Interior Health

Clinical Practice Recommendations

Providing Client and Caregiver Support in the MCI Phase

The following Clinical Practice Recommendations were created as part of the IH Phased Dementia Pathway. These recommendations are evidence-informed or "best practice", and were created by the process described in the IH Dementia Care website[*]. Clinical Practice Recommendations at the Mild Cognitive Impairment phase of the pathway highlight the need for interdisciplinary health professionals to recognize early cognitive changes, understand the clinical and ethical challenges related to early diagnosis and disclosure, and be able to meet the support and informational needs of the client and caregiver throughout the uncertainty of this phase.

Levels of Evidence and Strength of Recommendations

The SORT research grading tool[†] emphasizes client-oriented outcomes – outcomes that matter to clients and help them live longer or better lives, including reduced morbidity, mortality or symptoms, improved quality of life and lower cost of health care services. Levels of evidence are ranked "**1, 2, 3**" based on the validity (quality) of the study design. Where existing relevant guidelines were found, they are cited as **"G"** in the level of evidence. Strengths of recommendations (**A, B, C**) are based on grading the quantity and consistency of the body of evidence. Ratings are listed following each recommendation or group of recommendations as needed.

Levels of Evidence and Strength of Recommendations Taxonomy

Levels of Evidence are ranked 1-3 based on the validity (quality) of the study design.
1 = Good quality client-oriented evidence
2 = Limited quality client-oriented evidence
3 = Other evidence

Evidence-based Recommendations are rated as follows:
A = consistent and good quality client-oriented evidence;
B = inconsistent or limited-quality client-oriented evidence;
C= evidence lacking, more research needed; based on expert consensus/usual practice

Qualitative Evidence

No comparable grading tool was found for qualitative research, however the well established criteria of *credibility, applicability (or fittingness), auditability and confirmability* are used. All four criteria must be met in order to be considered suitable evidence for practice recommendations. A designation of "Q" is given under level of evidence and source cited.

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[†] Ebell MH, Siwek J, Weiss BD, Woolf SH, Susman J, Ewigman B, & Bowman M. Simplifying the language of evidence to improve patient care: Strength of Recommendation Taxonomy (SORT): A patient-centered approach to grading evidence in the medical literature. *The Journal of Family Practice* 2004;53(2):111-120, available in the public domain from http://www.aafp.org/afp/20040201/548.pdf

Clinical Practice Recommendations

The Dementia Clinical Practice Working Group advises the following clinical practice recommendations concerning the provision of client and caregiver support and information following the diagnosis of possible or probable mild cognitive impairment**:**

1. Education/Training:

Provide interdisciplinary education and training opportunities regarding:	Level of Evidence (sources cited)	SOR[‡]
• the importance of follow-up visits and/or interdisciplinary referrals to address client and caregiver needs for further monitoring, emotional support, and information and support services following the diagnosis of mild cognitive impairment.	Q(13,17,18) 3(§,††,‡‡)	A
• current knowledge of cross-sector program information and available resources that assist clients and caregivers to connect with appropriate services in the formal health system (as needed);	3[**]	B
• current knowledge of information and material resources that assist clients and caregivers to initiate advanced planning for financial, legal and domestic personal matters	3[**]	B
• current knowledge of informal health resources (i.e., Alzheimer Society of BC) that assist clients and caregivers to connect to support and information services.	3[**]	B

2. Information:

a) Communicate the following key information about the need for information and support for clients with Mild Cognitive Impairment and their caregivers for use in planning and delivering care.	Level of Evidence (sources cited)	SOR[‡]
• There is limited research evidence concerning the psychological consequences of receiving a diagnosis of MCI (i.e, both first reactions and longer term emotional outcomes of living with MCI) available to guide practitioners in providing effective emotional support. It is reasonable to suspect that because the diagnosis of MCI is often a challenging and extended process, the uncertainty of this phase can produce anxiety and stress for clients and caregivers. Reported emotional reactions during the MCI phase include depression, apathy and irritability.	Q(1,20) 3(††,‡‡) 1(2,3,4); 2(5,6)	C
• It is reasonable to believe that some of the limited evidence from investigation into disclosure of early stage dementia may be applicable to clients with MCI. However, care must be taken not to confuse or equate a	Q(7)	B

[‡] Strength of Recommendation

[§] Based on interview results from discussions with both the Kelowna Early Dementia Client Support Group and the Kelowna Early Dementia Caregiver Support Group (see other footnotes) held in Kelowna on June 2005 and April 2006. The Kelowna Early Dementia Support Group is comprised of people with diagnoses of both MCI and various dementias in the early stages of disease progression. Both clients and caregivers report feeling "lost" and "isolated" and identified that their priority need following diagnosis is information about what to expect and how to connect to the health care system to find resources for further or future assistance.

[**] Both clients and caregivers reported receiving outdated contact information (i.e., telephone numbers, names) and brochure information on support services, and expressed frustration that health providers were not knowledgeable and up-to-date in these areas.

diagnosis of MCI with dementia, and some key differences between MCI and dementia may result in very different emotional needs. These differences include: ○ the degree of personal awareness into cognitive disabilities (anosognosia); ○ the variance in diagnostic certainty (MCI does not currently have diagnostic consensus, whereas criteria do exist for Alzheimer Disease and related dementias); ○ the long term cognitive prognosis (uncertain cognitive outcome for MCI vs. progressive debility for dementias).	Q(13,14,15,16) 3(8,9); Reviews(10,11,12)	
• There is good evidence that compared to persons with early stage dementia, persons with MCI have significant insight into their cognitive and functional abilities. As a result of studies into this unique increased awareness, emotional reactions such as embarrassment, fear and depression have also been identified. Therefore, taking a ***client-led*** approach to providing emotional support is likely the best clinical practice focus available.	Q(13,14,15, 16)	A
• Practitioners should realize that caregivers may have different information and support needs and these needs may change throughout the caregiving experience.	Q(17, 18)	B
b) Communicate to the general public the following key information about Mild Cognitive Impairment:		
• The diagnosis of mild cognitive impairment is not a diagnosis of dementia, yet the literature suggests that some clients with MCI may already be convinced that they have dementia. Provide accurate and current public information that while MCI is associated with an increased risk of dementia, many people with MCI do not progress to dementia, even after several years.	3(19)	B
• Provide public information about the benefits of contacting a local coordinator of The Alzheimer Society of British Columbia (a national non-profit health organization) as a valuable resource that provides information, education and support to people affected by Alzheimer's disease and related dementias, including MCI.	3§,**,††,‡‡)	A
• Provide public information about the benefits of advanced personal planning and ensuring personal voice in decision-making in the event that one should not be able to speak for one self.	3(§)	C
• Provide public information regarding access to resources for advanced personal planning.	3	C

3. Program Planning:

It is recommended that the following information (which identifies potential and actual gaps in providing emotional support for clients and caregivers following the diagnosis and disclosure of Mild Cognitive Impairment) is used for clinical program planning across disciplines and sectors as relevant:	Level of Evidence (sources cited)	SOR‡
• There is limited phenomenological research into the client's emotional needs following the diagnosis of cognitive loss, particularly for MCI. This is an area that needs further research attention.	2(20); Q(7)	C
• It is reasonable to expect this phase to be a period of turmoil, uncertainty and stress for both client and caregiver, and a critical time for families to receive support through follow-up contact, either with their	3(§,**,††,‡‡)	A

physician or through interdisciplinary (e.g., social work or mental health) support services. Yet, the feedback received from clients with MCI in Support Groups[††], Caregiver Support Groups[‡‡] and from various providers in Interior Health (case managers, social workers, mental health clinicians) indicate that this follow-up support is infrequently practiced. This appears to be a gap in care delivery that could be addressed.		
• The idea that individuals may benefit from a short series of counseling following the disclosure of a diagnosis such as MCI or dementia is mentioned in literature, yet this is not an identifiable interdisciplinary practice within IH programs. While some physicians disclose diagnoses and request a follow-up visit to assess coping and answer questions, client and clinical group feedback[††‡‡] indicates that this is also not common. More frequently, follow-up visits with the physician are booked at 6 month to 1 year intervals for the purposes of monitoring cognitive losses to see if they have progressed or clearly converted to early dementia. This appears to be a gap in existing program planning that could be addressed.	Q(7) 3(§,††)	B
• The Kelowna client group also identified that during this period they did not always feel they could speak with their family and friends as talking about it was upsetting for both of them, and clients wanted to protect their family members from further distress. Allowing for variability in coping styles, it appears that the immediate emotional care needs (first reactions) in the weeks following diagnosis are a potential gap between the formal and informal health system.	3(††,§)	B
• Providing clients and caregivers with opportunities to talk about the diagnosis and what it means to them with a professional may be very useful intervention. This need could potentially be met through existing individualized home-based programs or in through “memory clinic” referrals (support and education *following* diagnosis) via shared or integrated care programs that involve interdisciplinary staff from HCC, Mental Health, Acute or Primary Care Centers, etc. and which could provide a few brief intervention sessions. Such contact is also an opportunity for clients and caregivers to learn and understand how and when to make contact with the formal health system in the future as their needs may change.	Q(1,713,17,) 1(21); 2(22,23)	B
• Although the Alzheimer Society of B.C. has expanded their focus for care beyond Alzheimer disease to include support, information and education for people experiencing related dementias, as well as for people with MCI, this fact is not well understood by practitioners or the public. Identifying the Society as an appropriate resource for clients with MCI and their caregivers should be incorporated into appropriate client pamphlets web-based sites and other dementia-related resource brokering tools used by staff.	3**	B
• Early advanced planning of financial, legal and personal affairs is essential to addressing future crisis problem solving and decision making should a client’s autonomy become incapacitated by cognitive losses. Advance planning involves building a trusting relationship with client and caregivers, engaging in psychosocial and	Q(24,25) 1(26) 3(27,28)	A

[††] Based on interview results from discussions with the Kelowna Early Dementia Client Support Group (validation client focus groups for this project) held in Kelowna on June 2005 and April 2006). The Kelowna Early Dementia Client Support Group is comprised of people with diagnoses of both MCI and various dementias in the early stages of disease progression. Clients report that once they have been given their diagnosis, they find themselves trying to adjust and cope with this life-altering event without further assistance. Members of the group used words like “scary”, “confusing”, “dismal” to describe the period after diagnosis.

[‡‡] Based on group discussions held with Kelowna Early Stage Caregiver Group, April 2006.

lifestyle discussion, and providing basic information about B.C. tools such as enduring power of attorney, Representation Agreements, financial arrangements, living will directives, etc. During the Mild Cognitive Impairment phase, clients are able to actively participate in advanced financial, legal and personal planning and decision-making and should be encouraged to do so. There is good evidence that a team approach to early advanced planning results in better client outcomes than relying or assuming that physicians alone will address these issues.		
• LTC case managers, mental health clinicians and social workers have special educational and practice needs to both advise and use knowledge regarding details of advanced planning resources, legislation, etc. Programs need to plan education and support time to these clinicians to ensure currency of knowledge, skills and abilities.	3(**,29,30,31)	C

4. <u>Provision of Care:</u>

*Interdisciplinary professionals in all sectors are encouraged to use the following practice recommendations to guide the provision of emotional support and informational/educational needs related to clients with Mild Cognitive Impairment and their family/caregivers. The focus for care is to **connect** clients and their caregivers to appropriate support and information services both in the formal and informal health care system to assist adjusting to the diagnosis of MCI..*	Level of Evidence (sources cited)	SOR[§§]
A. Supporting Emotional Needs:		
• Use knowledge of MCI as different from Alzheimer Disease and Related Dementias to appropriately assess and provide sensitive emotional support and care.	3(§,††,‡‡)	B
• Assess client and caregiver coping in the period following diagnosis of MCI, particularly in the areas of adjustment to uncertainty, current and past coping behaviours, knowledge and availability of formal and informal supports, etc.	3	C
• Assess the quality of social support networks for both client and caregiver, and encourage clients to identify a close trusted companion (family member, friend) who can provide emotional support at a personal level throughout this period of time (e.g., accompany to physician offices, be available to talk, etc.);	3[32]	C
• Recognize client or caregiver emotional distress in the period following diagnosis and provide emotional support, either by direct brief counselling or referral to appropriate interdisciplinary support services (social work, mental health, physician, etc).	3	C
B. Supporting Information and Educational Needs		
• Provide clients and families with current information of MCI, particularly enforcing that MCI is *not* dementia and that while MCI is a risk factor for dementia, many people with MCI do not progress to	3(††,‡‡)	B

[§§] Strength of Recommendation

develop disease, even after several years. Truthful and accurate information can assist clients and families to balance hope and understanding of what the future might bring, and may help them to adjust to the shock by using this information and taking action to plan ahead.		
• Refer clients and families to the Alzheimer Society of B.C. or other relevant client-support sites for easy to understand information, information on local support persons, groups and other resources.	3**	B
• Encourage clients and families to openly discuss and prepare for the future by planning and organizing financial, legal, health and personal affairs in advance, including the use of advance planning tools	Q(24,25); 3(27,28)	B

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