

Clinical Practice Recommendations

Understanding Clinical and Ethical Challenges of Early Diagnosis and Disclosure

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-related changes, understand the clinical and ethical challenges related to early diagnosis and disclosure, and be able to meet the support 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.

† 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 *understanding the clinical and ethical challenges associated with the early diagnosis and disclosure of mild cognitive impairment (MCI)*:

1. Education/Training:

<i>Provide interdisciplinary education and training opportunities regarding:</i>	Level of Evidence (sources cited)	SOR [‡]
<ul style="list-style-type: none"> current concepts and basic knowledge of MCI. (e.g., clinical definition, risk factors and clinical predictors, sub-type relationship to AD/DRD, known conversion rates and current diagnostic criteria for MCI – <i>note: no diagnostic consensus at this time</i>) 	<i>Knowledge content evidence:</i> 1 ^(1, 2, 3, 4) ; 3 ^(5,6,7) ; Meta-analysis ⁸ ; International Working Reports ^(9,10)	C
<ul style="list-style-type: none"> the benefits, barriers and impacts of early diagnosis and disclosure of mild cognitive impairment from multiple perspectives, including client, caregiver, physician and socio-cultural views (e.g., right to know, self-determination while capable, clinical uncertainty, “labelling”, fear of emotional distress response, etc.) 	Q ^(11, 12, 13, 14, 15,16, 17) 1 ⁽¹⁸⁾ ; 3 ^(19,20)	C
<ul style="list-style-type: none"> common ethical challenges that can arise during the diagnostic and disclosure period (e.g., conflicting beliefs and attitudes between client, family and physician, competing rights and principles of practice) 	Q ^(14, 15, 21)	C

2. Information:

<i>a) Communicate the following key information about the diagnosis and disclosure of Mild Cognitive Impairment to relevant clinical managers and front-line interdisciplinary professional staff:</i>	Level of Evidence (sources cited)	SOR [‡]
<ul style="list-style-type: none"> Self-awareness and subjective complaints of cognitive-related changes, especially episodic memory loss, is a hallmark clinical feature that may help to distinguish MCI from early dementia (<i>often self-awareness is further eroded in early dementia</i>). Evidence from research and client interviews indicates that it is not uncommon for client complaints of memory loss to be minimized (e.g., discounted as part of normal aging or attributed to stress without further investigation) and not taken seriously by health professionals, including family physicians. 	1 ^(22, 23, 24)	A
<ul style="list-style-type: none"> Cultural perceptions of cognitive impairment and knowledge of dementing illnesses such as Alzheimer disease are two of the major factors influencing client and caregiver help-seeking behaviours. This information needs to be incorporated into both program planning for dementia services, and the provision of care. 	Q ^(25,26,27,28,29)	A

[‡] Strength of Recommendation

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<ul style="list-style-type: none"> Seeking a diagnosis is often a difficult and extended process that can be anxiety producing for clients and caregivers due to the uncertainty. 	Q ^(13,14,15,18)	A
<ul style="list-style-type: none"> There is evidence that the majority of clients wish to be told of a diagnosis that explains their cognitive changes, yet it is frequently reported by clients^s that they were not directly told their diagnosis by their physician. 	Q ^(11,12,13,14) 1 ⁽¹⁸⁾ ; 3 ^(8,30)	A
<i>b) Communicate to the general public the following key information about the importance of reporting cognitive changes in mid and later life in an effort to increase awareness and decrease stigma:</i>		
<ul style="list-style-type: none"> Provide public information identifying normal cognitive changes that can be expected with aging, especially into the 7th and 8th decade of life. Provide public information that memory loss, cognitive impairment and dementia is <i>not</i> a part of normal aging. 	1 ⁽³¹⁾ 3 ^(32,33,34,35)	A
<ul style="list-style-type: none"> Provide public information that observed declines in thinking, memory, mood, behaviour and ability to function in everyday living are not associated with normal aging and require reporting to, and further investigation by, the family physician. 	Guidelines ^(36,37,38)	A
<ul style="list-style-type: none"> Provide public information that brain health strategies such as healthy blood pressure, normal blood sugars and lipids, and engaging in regular social, mental and physical activity can reduce the burden on the brain, and are appropriate (secondary prevention) strategies for any age. 	Guidelines ^(39, 40, 41,42)	A

3. Program Planning:

<i>It is recommended that the following information about diagnosis and disclosure of Mild Cognitive Impairment is used for clinical program planning across disciplines and sectors as relevant:</i>	Level of Evidence (sources cited)	SOR [‡]
<ul style="list-style-type: none"> Cognitive impairment carries a social stigma in Canadian society^{**}, and stigma is a significant deterrent to seeking early diagnoses and care. Engaging in opportunities to partner with local Alzheimer Society offices in efforts to raise public awareness, and provide early information and positive public messaging may assist in reducing social stigma and enhance public knowledge and acceptance of cognitive loss associated with Alzheimer Disease and related dementias (ADRD) 	3 ^{**}	C
<ul style="list-style-type: none"> There is limited phenomenological research into the client's experience of receiving a diagnosis of cognitive loss. This is an area that needs further research attention. 	Q ^(11,12,18)	C

[§] Based on limited phenomenological research evidence and results from discussions with the Kelowna Early Dementia Support Client Group (validation client focus groups for this project held in June 2005 and April 2006).

^{**} Based on the results of an Ipsos-Reid public opinion poll that was conducted on behalf of the Alzheimer Society of Canada between July 23rd and July 25th, 2002 . See <http://www.alzheimer.ca/english/media/stigma03-poll.htm> for details.

4. Provision of Care:

<i>Interdisciplinary professionals in all sectors are encouraged to use the following practice recommendations to guide assessment, problem-solving, decision-making and all aspects of direct care related to clients with Mild Cognitive Impairment and their family/caregivers.</i>	Level of Evidence (sources cited)	SOR ^{††}
<ul style="list-style-type: none"> Be sensitive to various perspectives (client, caregiver, physician and societal and cultural views) concerning early diagnosis and disclosure of cognitive loss. 	Q ^(25,27,28,43)	B
<ul style="list-style-type: none"> Provide non-judgemental and neutral support and information to clients, caregivers and physician colleagues throughout the process of early diagnosis and disclosure. 	3 ^(group consensus)	C
<ul style="list-style-type: none"> Use knowledge about the barriers and benefits associated with an early diagnosis and disclosure of cognitive loss to plan individualized care and support. 	Q ^(11,12,13,14,15,16,17) 1 ⁽¹⁸⁾ ; 3 ^(19,20)	B
<ul style="list-style-type: none"> Support clients and caregivers in understanding the significance of observed changes in cognition, mood, behaviour and daily functioning and to seek physician consultation. 	Guidelines ^(36,37,38)	C
<ul style="list-style-type: none"> Provide emotional support to clients and/or caregiver(s) during the uncertainty of seeking and receiving a diagnosis of mild cognitive impairment; For example, <ul style="list-style-type: none"> Elicit the client and caregiver(s) beliefs and understanding about what is happening and what and how much information they wish to know. <ul style="list-style-type: none"> “What do you think is wrong with you?” “What have you been told by your doctor?” “What would you like to know?” Encourage open family discussion of questions, fears, observations; Encourage clients and family members to write questions down <i>before</i> the doctor’s appointment; Encourage clients and family member(s) to discuss options to visit the physician together but provide opportunity for privacy if desired. 	Q ^(11,12,13,14,15,18,24) 3 ^(group consensus)	C
<ul style="list-style-type: none"> Provide emotional support during the uncertainty of seeking and not receiving a definitive medical diagnosis, but receiving recognition of possible/probable cognitive loss/change(s) that will require ongoing monitoring. <ul style="list-style-type: none"> Assist client and family to articulate their concerns re: changes (details, timeline, etc) Acknowledging the stress of living with uncertainty; Reinforce messages of hope (e.g., early awareness of small changes, physician will follow-up regularly, self-management of life-style behaviours that promote brain health, etc) Suggest the use of a journal to note changes over time. 	3 ^(34, group consensus)	C
<ul style="list-style-type: none"> Provide client and family support to first reactions (e.g., shock, anger, fear, embarrassment, relief, validation) in the first days and weeks following the receiving of a diagnosis of mild cognitive impairment; 	Q ^(14,15,18) 3 ^(group consensus)	B

^{††} Strength of Recommendation

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<ul style="list-style-type: none"> Recognize the ethical dilemmas and challenges that arise when physician and caregiver beliefs, attitudes and practices about truth-telling of the diagnosis conflict with the individual client's rights (e.g., to know, to not know, for privacy of information, autonomous decision-making, etc.) and principles of practice (beneficence , non-maleficence “do no harm”). 	Q ^(14, 15, 21)	C
<ul style="list-style-type: none"> Recognize that the decision to disclose the diagnosis of mild cognitive impairment is a complex one that needs to be considered individually 	3 ^(9,10, group consensus)	C

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