DEMENTIA DIAGNOSIS PRACTICES OF PRIMARY CARE PHYSICIANS IN BRITISH COLUMBIA: WHO KNOWS?

by

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ABSTRACT

Three hundred and twelve primary care physicians, working in British Columbia, responded to a survey describing their practices with dementia patients and their families. The decision of whether or not to disclose a dementia diagnosis and to whom, factors influencing a physician's practice, confidence in diagnosis, and the impact of medical training was queried. The typical participant practiced in a Metro Urban centre, had over 10 years of experience and has taken between 1-10 hours of dementia- related training in the past 5 years. Approximately 80% of physicians were trained in Canada; almost half of those in British Columbia. The questionnaire was designed in cooperation with the British Columbia Medical Association (BCMA) and geriatric specialists. Univariate (t-test, chi-square) and Anova calculations were used to identify significant results. Almost 60% of primary care physicians are disclosing a dementia diagnosis in over 75% of their cases. Caregivers are regularly informed of a dementia diagnosis more frequently than patients. Physicians with more experience were associated with reduced disclosure frequency. A smaller number of participants reported a significant result in the influence of non- professional experience as a factor in their disclosure practice. Significance was observed noting a difference between the influences of various factors on a physician's dementia diagnosis practices. Physician's reported feeling unequally confident in their skills relating to dementia disclosure, and consider some factors as more important than others in how they influence their practice of disclosure.

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CHAPTER 1: INTRODUCTION

Professionals in every area of human service struggle with difficult issues. Financial advisors, teachers, counsellors, and medical professionals balance decisions they make each day. Physicians, among others, have guiding principles such as beneficence and non-malificence as they carry out their duties with patients and families. "Do good for others" and "Do no harm" becomes an even more difficult principle to apply when patients have only partial insight into their condition; as is the case with many people with dementia. Primary care physicians are the front line professionals who diagnose and manage dementia care in the community. Despite well-established general ethical principles, thorough training and clinical experience, dementia disclosure practices vary significantly.

Dementia disclosure practices have been widely studied around the world. In a recent systematic review on the topic, a group of United Kingdom researchers, Bamford Lamond, Eccles, Robinson, May, and Bond , found fifty-nine English studies with original empirical data (2004, p. 152). The study found continuing diversity in practices of dementia disclosure as reported by physicians, other healthcare professionals, patients and caregivers.

The noteworthy controversy regarding dementia disclosure continues, as it remains unresolved. Similar discussions regarding other terminal illnesses such as cancer reached consensus decades ago. Cancer disclosure practices received attention in the 1960's by Dr. Donald Oken, when he identified that 90% of physicians did not disclose a diagnosis of cancer to patients (Novack, Plumer, Smith, Ochitill, Morrow & Bennett, 1979). This has changed, and in 1979, researchers were able to document regular disclosure practices for cancer patients (Novack, Plumer, Smith, Ochitill, Morrow & Bennett,1979). Researchers have identified numerous factors, including the lack of certainty of diagnosis, few therapeutic options and concerns that giving a diagnosis will be harmful to the patient, that contribute to non-disclosure practices for primary care physicians with dementia patients (Drickamer & Lachs, 1992).

Dementia refers to a group of diseases often characterized by progressive memory loss, declining cognitive function, and changing mood and behaviour (Alzheimer's Society of British Columbia website: http:// www.alzheimersbc.org/ alzheimer.php). The two most common forms of dementia are Alzheimer's Disease (AD) and Vascular Dementia (VaD) accounting for over seventy percent of dementia diagnoses, however, other common forms of dementia include Lewy Body dementia (LBD) and Fronto-temporal dementia (FTD). “ Dementing disorders are primarily distinguished by the parts of the brain affected and by the pathological changes occurring in brain cells” (Yeaworth, 2002 p. 29) although changes in an individuals standard daily functioning may be the most clear indicator for the primary care physician.

Dementia is often assumed to be a natural part of aging because as people age, they are more susceptible to dementia. Yet, dementia is not the result of aging. While people as young as twenty have been diagnosed with dementia, the majority of those with the disease are over the age of sixty-five (Molloy & Caldwell, 1998, p. 12). One third of people over the age of 85 in British Columbia have dementia (BCMA, 2004, p.5) and as the aged population increases, so does the cost to our communities.

In recognition of the personal impact on individuals and families, as well as the effects on the growing utilization of resources, dementia-focused associations around the world, such as Alzheimer’s New Zealand and Alzheimers Scotland, have been calling for practice guidelines for physicians managing dementia care. The Canadian Medical Association published numerous recommendations resulting from the Canadian Consensus on Dementia (Canadian Medical Association, 1999). Regarding disclosure of dementia, they concluded that "although each case should be weighed on its own merits, it is considered ethically preferable to inform persons with dementia of their diagnosis (p.S7)". The Canadian Alzheimer's society amended their ethical guidelines detailing appropriate disclosure practices for physicians in 2003 (www.alzhemer.ca/home/html). Despite such recommendation, the Province of British Columbia, unlike most other Canadian provinces, does not have a dementia strategy in place or some basic dementia-specific resources, such as access to dementia drugs.

One of the main contributions of this study is to document the dementia disclosure practices of primary care physicians in British Columbia. Quantitative statistical analyses are useful in describing practices and determining associations between factors and practices. Overall, this study attempts to increase discourse about the ethical and disease-related factors that influence the dementia disclosure practices of B.C. physicians. More specifically, it attempts to explore the difficult questions about the value of people with limited capacity, and the commitment of our society to treat them with respect.

While many research projects are exploratory and seek to add new knowledge to existing theories, this study is an example of applied research and can best be assessed by its usefulness to the community. While the research presented in this study is specifically addressing dementia disclosure issues, the larger information documented and presented to the Dementia Strategy Project group was used as part of a larger initiative by the British Columbia Medical Association to advocate for a coordinated dementia strategy in British Columbia. Assisting in efforts to influence the provincial government’s approach to dementia care is a useful and significant contribution of this research study.

CHAPTER 2: LITERATURE REVIEW

Alzheimer’s disease became a part of mainstream consciousness in 1994 when former United States president, Ronald Reagan, announced he had been diagnosed with dementia. The Reagan’s founded the Nancy and Ronald Reagan Research Institute to search out advancements and treatments for Alzheimer’s disease (http://www.alz.org/Research/Reagan/overview.asp). In the years since his announcement, Alzheimer’s disease has become a part of the collective consciousness as people understand it affects the memory of elderly people.

This study is about the importance of communicating a diagnosis of dementia. As primary care physicians are the first medical professionals presented with symptoms, they play a very important role in the lives of patients and caregivers. Interestingly, the issue of disclosure is controversial and has been for many years. Numerous researchers from around the world have attempted to understand and clarify the issues, yet, no common approach has been agreed upon by primary medical staff.

The literature review attempts to illuminate the reoccurring issues presented; the research examines how often disclosure of dementia occurs and what factors are seen as important in the decision to disclose. One issue that has not received as much attention is the role of ethical decision-making in dementia diagnosis. This issue is discussed briefly.

Dementia diagnosis is looked at from numerous psychological perspectives, although no one theory fully encapsulates the issue. Humanistic and existential theories tend to most closely pull together ethical and practice perspectives.

Lastly, approaches to managing dementia are discussed in the hopes of identifying what proactive measures have been taken in other Canadian provinces. This is also a discussion of the approach British Columbia has adopted, the possible inclusion of psychologists as a part of the funded health care approach as well as what further needs exist.

Disclosure Practices

Dementia disclosure practices by primary care physicians vary. Those who oppose disclosure cite concern for the welfare of the patient. Researchers Rohde, Peskind, and Raskind (1995) note two suicides following the disclosure of a dementia diagnosis. Other studies are equally concerned about the more common occurrence of depression as a result of disclosure (Rice & Warner, 1994; Smith and Beattie, 2001). Others contend it is also the patients right to not know their diagnosis (Downs, 1999).

Others oppose disclosure of diagnosis for reasons external to the patient. For example, some physicians feel they have little to offer a patient (Wolff, Woods & Reid, 1995), as there are few treatments and no cure. Similarly, many physicians see disclosure as futile where impaired cognitive ability limits understanding of the disease. It is also difficult to provide an accurate prognosis (Molloy & Caldwell, 1998).

Another external factor is the request of a caregiver or family member who asks the physician not to disclose the diagnosis (Kirby & Maguire, 1998). In a 1994 survey of British Columbia Family physicians, Bell-Irving, Donnelly and Berkowitz found that 86% of physicians agreed with the following statement: “although people differ in their ability to accept the diagnosis, in most cases they should be told what the diagnosis is, and what the future may hold”. Only 73% of caregivers surveyed agreed with the same statement (personal communication). Smith and Beattie found some family members requested the patient not be included when the diagnosis was reviewed in a recent British Columbia Study (2001). The above-noted studies reflected the commonly protective attitude of the family members and caregivers toward the patient (Rice& Warner, 1994).

This sentiment was confirmed by a 1996 study by Maguire, Kirby, Coen, Coakley, Lawlor and O'Neill, showing 83% of family members said they would want a dementia diagnosis withheld from their relative. Yet, when asked if they themselves would like to be told their diagnosis, 71% said yes. Even among respondents, a certain inconsistency appeared, as the issue of disclosure is complex.

Those in favour of disclosure root their arguments repeatedly in the autonomy of the individual. This ethical principle is a primary value held by the World Medical Health Association (2002) in their Charter of Medical Profession (accessed from http://www.crp.org/library/ethics/geneva on April, 2004). The proponents of disclosure highlight the right of patients to know and to make decisions about their future. Choices about advance directives, power of attorney, and treatment and research opportunities can only become available once a diagnosis has been provided. The Canadian Consensus Conference on dementia (Canadian Medical Association 1999) holds this value in relation to dementia disclosure, representing it as the appropriate ethical choice (Canadian Medical Association 1999, S7). Smith and Beattie (2001) conclude disclosure of diagnosis is generally beneficial, but people require some assistance with interpretation of the information given.

Other researchers agree that information, resources and treatments are opportunities lost without disclosure. Iliffe, Walters and Rait note Levin's research findings: "Early diagnosis is also important because it allows for individuals and carers [sic] to be informed, and to be introduced to appropriate agencies and support networks which can relieve the disabling psychological distress that carers[sic] can experience (as cited by Iliffe, Walters & Rait, 2000, p. 286).

Yet others in favour of disclosing a diagnosis recognize the advances of pharmaceutical treatments that can delay, although temporarily, the progression of the symptoms and provide a delay of six months and in some cases longer (Lanctot, Herrmann, Yau, Khan, Liu, et al., 2003).

While the debate concerning disclosure to patients lacks consensus, there is much more agreement about caregivers' access to the same information. One United Kingdom study by Rice and Warner (1994) noted there was a significant difference between the practice of disclosing a prognosis and diagnosis to a caregiver as opposed to the patient. Almost 100% of caregivers were given the patient's diagnosis, compared to 40% (mild diagnosis) of the respondents who answered "almost always tell", 15% (moderate diagnosis) of the respondents who answered "almost always tell" and 7% (severe diagnosis) of the respondents who answered "almost always tell". Subsequently, Fortinsky, Leighton,and Wasson (1995) reported 53% of primary care physicians would disclose a diagnosis of mild dementia and 55% moderate dementia to a patient. They also noted 90% of respondents indicated they would disclose the diagnosis to a caregiver regardless of the severity of the disease. Even more recently, in 2001, Rae, McIntosh, and Colles looked at the same issue and found 70% of G.P.'s disclosed a diagnosis to patients, while 99% disclosed to caregivers. Researchers of disclosure practices among primary care physicians consistently find more frequent disclosure to caregivers than to patients themselves.

Primary care physicians' choice to disclose to caregivers more than patients alludes to a decision-making process which uses some rationale about their policy in disclosure practices. This is accounted for in one line of questions asked by Dr. Oken (1961) in his study of physician's disclosure practices with cancer patients. Dr. Oken surveyed 219 physicians at a teaching hospital in Chicago. He examined, among other factors, the following: (a) factors involved in disclosure with a particular patient, (b) the sources from which the policy had been acquired, (c) the role of personal emotional factors and (d) personal choice. Dr. Oken found

> Although clinical experience was cited by three-quarters as the major policy determinant, the data bear no relation to experience or age. Instead inconsistencies, opinionatedness, and resistance to change and to research were found which indicated emotion-laden "a priori" personal judgments as real determinants. Feared reactions to telling (e.g. suicide) could rarely be substantiated, equally undocumented assumptions were give and justification for telling. Underlying were feelings of pessimism and futility about cancer (p. 86).

These conclusions have been cited to draw attention to the similarities between cancer and dementia in much of the previously noted research. The cancer studies have influenced the hypotheses for dementia disclosure practices in this study.

Drickamer and Lachs (1992) criticize the common comparison between cancer and dementia; pointing out the notable difference in capacity for understanding between dementia patients and cancer patients. Cancer patients are much more likely to retain the ability to process diagnostic information throughout the course of the disease. So, while many studies have looked at the similarities between influences similar to cancer and dementia diagnosis practice, not all research supports the comparison. With that said, many characteristics are similar and the factors that have influenced disclosure in cancer (Novack, Plumer, Smith, Ochitill, Morrow & Bennett,1979) are recognized as influential to disclosure practices with dementia patients.

The age of the physician has been recognized as a factor in disclosure practice.

One study by Fortinsky, et al. (1995) concluded that physicians in practice five years or less were more likely to disclose to the patient. Another study by Downs, Cook, Rae, and Collins (2000) confirmed these results when they concluded younger physicians disclosed dementia more often.

Training is assumed to be an important factor in how physicians decide upon their policy of dementia disclosure. Dr. Martha Donnelly, Director of the Division of Community Geriatrics Department of Family Practice and Director of the Division of Geriatric Psychiatry, Department of Psychiatry, University of British Columbia advised students could be exposed to dementia disclosure training in clerkship, family practice residency, continuing medical education or through personal interest i.e. reading (personal communication). Angela Towle, Associate Dean of Curriculum said medical curriculum regarding disclosure the University of British Columbia may be addressed in the context of ethics training (personal communication). The current curriculum design means a medical student could graduate without any specific training in disclosure of dementia diagnosis.

Vassilas and Donaldson (1998) found the three most important factors influencing a physician’s decision to disclose were diagnostic certainty, patient’s request for a diagnosis and the emotional capacity of the patient. Johnson, Bouman,and Pinner, (2000) concluded insight of patients, desire to be told the diagnosis, stage of the disease and diagnostic certainty were the most important factors influencing their decision to disclose a dementia diagnosis. There are clearly similarities in the factors to influence disclosure practices with cancer and dementia patients.

The factor that has not been discussed in the dementia literature is the legitimacy of physicians using personal experience to influence their disclosure practices. 'A priori' knowledge is noted in both Oken's (1961) and Novak's (1979) studies on cancer disclosure practices. Oken concluded in his original study that physician's disclosure policies were based on "...a priori personal judgements....", and not on clinical experience, as was cited by three quarter of respondents (p.86). Novak’s (1979) follow up study concluded that while there was a distinct and significant shift in the practices of physicians to disclose to cancer patients, their reasons for doing so remained the same. Practice was based on physicians’ individual values.

These authors criticize the legitimacy of 'a priori' knowledge in cancer disclosure practices. They claim they found a difference between the perception of the physician's policy on disclosure and the reality of their attitudes towards it. Yet, there is no disagreement that disclosure is largely an ethical issue, and as such, requires some rational thinking in considering any such decision. As mentioned earlier, the Canadian Consensus Conference on Dementia (Canadian Medical Association 1999) noted that while disclosure was the appropriate ethical decision, each situation needed to be considered individually (S7). So how do personal values and the ability to make ethical decisions complement one another, and to what degree?

This discourse about knowledge has been debated by some of history’s greatest minds. Rene Descartes, the sixteen century French philosopher, believed the essential source of knowledge was based in more than observation and that some knowledge existed 'a priori', or independent of, experience or science (Gould, 1985). It was in the eighteenth century that Immanuel Kant attempted to reconcile these two views (Gould, 1985). Kant felt these parts of knowledge, rationale, and empiricism were intertwined with one another in so far as judgment is dependent on experience and experience is more flavourful with each person's sense of meaning or judgment of it (Gould p. 259).

Therefore, a disclosure practice based on a complement of scientific data and a person’s view of what makes the data meaningful or ethical provides for a greater sense of knowledge and practice.

Ethical Decision Making

Wulff offers a structure of ethical reasoning in his book called *Rational Diagnosis and Treatment: An Introduction to Clinical Decision-Making* (1981).

He goes on to say that ethical reasoning requires physicians to balance three positions: (a) what is most useful for their patient at that time, (b) what is most useful for the patient's general wellbeing if each physician adopted the same course of practice, and (c) what is most useful for the future patient and profession as a whole. In doing so, the physician considers the outcomes from each perspective. It is understandable that a physician could be challenged by dementia disclosure when the consequences of a decision focused upon principles of "do no harm" result in a different outcome than a decision based on "patient autonomy".

Medical associations exist to support physicians and foster integrated medical practice. One of the greatest ongoing challenges for physicians is how to balance increasing demands with changing resources, new diseases, and new treatments. Physicians need to prioritize their responsibilities, ensuring each patient is cared for adequately.

I suggest that the focus of applied ethics has shifted with changing circumstances over time. While ethical principles are usually considered in the context of daily practice, the introduction of diseases such as SARS have shown us how physicians and administrators prioritize competing ethical principles in their attempts to manage healthcare in the larger sense. For example, if Canadian officials were unable to contain the spread of SARS, many additional resources would have been pulled from other areas of healthcare to meet the larger communities' needs over the needs of the individual. The prioritization of service and resources to address the needs of SARS patients and the larger community was relatively short in comparison with other shifts that have occurred over greater periods of time.

The ethical principle of patient autonomy has, over many years become a priority in healthcare. Physicians in the 1960's were considered scientists and their approach to patient care was secondary. The significant shift in cancer disclosure practices is an example of how practice can change, despite unchanging ethical principles. Humanistic dementia disclosure practices have lagged behind those of cancer. However, as noted in the research, it has now has become a priority.

While much attention has been given to dementia disclosure, I believe few studies have assessed practice from a purely ethical perspective. It seems clear that ethical decision-making is at the root of the factors influencing practice in cancer and dementia studies alike, and deserves further research. Perhaps additional studies can further clarify the complex issues in disclosure research.

It is clear that the debate about dementia disclosure practices remains unresolved. Despite the ongoing controversy about which practice is best, which factors are most influential, and whose interests should be considered first: the decision of primary care physicians to disclose or not appear to be motivated by a common effort to be ethical, and to consider the quality of life of people with dementia and their families.

Conceptual Models

The psychological models presented in this section were chosen because of what they contribute to our understanding of the dementia patient. The underlying assumption of all the theories presented is that people continue to develop and are motivated to improve regardless of their stage of life, circumstances, or illness. While some people with milder forms of the disease have less obvious impairments, all patients need to be seen as people first.

Human development theories are based in assumptions of growth and maturation. Even in later stages of life, most people are able to learn even if the rate of growth decreases. This growth is compromised to varying degrees for patients with dementia. Even so, each person experiences impairments in different ways. It cannot be assumed that all growth stops for dementia patients, at least until the final stage of the disease.

It is important to consider people with dementia as a person first: a person with limitations and on whom the effects of their environment may have either a positive or negative impact. Holmes and Rahe (http://www.covenanthealth.com/aboutus/pbh/pbh-lifechange.cfm) identified common stressful life events that impact healthy functioning throughout life. Death of a spouse, death of a close family member and personal injury or illness is listed within the top five most stressful events. At an older age people, including many with dementia, often experience such stressors. These authors indicate personal resources such as coping ability, sense of personal coherence and social competence all mitigate stressful experiences. While people with dementia may experience impairments in their personal resources, a humanistic approach would support creating an environment where life is predictable and simplified, creating meaningful social environments and exposing people to meaningful experiences such as religion.

Erik Erikson’s developmental theory covering the lifespan is divided into eight stages to be mastered consecutive (Savimaki & Stenbock-Hult , 2000). The underlying premise is that development is a social process and is available through interaction with others. The last life stage noted is called ‘Late Adult’, and the challenge at this stage is to develop integrity, or find oneself in despair. Erikson identifies that a person has successfully resolved this stage of life when they develop a sense of wisdom- informed a detached concern with life itself in the face of death itself‘(as cited by Savimaki & Stenbock-Hult, 2000).

The contribution for application to the issue of dementia disclosure is to identify the continuum of experiences a person may have in the late stage of their life span. The person with dementia may experience loss of integrity if success has been achieved and then compromised. The greater contribution may be in the assumption that development is a social process and that people with dementia, caregivers and professionals contribute to the degree of the experience constructively or negatively.

Carl Rogers agreed that a person’s environment was influential to their well-being (Kirschenbaum, 2004). More so, Rogers, one of the first “humanists”, was confident that people’s view of the world was their true perception, that people moved towards maturation and growth beyond adjustment, and that human characteristics such as freedom to choose, individual will, feelings and goals were central qualities of personhood (Kirschenbaum, 2004). These characteristics of personhood also exist for people with dementia. Communicating the worth of the person with dementia, through positive regard and unconditional acceptance despite limitations in health or cognitive abilities, was possible through the therapeutic relationship. As such, physicians have a therapeutic role to play in their approach to disclosure.

This person-centred approach was championed and specifically applied to dementia by the late social psychologist Tom Kitwood, who felt that a purely medical response to dementia was insufficient (Adams, 1996). Kitwood felt psychological factors contributed to the development of dementia. “Kitwood argues the extent of a person’s dementia is not only dependent upon the extent of the brain damage but upon various factors including personality, biography, neurological impairment and social psychology” (Adams, 1996 p. 949).

Based on observations and information provided by caregivers, Kitwood felt crucial life events such as rejection or disgrace, retirement, major physical illness could exacerbate the development of dementia (Adams, 1996). Kitwood went even further, acknowledging the contributions of each member of society in so far as people discriminate and treat people with disabilities differently. Kitwood names the accepted characterization of dementia as the ‘existing paradigm’. He says there is a moral vacuum that exists in the understanding of dementia and the practices of primary care. His criticism is that in accepting the medical presentation of dementia, it excludes the consideration of psychosocial and sociological approaches to patients with dementia.

A critical approach highlights the power differential between the physician and the patient and focuses on the absence of a cure and the limits of psychosocial approaches. Kitwood’s criticism of patriarchal systems marries with the humanistic values of person-centred theory (Adams, 1996). In fact, Wulff (1981) even acknowledges in his discussion of rational decision making that the patriarchal approach is outdated .

Kitwood (Adams, 1996) draws the communities’ attention beyond medical explanations to reframe dementia care. In doing so, he criticizes the existing approaches to dementia care and more importantly contributes a new way to see dementia. He presents it as an integrated and malleable condition that affects, and is the responsibility of, all citizens, caregivers, and professionals. The social interaction premise underlying Erikson’s theory is relevant and applied here in Kitwood’s approach.

Specifically, Kitwood supports values which focus attention to the person and notes that people with dementia do not have a voice in dementia research (Adams, 1996). Woods (1999) also notes that patients are underrepresented in the research. This theme continues to be documented in 2004 as Bamford, Lamond, Eccles, Robinson, and May, et al. in their systematic review of the literature on disclosure practices notes the absence of studies representing the voice of dementia patients.

Policy Implications

The Canadian Alzheimer's Society amended their ethical guidelines regarding disclosure of dementia diagnoses, in April, 2003, calling for physicians and others to disclose diagnoses to patients in an accurate, consistent, and compassionate manner (Alzheimers Society, 2003). Policy statements like these have become more common around the world, as studies continue to identify irregular disclosure practices by primary care physicians (Bamford et al., 2004). Similar guidelines are being adopted by associations and government bodies as recognition of the aging population and the increasing incidents of dementia are identified. In many cases, dementia strategies have been developed in order to establish a process for managing the impact on communities. In Canada, only two provinces are without a dementia strategies; British Columbia is one of them (BCMA, 2004).

Most provinces have established a formal process to consult with those involved in and affected by dementia care. Physicians, patients, Alzheimer Associations, medical associations, researchers, caregivers and long term care administrators, among others, have been brought together to establish the needs and requirements essential to an effective dementia strategy. Each process has been somewhat different and has resulted in a dementia strategy that responds to the specific needs of individuals in each province.

Similar to British Columbia, Ontario has a large urban population, concentrated in the southern part of the province. It also is home to many small communities who have varying needs. The Ontario Strategy for Alzheimer Disease and Related Dementias was presented in 1999 and was the first dementia strategy in Canada (Government of Ontario, 2003). The government of Ontario committed 68.4 million dollars over five years to address the communities' needs relating to dementia. This strategy consists of a ten point action plan addressing issues of staff and volunteer training, short- and long-term care, public education, access to specialists, supports for caregivers and patients and ongoing research.

Alberta shares the border with British Columbia and as well as some similar geographical and regional issues. In 2000, the Alberta Government released their more generic health strategy called Strategic Directions and Future Actions: Healthy Aging and Continuing Care in Alberta (Government of Alberta). This document consists of a nine point plan to provide care to the elderly. One of the nine points specifically addresses dementia care. The report addresses "…education and training, support for caregivers, development of supportive housing models and residential centres designed for dementia clients, and supports for long term care centre to meet the needs of residents with sever Alzheimer's Disease and dementia" (p. 9).

While provincial governments are attempting to address chronic illnesses such as dementia, the larger policy issues have examined the current medical system and its viability in its present state in Canada. In a recent edition of Canadian Psychology (August 2004 p. 239-243), Roy Romonow, former premier of Saskatchewan and former chair of the Commission on the Future or Health Care in Canada along with Gregory Marchildon, Former Executive Director of the commission on the Future of Health Care in Canada, respond to three articles written about the transitions of the health care system and the possible role of psychologists. Romonow and Marchildon acknowledge that the system designed in the 1960’s does not meet the current needs expressed by Canadians and could be improved with an expanded role of psychologists in addressing needs of people with mental and physical health issues.

> Without a doubt, the legacy of Medicare is associated with some important institutional rigidity, including the physician-centred nature of the system. We agree with Arnett et al. that, with a broadening of their training and education, psychologists can play a vital role in transforming primary health care, illness prevention and health promotion, and the treatment modalities for chronic mental and physical diseases (p.239).

The dementia care initiatives are moving in the same direction as those suggested by Romonow and Marchildon, in that they maintain the best of current car practices while cultivating a more patient-centred approach.

While this study is focused on the role of primary care physicians and their dementia disclosure practices, there may be a time when administering care for people with dementia and their caregivers will be achieved through partnership with non-medical professionals.

This partnership with psychologists and others may be especially helpful to people who are receiving a diagnosis of dementia because of the multifaceted nature of the disease.

While some experts in health psychology are waiting at the door hoping to contribute as partners with primary care physicians, the present structure of health care, excludes psychologists as publicly- funded professionals recognizing counselling as a privately accessed resource. The existing physician-centred approach that has been maintained by other provinces in their dementia strategies is also the basis of British Columbia government as they work towards their own dementia strategy.

The effective implementation of a dementia strategy in BC requires information on current practices and needs to guide planning and innovation. Disclosure is an example of an area where concerns addressing patient-centred approaches can be workable, sustainable and affordable in the evolution of health care reform.

Research Focus and Tentative Hypotheses

To date, there are few designated dementia resources in British Columbia, despite the increasing numbers of patients who require specific care. The British Columbia Medical Association (BCMA) indicates the fastest growing part of B.C.'s population are those 85 years and older (Dementia Strategy Report, 2004 p. 5). This is notable, as almost one third of people in this age group have dementia. Given that systematic research into physician practices having to do with the disclosure of dementia diagnoses is quite rare, the establishment of basic descriptions of current practices are very helpful.

Beginning to define best practices in dementia diagnosis called for documentation of what practices exist in dementia care in B.C. The formulations of preliminary hypotheses were based primarily on conceptual and policy principles because empirical evidence is largely lacking. A survey of primary care physicians in BC was conducted to establish some such beginnings. Exploration of the survey data will focus on four main areas: what are B.C. physicians current practices of disclosure of dementia diagnoses, the perceived influences on BC physician's practices of disclosure, to whom the doctors reveal the diagnoses, and the impact of the traditional medical training system. The analysis of the survey responses will emphasize descriptive strategies to examine the results. This is based on previous literature that has taken a similar approach (see appendix A for a listing of survey questions).

More specifically,

1. I expect to find, in the survey results (question 18) that the modal physician’s practice is to disclose a diagnosis to the patient in over 75% of their cases.
2. I expect to find, in the survey results (questions 5 & 18), the longer the physician has been in practice the less likely they are to disclose a diagnosis to a patient.
3. I expect to find, in the survey results (question 19), a higher proportion of family members are told, compared to the proportion of patients who are told.
4. I expect to find, in the survey results (question 20), that when ranked, clinical experience, CME and non-professional experience have influenced their typical approach to disclosure over medical school training and residency.
5. I expect to find, in the survey results (questions 5 & 12), that physicians in practice 10 years or less and trained in the UK will disclose more often than physicians from other jurisdictions.
6. I expect to find, in the survey results (questions 18 & 21), that certainty of diagnosis of dementia, cognitive status of the patient/stage of the disease, request of a caregiver and personal experience will be more influential than the remainder of the noted factors.
7. I expect to find in the survey results (questions 17 & 18), non-disclosing physicians will report lower confidence in their skills for dementia diagnoses when compared with disclosing physicians.
8. I expect to find in the survey results (questions 18 & 21) Non-disclosing physicians will report less importance for all factors influencing disclosure when compared with

disclosing physicians.

CHAPTER 3: METHOD

Participants

The participants were a randomly selected from the 4500 primary care physicians who are members of the British Columbia Medical Association. Over 95% of physicians in B.C are members of the association. Almost 25%, or 1000, of primary care physicians were mailed surveys. Three hundred and thirty-five responses were mailed back. Twenty-three were scratched because surveys were either returned blank or were returned from members who functioned in another capacity such as an administrator. Three hundred and twelve responses were used for the survey. Three questions had slightly over 5 % of the data missing. In two instances the question asked respondents to evaluate their training in residency. One question, regarding general practice, had 38% of the data missing. The remainder of questions was answered by the respondents.

Over 46% of physicians surveyed work in large Urban (over 75,000) settings in British Columbia. Over 65% of physicians surveyed care for 1000 or more patients. Over 54% of physicians surveyed work in group practice. Nearly 35% of physicians surveyed care for 1-10 patients with dementia. Over 75% of respondents attended between 1-10 hours of dementia related CME training in the past five years. Approximately 80% of physicians surveyed completed their residency in Canada and over half of those in British Columbia. Gender and age were not requested of the respondents.

Metro, rural and urban physicians’ opinions about diagnostic disclosure were requested, in addition to general information about their practices when dealing with dementia patients (Appendix A). Physicians were randomly and anonymously selected from the BCMA database of physicians. The identity of survey respondents were kept confidential and each survey was assigned a code number for analysis purposes.

As an incentive, all respondents were offered a chance at winning one of three, $100 Future Shop gift certificates. While this research focused on the issue of disclosure practices of primary care physicians the broader information gathered was used by the BCMA in an in-house report (British Columbia Medical Association, 2004).

Analysis

The results were analyzed with a variety of statistical procedures including: Univariate Descriptive statistics (including frequency tables and percentages), Bivariate statistics (cross tabulations, Chi square and t-tests), and Repeated Measures and Manova calculations.

CHAPTER 4: RESULTS

Preliminary/Descriptive Analyses

Analysis of the survey data is focused on four main areas: Firstly to describe the practices of British Columbia primary care physicians in disclosing dementia diagnoses, secondly, to identify correlates of physician proclivities to disclose a diagnosis, thirdly, to describe physician's practices surrounding dementia diagnosis and finally, to summarize physician viewpoints on dementia-related training.

Hypotheses

In the first hypothesis, I expected to find that the typical physician's practice is to disclose a diagnosis to the patient in over 75% of their cases (question 18) in appendix A. The results support this hypothesis, $\chi^2(3) = 153.5$, $p < .001$, $N = 281$. The majority of BC physicians (59%) report disclosing a diagnosis to patients 75% - 100% of the time, and this proportion shows a clear, statistically significant preference for physicians to disclose frequently. The responses also show that 41% of physicians disclose a diagnosis less than 75% of the time.

According to hypothesis two, I expected to find the longer the physician has been in practice the less likely they are to disclose a diagnosis to a patient (questions 5 & 18). The analysis was done with a Chi-Square-two way tables and the results supported this hypothesis, $\chi^2(3) = 1064$, $p < .005$, $N = 281$. The physicians who have been practicing more than 20 years tended to disclose dementia diagnosis less frequently, while physicians in practice less than 20 years tended to disclose dementia more frequently.

In relation to hypothesis three, I expected to find, in the survey results a higher proportion of family members are told in comparison to the proportion of patients who are told (questions 18 & 19). The analysis was a Chi-Square goodness of fit. $X^2 = 99.0$

(1), $p < .001$, $N = 280$ and the results supported the hypothesis. Physicians are more likely to disclose to family members than to patients.

In the fourth hypothesis, I expected to find, in the survey results, that rankings of the importance of experiences and training in shaping dementia diagnosis practices would be associated with frequency of disclosure to patients (questions 18 & 20). Clinical experience, continuing medical education (CME) and non-professional experience have influenced physician's typical approach to disclosure over medical school training and residency.

Over 50% of physicians rated clinical experience as the most important training experience influencing their policies towards disclosure. Approximately 30% of physicians rated continuing medical education as the most important training experience influencing their policies towards disclosure. A notable result is the association of non-professional experience with disclosure to a patient. ρ (268) = .23, $p < .001$, $N = 270$. There is a significant correlation between frequency of physicians' disclosure to patients and the rank of non-professional experience among important influences on disclosure practices. There are a relatively high number of doctors who made fewer disclosures to patients who gave high rankings to the importance of non-professional experience. In these instances the primary care physicians gave a higher priority to non- professional experience as a basis on which they decided to disclose dementia diagnoses less often. High rankings of non-professional experience are associated with disclosing to patients less often.

Another significant result ρ (273) =.123, $p < .042$, $N = 270$ on the issue of medical school. Physicians who ranked medical school as important tended to disclose less often. Although not significant, a trend did appear for physicians who said medical school was less important in their decision to disclose a dementia diagnosis to their patient and more important in their decision to disclose a diagnosis to the family.

Hypothesis five: I expected to find that physicians in practice 10 years or less and those physicians trained in the United Kingdom would disclose more often than physicians from other jurisdictions (questions 5, 12 & 18). The results confirmed that those in practice fewer than 10 years do disclose more often. T-test = 2.2478, $df = 89.948$, sig (2 tailed) = .015. In regards to the disclosure practices of U.K. physicians, the results were significant. In fact there was a significant result with the Mann Whitney non-parametric analysis. $X^2 = 2326$, $p <.013$, $N = 305$. Contrary to hypothesis, these results indicated that those who were trained in the UK medical schools were less likely to disclose a dementia diagnosis to patients.

In hypothesis six, I expected to find in the survey results that four factors; certainty of the diagnosis, cognitive status of the patient, the request of the caregiver and personal experience would be more influential to a physician than insight and emotional status of the patient, the request of a patient and medical treatment planning (question 21). There was a significant result using repeated measures ANOVA. $F = 47.6$, $df = 5.1$, ή = .147, $p < .001$. The results were significant showing that the physicians, overall, rated the different factors at different levels (see figure 1).

The results identified two clusters of factors. The majority of the factors, five, were found to be highly influential while two factors were seen to be less influential by physicians. Certainty of diagnosis, cognitive status of the patient, and the request of the caregiver were factors found in the highly influential cluster as predicted in the hypothesis. Personal experience was found in the cluster of factors with low influence and this result did not support my hypothesis. In addition, insight and emotional status of the patient and the request of the patient were found to be highly influential factors. Medical treatment planning was found as having low influence on physician's decisions to disclose a diagnosis to the patient.

According to hypothesis seven, I expected to find in the survey results, those physicians less likely to disclose will also report lower confidence for each skill than physicians who are more likely to disclose (questions 17 & 18). There was a significant result for a mixed design ANOVA. The interaction between the level of disclosure and the kind of clinical skills required to care for dementia patients shows that low disclosure physicians report the least amount of confidence in their communication of dementia diagnosis with patients compared to high disclosure physicians. There is a mean difference between some of the confidence levels reported by physicians. The results clearly show that physicians feel a difference in confidence among various skills used with dementia patients (see figure 2). Those who disclose less often tend to have less confidence about disclosure of dementia diagnosis. $F = 3.798$, df (5)(265), $p < .002$, $\text{eta}^2 = .067$.

In the eight hypothesis, I expected to find in the survey results, those non-disclosing physicians will report less importance for all factors influencing disclosure when compared with disclosing physicians (questions 18 & 21). There is a significant result using a mixed design ANOVA. The mean difference between the level of importance given to various factors by physicians was significant, as noted under hypothesis 6. There was no overall difference in ratings for the factors influencing disclosure to patients between low disclosure physicians and high disclosure physicians. However, an interaction between the level of disclosure and the importance of factors affecting disclosure identifies that the hypothesis was supported only for the factors of medical treatment planning and insight and emotional stability of the patient $F = 2.846$ *df* (6)(255), $p < .001$, $\text{eta}^2 = .063$.

Summary

Three hundred and twelve primary care physicians answered a survey about dementia practices in BC. The information reported speaks to how physicians communicate a diagnosis of dementia to patients and their family members and the influences of various factors. We now can say the majority of BC physicians (59%) report disclosing a diagnosis to patients 75% - 100% of the time. This proportion shows a clear, statistically significant preference for physicians to disclose frequently however it also means that 41% of physicians disclose a diagnosis less than 75% of the time.

Physicians who have been practicing more than 20 years tend to disclose dementia diagnosis less frequently than physicians in practice less than 20 years. Physicians are more likely to disclose a diagnosis of dementia to family members than to patients.

Clinical experience, continuing medical education (CME), non-professional experience and medical school training influenced physician’s typical approach to disclosure over residency. It is notable that a relatively high number of doctors who made fewer disclosures to patients also gave high rankings to the importance of non-professional experience. In these instances the primary care physicians gave a higher priority to non- professional experience as a basis on which they decided to disclose dementia diagnoses less often. A high ranking of non-professional experience is associated with disclosing to patients less often. Physicians who ranked medical school as important also tended to disclose less often.

One of the original hypotheses predicted that those physicians trained in the United Kingdom would disclose a diagnosis of dementia more often. The data shows a significant result but contrary to the hypothesis. The results indicated that those who were trained in the UK medical system were less likely to disclose a dementia diagnosis to patients.

Survey question 18, Appendix A, asked physicians to evaluate the various factors and how influential they were in their practice of disclosure. Certainty of diagnosis, cognitive status of the patient, and the request of the caregiver were factors found in the highly influential cluster as predicted in the hypothesis. Personal experience was found in the cluster of factors with low influence and this result did not support the original hypothesis. In addition, insight and emotional status of the patient and the request of the patient were found to be highly influential factors. Medical treatment planning was found as having low influence on a physician's decisions to disclose a diagnosis to the patient.

Physicians were asked to evaluate how confident they felt regarding their skills with people with dementia. The data clearly indicates that physicians feel a difference in confidence among various skills used with dementia patients. Those who disclose less often tend to have less confidence about communicating the diagnosis of dementia to patients.

While this study does not provide an exhaustive analysis of dementia disclosure practices, it does provide an ample description of how B.C. physicians communicate a dementia diagnosis and what is influential in their decision to do so. This study establishes an important benchmark as the issues related to dementia care for practitioners and the community are under increased examination.

CHAPTER 5: DISCUSSION

Three hundred and twelve primary care physicians currently working in BC were surveyed about their practices with people with dementia. Of particular interest are practices surrounding the disclosure of diagnosis to patients and their families. The typical physician practiced in a metro-urban centre, worked for over ten years, was trained in Canada, and had some patients who were diagnosed with dementia. The sample provided a fair representation of the nearly 4500 primary care physicians in British Columbia.

Hypotheses

The results suggest the following information about the practices of physicians when diagnosing a patient with dementia. Fifty-nine percent of primary care physicians in British Columbia disclose a dementia diagnosis to patients in over seventy-five percent of their cases. While this result suggests that most patients are given a diagnosis, it also indicates that forty-one percent of physicians provide a diagnosis to their patients less than seventy-five percent of the time. This means that there is a need to analyze in greater detail which patients are receiving a diagnosis and why. This statistic about disclosure gives us a picture of current practice, and sets the foundation for discussion about best practice guidelines. Establishment of practice guidelines can be useful in standardizing service, for setting a threshold for under disclosure and for identifying training needs.

The results for the second hypothesis show that those physicians in practice less than 20 years have received more training about dementia-related issues than in the previous twenty years. Possible explanations could include: the profile of the disease has increased significantly in this time frame, more specific training regarding disclosures has occurred, or there may be an increase in those with specialized training, such as certified family physicians.

As is well documented in the literature, physicians disclose a dementia diagnosis to caregivers more often than they do to patients. This, too, is the case in British Columbia. The results of the fourth hypothesis confirmed expectations in that physicians indicated clinical experience and continuing medical education (CME) were the most highly ranked influences in their practice of the disclosure of dementia diagnosis to patients. The notable results suggested that while only slightly significant there was a group of physicians who disclosed less often and ranked non-professionals experience as influential of their practices regarding dementia disclosure. High rankings of non-professional experience are associated with disclosing to patients less often. While this is not a causal relationship, further investigation may be worthwhile to clarify if non-professionals experience is exclusively related to physicians who do not disclose. Interestingly, physicians who ranked medical school as influential also tended to disclose less often.

The results of the fifth hypothesis show that physicians in practice less than 10 years disclose more frequently than those in practice over 10 years. It appears that fewer years in practice are associated with more frequent disclosure practice to patients. While developments in training may account for increased disclosure practice so too might the ethical focus on autonomy of the patient.

The second part of the fifth hypothesis predicted physicians trained in the United Kingdom would disclose more often than other physicians. The hypothesis stemmed from the large concentration of research done in the area of dementia disclosure in the United Kingdom. The results were significant, but in the opposite direction. It appears physicians trained in the United Kingdom are less likely than those trained in Canada to disclose dementia diagnoses. Further investigation may reveal this group of physicians were trained in the past ten, twenty years or trained more than twenty years ago.

The sixth hypothesis examined at how the six noted factors influenced physician's practice of disclosure. The results showed that not all factors influenced practices equally. In fact, two clusters appeared; certainty of diagnosis, cognitive status of the patient, and the request of the caregiver. These were found as highly influential on the physician. Personal experience and medical treatment planning were not found to be significant. Physicians who felt confident of the diagnosis, who felt the patient could understand the diagnosis or who felt the caregiver would benefit were more likely to disclose.

It appears this choice to disclose is largely dependent upon ethical principles of beneficence and nonmalificence. Where the physician felt they were certain of the diagnosis and the patient would benefit, and it was their duty to disclose, and a diagnosis was given. This is an example of how a physician may balance ethical principles integrating knowledge, expertise and focusing on each person with unique circumstances.

The results of the seventh hypothesis were interesting in that the interaction between the level of disclosure and the kind of clinical skills required to care for people with dementia shows that physicians feel a different level of confidence among various skills used with people with dementia. Specifically, low disclosure physicians report lower levels than high disclosure physicians in the area of communicating a diagnosis to the patient. There was much less of a difference in confidence between disclosing physicians and non-disclosing physicians regarding other noted skills.

Similarly, it was the interaction effect that best answers the query posed in hypothesis eight; do non-disclosing physicians report less importance for all factors influencing disclosure than disclosing physicians? The results show there is a difference between the levels of importance of various factors rated by all physicians. Disclosing and non-disclosing physicians showed the most consistent practice where there was diagnostic certainty, when a request for disclosure was made by the patient or the caregiver, and when influenced by their personal experience. Practice differed the most when physicians considered the status of the patient, the stage of the disease and issues surrounding medical planning. It may be that physicians feel they are required to use their expertise to determine if it is in the patient’s best interest to disclose a diagnosis. It is commonly understood among experts that people unable to understand their diagnosis and those who no longer have the capacity to make decisions about treatment are only confused by or burdened by a diagnosis. If this is true, then, determiners of the threshold at which diagnostic usefulness is lost become even more important for patients and early diagnosis should be give greater priority.

In summary, British Columbia primary care physicians have some similar practices regarding dementia disclosure yet there is inconsistent service provided to patients across the province. Exposure to up to date training, years in service and factors specific to patients all affect the practice of physicians. Ethical interpretation is also a contributing factor.

Future Research and Limitations

Although this study is similar to research conducted in other jurisdictions it adds to the literature by documenting the practices of physicians in British Columbia. However the study is somewhat limited because descriptive analyses do not allow for causal statements or absolute relationships. This study documents disclosure practices from self-report statistics of physicians. It does not document the perspectives of people with dementia confirming the reports made by physicians. The literature review notes that there is a need for more research to capture the opinions of people with dementia about their experience of diagnosis. There is also room for further research in examination of ethical decision making and how it affects physicians approach to disclosure of dementia.

The survey could have been improved by defining vocabulary such as disclosure and non-professional experience. Although the disclosure questions were queried in a section of the survey called “Disclosure of Dementia”, more distinction between diagnosis and disclosure could have improved clarity for the respondents. More clear information about the survey population, specifically regarding the make up of the primary care physicians would also have improved the project.

Policy Implications

The goal of this study has been to describe the practices of British Columbia primary care physicians and their approach to disclosure of dementia diagnoses. The literature and the results of this study are consistent and confirm that the dementia disclosure practices of physicians vary. The literature also speaks to the factors influencing disclosure to dementia patients and physician’s confidence around communicating a diagnosis. These elements differ between physicians who disclose and those who do not disclose. In documenting such distinctions there is a context to discuss the appropriateness of practice guidelines as it relates to dementia disclosure. There is also a context to review how changes to the health care system could be resourced.

Alzheimer societies around the world have agreed and established their positions on disclosure policies. The Canadian Alzheimer Society amended their ethical guidelines in April 2003 calling for physicians to disclose dementia diagnosis to patients. Such ethical statements are based in principles of patient autonomy and a person-centred approach to medical decision making and care.

Most provincial governments have recognized the need to address dementia-related issues beyond disclosure and have funded initiatives to plan for the care of people with dementia and their families. Physician education, resources and community infrastructure have all been recognized as essential elements of a strategy to manage the demands on resource as the population ages and the incidents of dementia increases. British Columbia has no dementia strategy to date but it is presently considering labeling it as a chronic disease, such as diabetes, which could largely improve the structure of health care service available to patients and their families.

Dementia disclosure practices and the growing issue of dementia care is one example of how a changing population requires an adaptive and efficient health care system. Issues of dementia were considered largely unmanageable when the basic structure of Medicare was established. Now, Canadian policy makers are trying to reform a system designed to address the needs of Canadians fifty years ago, to meet present needs.

As noted earlier, Roy Romanow, the former chair of the Commission on the Future of Health Care in Canada and Gregory Marchildon, the former executive director of the Commission on the future of Health care in Canada acknowledge that changes are required in order to meet the needs of Canadians (2004). They advocate recommitting the best elements of our present health care system and adopting innovative and efficient elements to enhance and improve health care in Canada.

Romanow (2004) acknowledges the physician centred nature of the system may need to change to allow other professionals, including psychologists, to improve patient care. For people with dementia and their families such an approach could be very valuable in assisting people with illness to emotionally manage their experience of hearing their diagnosis and follow up care. Psychologists, among others, have the expertise to assist people to integrate this information with the practical aspects of daily living. Disclosing to friends and family, planning for future, addressing long-standing personal issues, dealing with grief and assisting with coordinating other resources are some areas which are suitably addressed by a professional with mental health expertise. Physicians, psychologists and others can work together to ensure gaps in service are filled. Establishing partnerships is one way in which the larger health care system can provide a person-centred response to patients with dementia and their families.

Conclusion

The purpose of this study was to describe the practices of British Columbia primary care physicians and their approach to dementia disclosure. Specifically, it examined certain factors and the consistency of practice among physicians. The research achieved its goals in a number of ways. Firstly, this study provides a picture of the approach British Columbian primary care physicians take towards dementia disclosure to patients; it identifies the differences in confidence towards skills and influences of factors to disclosure practices. Secondly, this study has identified there are varied disclosure practices and suggests that practice guidelines may assist physicians to provide more consistent care to patients. This study also identifies the need for greater understanding on how theoretical assumptions and ethical principles are internalized by physicians and the influences of applied ethics on physician’s approaches to dementia disclosure to patients.

Lastly, in the larger area of social policy, this study notes the present controversy about health care reforms. From a person-centred perspective this study supports a move away from the central role of physicians to a team approach of care: a variety of professionals providing for patients physical, psychological and emotional health. This approach would support an environment where the psychological community could partner with physicians allowing all to focus on their respective areas of expertise. Dementia patients are an excellent example of a group of health care users who would benefit from a team management model of care. As governments struggle to achieve reforms that meet the needs of users and providers such paradigms should be seriously considered.

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APPENDIX A

Survey Questionnaire

th, 2003. **Please mail the response card separately.** Those who complete the survey will be eligible for a chance to win one of three $100 Future Shop Gift Certificates. Please direct any questions or comments regarding the survey to Mr. Robert Hulyk, Government Relations Manager, BCMA at 604 638-2883 or rhulyk@bcma.bc.ca.

6) About what percentage of your patient's are caregivers for someone with dementia?

a) 0-25 %

b) 26-50 %

c) 51-75 %

d) 76-100 %

e) Not Applicable

7) About what percentage of your patients are currently over the age of sixty-five?

a) 0-25 %

b) 26-50 %

c) 51-75 %

d) 75-100 %

e) Not Applicable

8) About what percentage of your patients are currently over the age of eighty-five?

a) 0-25 %

b) 26-50 %

c) 51-75 %

d) 75-100 %

e) Not Applicable

9) About what percentage of your current patients are diagnosed with dementia every year?

a) 0-5%

b) 6-10%

c) 11-15%

d) 16-20%

e) over 20%

f) Not Applicable

Due to the growing and aging population combined with the physician shortage in British Columbia, a great number of family practices are no longer accepting new patients. We are interested in exploring how physicians decide to accept new patients, particularly those with dementia.

10) Are you accepting new patients?

a) Yes

b) Yes, with some restrictions

c) No

d) Not Applicable

11) If you answered

15) About what percentage of your training, received at Medical School, was specifically oriented to dementia?

a) 0-25%

b) 26-50 %

c) 51-75 %

d) 76-100 %

e) I don’t know

16) About what percentage of your clinical experience, acquired during residency, was specifically oriented to dementia?

a) 0-25%

b) 26-50 %

c) 51-75 %

d) 76-100 %

e) I don’t know

17) Over the past five years how many hours of CME have you taken on dementia?

a) 0

b) 1 -10

c) 11-20

d) 21-30

e) 31-40

f) 41-50

g) 51 or more

18) Over the next five years how many hours of CME do you expect to acquire on dementia?

a) 0

b) 1 -10

c) 11-20

d) 21-30

e) 31-40

f) 41-50

g) more than 50

19) How confident do you feel with your skills in the following areas regarding dementia?

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21) On what do you base your typical approach to a dementia diagnosis (Rank these sources in importance from 1-5.

23) How long do you spend over various appointments, disclosing a diagnosis of dementia to a patient?

a) I never disclose

b) less than fifteen minutes

c) 16 to 30 minutes

d) 31-45 minutes

e) 46-60 minutes

f) over 60 minutes

24) How long do you spend over various appointments, disclosing a diagnosis of dementia to a caregiver?

f) I never disclose

g) less than fifteen minutes

h) 16 to 30 minutes

i) 31-45 minutes

j) 46-60 minutes

g) over 60 minutes

25) Please add any comments you feel are relevant regarding dementia diagnosis and/or treatment in British Columbia.

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BRITISH
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MEDICAL
ASSOCIATION

Dementia care survey

A survey undertaken by the BCMA Council on Health Promotion

September 2003

This should take no more than 15 minutes of your time to complete.

Please mail your survey by October 17th 2003 to ensure you are entered for the prize draw.

INSTRUCTIONS

1. **PLEASE COMPLETE AND RETURN THIS SURVEY AS SOON AS POSSIBLE by mail in the self-addressed stamped envelope provided**.
2. **Please also return the self-addressed, stamped response card separately**. We require the response card to ensure that we only follow up with those physicians who have not yet responded – and to enter your name for the prize draw.
3. **Please WRITE CLEARLY and note that the survey is DOUBLE-SIDED**.
4. You may encounter questions that are not directly relevant to your own practice circumstances. **Please mark the 'not applicable'** category in these instances.
5. In order to maintain the confidentiality of your responses, this survey cannot be linked with your name. **Thank you in advance for your time.**

If, on completion of the survey, you wish to include comments on pertinent issues that have not been mentioned, please write them out on a separate sheet and enclose with the completed survey.

Sincerely,

Dr. Heidi Oetter
Chair
BCMA Council on Health Promotion

- Please circle the most appropriate answer -

PRACTICE INFORMATION

1) Please estimate the size of your practice by unique patients:
   a) 500 or less
   b) 501-1,000
   c) 1001-1,500
   d) 1501-2,000
   e) More than 2,000

2) What style of practice do you work in?
   a) Solo
   b) Walk in clinic
   c) Group practice
   d) Hospital
   e) Other ___________________

3) If you work in an outpatient (community setting) is your care for patients primarily episodic or continuing?
   a) Primarily episodic
   b) Primarily continuing
   c) Equal mix of both
   d) Not applicable

4) What size community do you practice in?

a) Rural	population less than 25,000
b) Urban	25,001 – 75,000
c) Large Urban	75,001 +

5) How many years have you been in medical practice since graduation?
   a) 0-5 years
   b) 6-10 years
   c) 11-20 years
   d) 21-30 years
   e) More than 30 years

6) Please estimate what percentage of patients in your practice are currently over the age of sixty-five:
   a) 0-5 %
   b) 6-10 %
   c) 11-15 %
   d) 16-20 %
   e) More than 20%
   f) Not Applicable

7) Please estimate what percentage of patients in your practice are currently over the age of eighty-five:

  a) 0-5 %
  b) 6-10 %
  c) 11-15 %
  d) 16-20 %
  e) More than 20%
  f) Not Applicable

DEMENTIA IN YOUR PRACTICE

8) How many patients in your care have dementia?

  a) 0
  b) 1-10
  c) 11-20
  d) 21-30
  e) More than 30
  f) Not Applicable

9) How many new cases of dementia do you estimate you diagnose each year?

  a) 0-5
  b) 6-10
  c) 11-15
  d) 16-20
  e) More than 20
  f) Not Applicable

10) Are you accepting new patients?

  a) Yes
  b) Yes, with some restrictions
  c) No
  d) Not Applicable

11) If you answered "yes with restrictions" to question 10, would you accept a patient with dementia?

  a) Yes
  b) No
  c) Not Applicable

DEMENTIA RELATED MEDICAL TRAINING

We would like to ask you questions about your medical school training, clinical experience and continuing medical education (CME) as it relates to dementia.

12) Where did you receive your
    a) Medical Degree
        i) British Columbia
        ii) Other Canadian Province
        iii) United States
        iv) United Kingdom
        v) Other European Country
        vi) South Africa
        vii) Other_______________
    b) Post-Graduate (i.e. residency) training
        i) British Columbia
        ii) Other Canadian Provinces
        iii) United States
        iv) United Kingdom
        v) Other European Country
        vi) South Africa
        vii) Other_______________

13) Given your experience, do you believe the instruction you received in <u>medical school</u> in the area of dementia was adequate?
    a) Yes - Adequate
    b) Somewhat adequate
    c) Somewhat inadequate
    d) No - Inadequate

14) Given your experience, do you believe the instruction you received in <u>post-graduate training</u> in the area of dementia was adequate?
    a) Yes - Adequate
    b) Somewhat adequate
    c) Somewhat inadequate
    d) No - Inadequate

15) Over the past five years how many hours of CME have you taken related to dementia?

a) 0
b) 1 -10
c) 11-20
d) 21-30
e) More than 30

16) Over the next five years how many hours of CME do you expect to spend on dementia?

a) 0
b) 1 -10
c) 11-20
d) 21-30
e) More than 30

17) How confident do you feel with your skills in the following areas regarding dementia?

	Very Confident	Somewhat Confident	Somewhat Unconfident	Not at all Confident	Not Applicable
Initial diagnosis	1	2	3	4	5
Discussing diagnosis/ disclosure to patient	1	2	3	4	5
Discussing diagnosis/ disclosure to family	1	2	3	4	5
Treatment	1	2	3	4	5
Knowledge about support services	1	2	3	4	5
Managing behavioural disturbances	1	2	3	4	5

DISCLOSURE OF DEMENTIA

Presently, there are no best practice guidelines in BC for communicating a diagnosis of dementia to a patient or family member. We are interested in your usual practice upon determining a patient has dementia.

18) If you have determined a patient has dementia, in what percentage of cases do you disclose a diagnosis of dementia to a patient?

a) 0-25%
b) 26-50%
c) 51-75%
d) 75-100%
e) Not Applicable

19) In what percentage of cases do you disclose a diagnosis of dementia to the family or caregivers of the patient?

   a) 0-25%
   b) 26-50%
   c) 51-75%
   d) 75-100%
   e) Not Applicable

20) On what do you base your typical approach to a dementia diagnosis (Rank each of these sources in importance from 1-5) with a rank of 1 being “very important” and a rank of 5 being “least important”. Please use each rank only once (e.g. only one of the following items would have a ranking of 1).

Medical School	
Residency	
Clinical Experience	
CME	
Non-professional Experience	

21) Please rate each of the following according to how strongly you feel they influence your decision to disclose a dementia diagnosis to the patient (these factors makes disclosure necessary/advisable):

Factor	Very Important	Somewhat Important	Somewhat Unimportant	Not Important	Not Applicable
Certainty of diagnosis of dementia	1	2	3	4	5
Cognitive status of the patient/stage of the disease	1	2	3	4	5
Insight and emotional status of a patient	1	2	3	4	5
The request of a patient	1	2	3	4	5
The request of a caregiver	1	2	3	4	5
Personal	1	2	3	4	5
Medical treatment planning	1	2	3	4	5

22) When you are certain of a diagnosis of dementia, on average how long do you usually spend disclosing that diagnosis of dementia to a patient?

a) 0-5 minutes
b) 6-10 minutes
c) 11-15 minutes
d) 16-20 minutes
e) More than 20 minutes
f) I usually do not disclose a diagnosis
g) Not applicable

23) When you are certain of a diagnosis of dementia, on average how long do you spend disclosing that diagnosis of dementia to a caregiver?

a) 0-5 minutes
b) 6-10 minutes
c) 11-15 minutes
d) 16-20 minutes
e) More than 20 minutes
f) I usually do not disclose a diagnosis
g) Not applicable

24) How long would you like or think is reasonable to disclose a diagnosis of dementia?

a) 0-5 minutes
b) 6-10 minutes
c) 11-15 minutes
d) 16-20 minutes
e) More than 20 minutes
f) I do not disclose a diagnosis
g) Not applicable

25) Following a diagnosis of dementia, how many times in the 1st year do see that patient?

a) 0
b) 1-5
c) 6-10
d) 11-15
e) More than 15
f) Not applicable

26) Please add any comments you feel are relevant regarding dementia diagnosis and/or treatment in British Columbia. Please use a separate sheet if needed.

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RESOURCES

27) Please rank each of these services by how frequently you use them for your patients with dementia:

Services	Very Frequently	Somewhat Frequently	Rarely	Not at all	Not Applicable
Specialists	1	2	3	4	5
Laboratory	1	2	3	4	5
Diagnostic Services	1	2	3	4	5
Regional Geriatric Services	1	2	3	4	5
Psychogeriatric Services	1	2	3	4	5
Emergency Room	1	2	3	4	5
Home Care	1	2	3	4	5
Respite Care	1	2	3	4	5
Adult Day Care	1	2	3	4	5
Home Support	1	2	3	4	5
Nursing Home Care	1	2	3	4	5

28) Would you find a comprehensive dementia information and treatment centre (e.g. a comprehensive dementia clinic) useful in your region to assist your practice with patients and caregivers?

a) Very useful
b) Somewhat useful
c) Very limited use
d) Not at all useful

29) From your experience, what additional resources are needed for dementia care and where would they have the greatest impact? Please use a separate sheet if needed.

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Thank you for taking the time to complete this survey.

Please mail both the survey and response card to ensure you are entered for the prize draw.

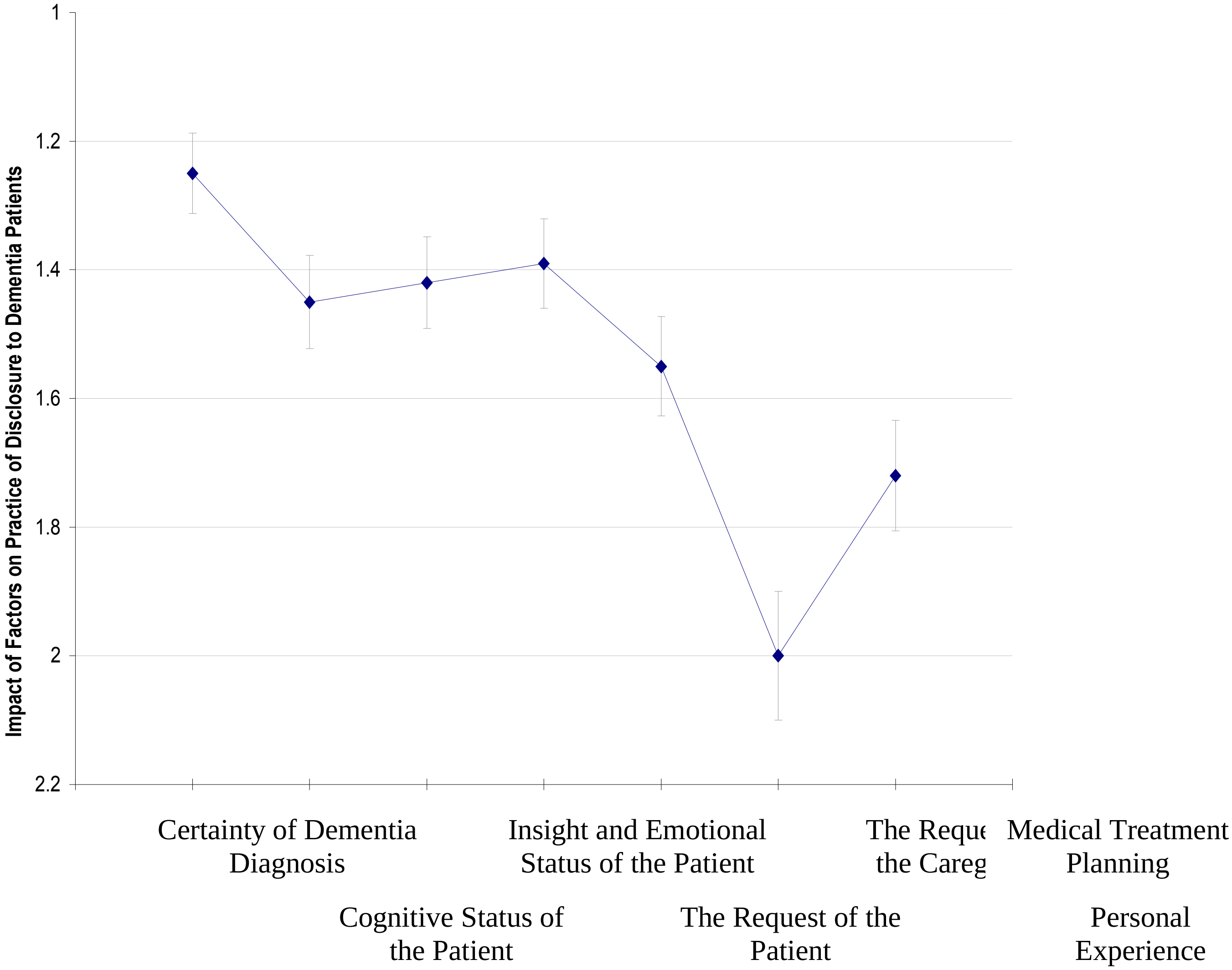
Please mail the response card separately.

<u>Thank you for taking the time to complete this survey.</u>

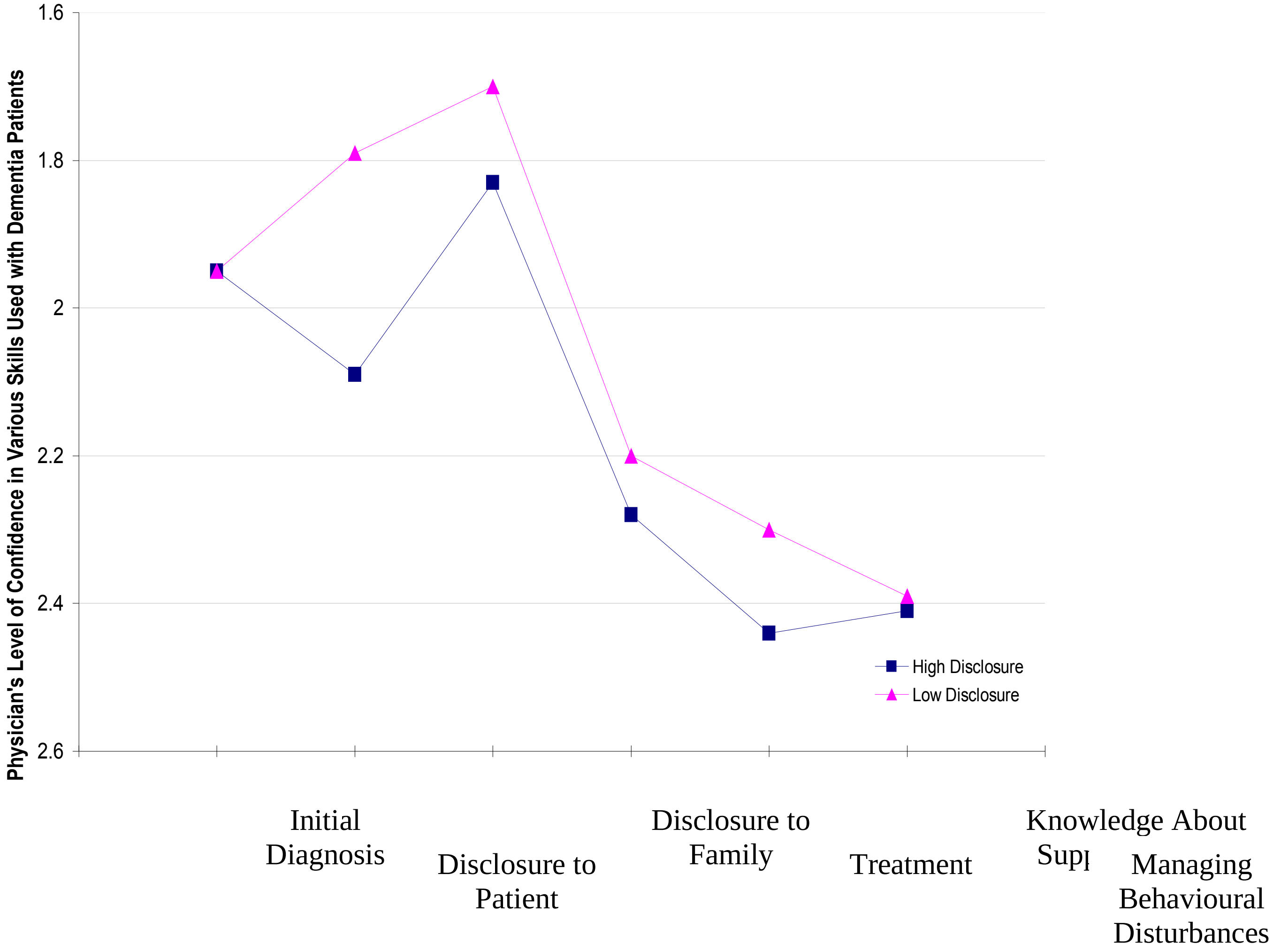
<u>Please don’t forget to mail both the survey and response card to ensure you are entered for the prize draw.</u>

APPENDIX B

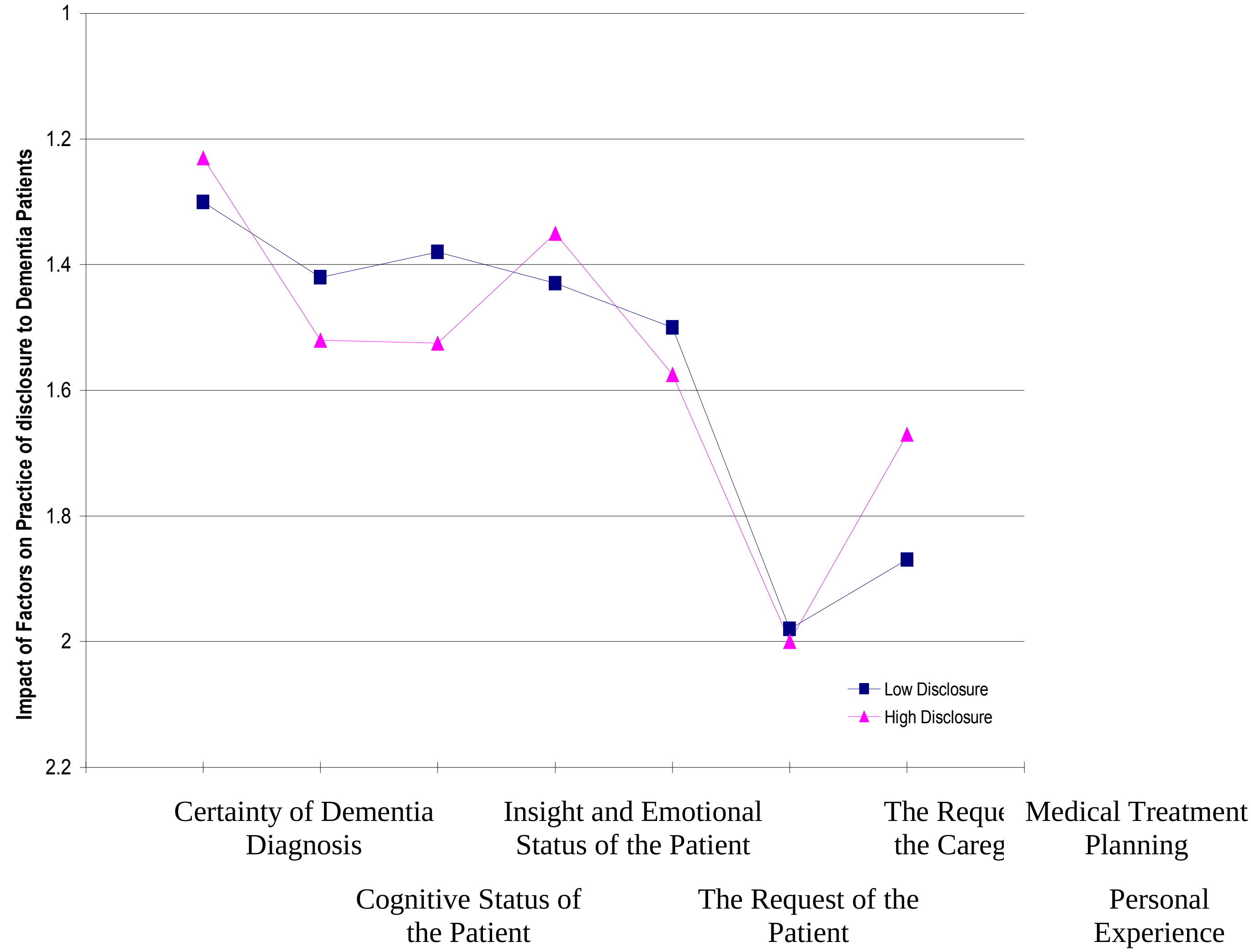
Figures



Physicians rate how influential seven factors are in their decision to disclose a dementia diagnosis to a patient. The factors were rated: 1 very important, 2 somewhat important, 3 somewhat unimportant, 4 not important. In hypothesis 6 there was a significant result as the physician rated the various factors differently. The first 5 factors were found to be more influential



The interaction effect shown here illustrates the differences between low disclosing physicians and high disclosing physicians and their level of confidence with various skills used with dementia patients. The greatest difference between the 2 groups of physicians is in the area of disclosure to patients. The physicians indicated they were: 1 very confident, 2 somewhat confident, 3 somewhat unconfident, 4 not at all confident.



Physicians rate how influential the 7 factors are in their decision to disclose a dementia diagnosis to a patient. The factors were rated: 1 very important, 2 somewhat important, 3 somewhat unimportant, 4 not important. The interaction effect shown here illustrates the differences between the practices of disclosing physicians and non-disclosing physicians. The greatest difference is in the influence of the 2 factors of insight and emotional status of the patient and in medical treatment