal of the American Geriatrics Society*, *51*(12), 1787-1793.
- Robinson, L., Iliffe, S., Brayne, C., Goodman, C., Rait, G., Manthorpe, J., . . . Moniz-Cook, E. (2010a). Primary care and dementia: 2. long-term care at home: Psychosocial interventions, information provision, carer support and case management. *International Journal of Geriatric Psychiatry*, *25*(7), 657-664.
- Robinson, L., Vellas, B., Knox, S., & Lins, K. (2010b). Clinical practice patterns of generalists and specialists in Alzheimer's Disease: What are the differences, and what difference do they make?. *Journal of Nutrition, Health and Aging*, *14*(7), 545-552.
- Robinson, A. L., Emden, C. G., Elder, J. A., Lea, E. J., Vickers, J. C., & Turner, P. A. (2008). Multiple views reveal the complexity of dementia diagnosis. *Australasian Journal on Ageing*, *27*(4), 183-188.
- Robinson, B. E., Barry, P. P., Renick, N., Bergen, M. R., & Stratos, G. A. (2001). Physician confidence and interest in learning more about common geriatric topics: A needs assessment. *Journal of the American Geriatrics Society*, *49*(7), 963-967.
- Rockwood, K., & Keren, R. (2010). Dementia services in Canada. *International Journal of Geriatric Psychiatry*, *25*(9), 876-880.
- Rondeau, V., Allain, H., Bakchine, S., Bonet, P., Brudon, F., Chauplannaz, G., . . . Dartigues, J. F. (2008). General practice-based intervention for suspecting and detecting dementia in France: A cluster randomized trial. *Dementia*, *7*(4), 433-450.

- Rudolph, J.L., Zanin, N.M., Jones, R.N., Marcantonio, E.R., Fong, T.G., et al. (2010). Hospitalization in community- dwelling persons with Alzheimer's Disease: frequently and causes. *Journal of American Geriatric Society*, 58(8). 1542-8.
- Ruof, J., Mittendorf, T., Pirk, O., & von der Schulenburg, J. M. (2002). Diffusion of innovations: Treatment of alzheimer's Disease in germany. *Health Policy*, 60(1), 59-66.
- Russell, G.M., Hogg, W., & Lemelin, J. (2010). Beyond fighting fires and chasing tails? Chronic illness care plans in Ontario, Canada. *Annals of Family Medicine*, 6(2).146-153.
- Russell, G.M., Hogg, W., & Lemelin, J. (2008). Integrated primary care organizations: The next step for primary care reform. *Canadian Family Physician*. 56. 216-218.
- Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2009). What is the role of the general practitioner towards the family caregiver of a community-dwelling demented relative? A systematic literature review. *Scandinavian Journal of Primary Health Care*, 27(1), 31-40.
- SegalGidan, F., Cherry, D., Jones, R., Williams, B., Hewett, L., Chodosh, J., et al. (2011). Alzheimer's Disease management guideline: Update 2008. *Alzheimer's and Dementia*, 7(3), e51-e59. (Retrieved from: [http://www.alzheimersanddementia.com/article/S1552-5260\(10\)02420-9](http://www.alzheimersanddementia.com/article/S1552-5260(10)02420-9))
- Snellgrove, C. A., & Hecker, J. R. (2002). Driving and dementia: General practitioner attitudes, knowledge and self-reported clinical practices in South Australia. *Australasian Journal on Ageing*, 21(4), 210-212.
- Speechly, C. M., Bridges-Webb, C., & Passmore, E. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189(9), 487-489.
- Sternberg, S.A., Wolfson, C., & Baumgarten, M. (2000). Undetected dementia in community-dwelling older people: the Canadian Study of health and aging. *Journal of American Geriatrics Society*, 48(11). 1430-4.
- Stoppe, G., & Maeck, L. (2007). Early diagnosis of dementia in primary care. *International Journal of Geriatric Psychiatry*, 22(5), 498.
- Szymczynska,P., Innes, A., Mason, A., & Stark, C. (2011)A review of diagnostic process and postdiagnostic support for people with dementia in rural areas. *Journal of Primary Care and Community Health* . 2(4) 262-276.

- Teel, C. S. (2004). Rural practitioners' experiences in dementia diagnosis and treatment. *Aging and Mental Health*, 8(5), 422-429.
- Teel, S..T., & Carson, P. (2003). Family experiences in the journey through dementia diagnosis and care. *Journal of Family Nursing*, 9(1), 38-58.
- Thyrian, J. R., & Hoffmann, W. (2011). Dementia care in family practices in Germany: Primary data on figures and attitudes. *Alzheimer's and Dementia*. 7(4 SUPPL), S636.
- Travers, C., Martin-Khan, M., & Lie, D. (2009). Barriers and enablers of health promotion, prevention and early intervention in primary care: Evidence to inform the Australian National Dementia Strategy. *Australasian Journal on Ageing*, 28(2), 51-57.
- Trigg, R., Jones, R.W., & Skevington, S.M. (2007). Can people with mild to moderate dementia provide reliable answers about their quality of life? *Age and Ageing*, 36(6), 663-669.
- Tsolaki, M., Papaliagkas, V., Anogianakis, G., Bernabei, R., Emre, M., Frolich, L., . . . Winblad, B. (2010). Consensus statement on dementia education and training in europe. *Journal of Nutrition, Health and Aging*, 14(2), 131-135.
- Turner, S., Iliffe, S., Downs, M., Wilcock, J., Bryans, M., Levin, E., . . . O'Carroll, R. (2004). General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age and Ageing*, 33(5), 461-467.
- Turner, S., Iliffe, S., Downs, M., Bryans, M., Wilcock, J., & Austin, T. (2003). Decision support software for dementia diagnosis and management in primary care: Relevance and potential. *Aging and Mental Health*, 7(1), 28-33.
- Valcour, V. G., Masaki, K. H., Curb, J. D., & Blanchette, P. L. (2000). The detection of dementia in the primary care setting. *Archives of Internal Medicine*, 160(19), 2964-2968.
- Van Hout, H. P., Vernooij-Dassen, M. J., Hoefnagels, W. H., Kuin, Y., Stalman, W. A., Moons, K. G., & Grol, R. P. (2002). Dementia: Predictors of diagnostic accuracy and the contribution of diagnostic recommendations. *Journal of Family Practice*, 51(8), 693-699.
- Van Hout, H., Vernooij-Dassen, M., Poels, P., Hoefnagels, W., & Grol, R. (2001a). Applicability of diagnostic recommendations on dementia in family practice. *International Journal for Quality in Health Care*, 13(2), 127-133.
- Van Hout, H. P. J., Vernooij-Dassen, M., Hoefnagels, W. H. L., & Grol, R. P. T. M. (2001b). Measuring the opinions of memory clinic users: Patients, relatives and general practitioners. *International Journal of Geriatric Psychiatry*, 16(9), 846-851.

- Van Hout, H., Vernooij-Dassen, M., Bakker, K., Blom, M., & Grol, R. (2000). General practitioners on dementia: Tasks, practices, and obstacles. *Patient Education and Counseling*, 39(2-3), 219-225.
- Venohr, I., Fine, R., Saunders, V., Tenney, E., Vahan, V., & Williams, M. (2001). Improving dementia care through community linkages: A multi-site demonstration project. *Home Health Care Services Quarterly*, 19(4), 51-63.
- Vernooij-Dassen, M., Moniz-Cook, E., Woods, R. T., De Lepeleire, J., Leuschner, A., Zanetti, O. . . . Iliffe, S. (2005). Factors affecting timely recognition and diagnosis of dementia across Europe: From awareness to stigma. *International Journal of Geriatric Psychiatry*, 20(4), 377-386.
- Vickery, B., Mitman, B., Connor, K., Connor, K.E., Pearson, M.L., Della Penna, R.D., . . . Lee, M. (2006). The effect of a disease management intervention on quality and outcomes of dementia care: A Randomized, Controlled Trial. *Annals of Internal Medicine*, 145(713).
- Villars, H., Oustric, S., Andrieu, S., Baeyens, J. P., Bernabei, R., Brodaty, H., . . . Vellas, B. (2010). The primary care physician and Alzheimer's Disease: An international position paper. *Journal of Nutrition, Health and Aging*, 14(2), 110-120.
- Waldemar, G., Dubois, B., Emre, M., Georges, J., McKeith, I. G., Rossor, M. et al. (2007). Recommendations for the diagnosis and management of Alzheimer's Disease and other disorders associated with dementia: EFNS guideline. *European Journal of Neurology*, 14(1), e1-26. (Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medl&AN=17222085>)
- Waldorff, F. B., Bulow, L. B., Malterud, K., & Waldemar, G. (2001). Management of dementia in primary health care: The experiences of collaboration between the GP and the district nurse. *Family Practice*, 18(5), 549-552.
- Waldemar, G., Phung, K. T., Burns, A., Georges, J., Hansen, F. R., Iliffe, S., . . . Sartorius, N. (2007). Access to diagnostic evaluation and treatment for dementia in Europe. *International Journal of Geriatric Psychiatry*, 22(1), 47-54.
- Waldorff, F. B., Rishoj, S., & Waldemar, G. (2005). Identification and diagnostic evaluation of possible dementia in general practice: A prospective study. *Scandinavian Journal of Primary Health Care*, 23(4), 221-226.
- Waldorff, F. B., Almind, G., Makela, M., Moller, S., & Waldemar, G. (2003). Implementation of a clinical dementia guideline: A controlled study on the effect of a multifaceted strategy. *Scandinavian Journal of Primary Health Care*, 21(3), 142-147.

- Waldorff, F. B., & Moller, S. (2001). Diagnostic evaluation of dementia in general practice in denmark: A national survey. *Scandinavian Journal of Primary Health Care*, 19(2), 117-121.
- Walker, D. (June, 2011). *Caring for our aging population and addressing alternative level of care*. Minister of Health and Long-Term Care, Ontario.
- White, N., Scott, A., Woods, R. T., Wenger, G. C., Keady, J. D., & Devakumar, M. (2002). The limited utility of the mini-mental state examination in screening people over the age of 75 years for dementia in primary care. *British Journal of General Practice*, 52(485), 1002-1003.
- Wijeratne, C., & Harris, P. (2009). Late life depression and dementia: A mental health literacy survey of Australian general practitioners. *International Psychogeriatrics*, 21(2), 330-337.
- Wilcock, J., Iliffe, S., Turner, S., Bryans, M., O'Carroll, R., Keady, J., . . . Downs, M. (2009). Concordance with clinical practice guidelines for dementia in general practice. *Aging and Mental Health*, 13(2), 155-161.
- Wilkins, C. H., Wilkins, K. L., Meisel, M., Depke, M., Williams, J., & Edwards, D. F. (2007). Dementia undiagnosed in poor older adults with functional impairment. *Journal of the American Geriatrics Society*, 55(11), 1771-1776.
- Wilkinson, D., Sganga, A., Stave, C., & O'Connell, B. (2005). Implications of the facing dementia survey for health care professionals across Europe. *International Journal of Clinical Practice* (Suppl), 59, 27-31.
- Wilkinson, D., Stave, C., Keohane, D., & Vincenzino, O. (2004). The role of general practitioners in the diagnosis and treatment of Alzheimer's Disease: A multinational survey. *Journal of International Medical Research*, 32(2), 149-159.
- Wilkinson, H., & Milne, A. J. (2003). Sharing a diagnosis of dementia - learning from the patient perspective. *Aging and Mental Health*, 7(4), 300-307.
- Williams, I. (2000). What help do GPs want from specialist services in managing patients with dementia? *International Journal of Geriatric Psychiatry*, 15(8), 758-761.
- Wilson, L. R., & Kirby, N. H. (2008). Individual differences in south Australian general practitioners' knowledge, procedures and opinions of the assessment of older drivers. *Australasian Journal on Ageing*, 27(3), 121-125.

- Woods, R.T., Moniz-Cook, E., Iliffe, S., Champion, P., Vernooij-Dassen, M., et al. (2003). Dementia: Issues in early recognition and intervention in primary care. *Journal of the Royal Society of Medicine*, 96: 320-324.
- Yaffe, M. J., Orzeck, P., & Barylak, L. (2008). Family physicians' perspectives on care of dementia patients and family caregivers. *Canadian Family Physician*, 54(7), 1008-1015.
- Yaffe, K., Fox., Newcomer, R., Sands, L., Lindquist, K., et al. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *Journal of American Medical Association*, 287(16), 2090-2097.
- Zilken, R.R., Spilsbury, K., Bruce, D.G., & Semmens, J.B. (2009). Clinical epidemiology and in-patient hospital use in the last year of life (1990-2005) of 29,884 Western Australians with dementia. *Journal of Alzheimer's Disease*. 17(2), 399-407.

APPENDIX A

Primary Care physicians & Dementia: Screening, Diagnosis, Disclosure & Management

**A Collection of Over 300 Relevant Published Manuscripts
(2000-2011)**

**F. Aminzadeh
D. Ayotte
C. Mounde**

January 2012

Available at www.rgpeo.com



To ask for copies of this guide contact:

Regional Geriatric Program of Eastern Ontario
RGP Administration – Box 678
The Ottawa Hospital, Civic Campus
1053 Carling Avenue, Ottawa, ON K1Y 4E9
Tel: 613-761-4458
Fax: 613-761-5334
www.rgpeo.com

This guide is copyrighted © by the Copyright Act of Canada.

This means that you are welcome to reprint or photocopy any of the materials for individual use only, but not for commercial purposes. Please acknowledge the source, if you use this material in presentations, publications or any other formats.

