The Canadian Journal of Neurological Sciences (2025), 1–5
doi:10.1017/cjn.2024.368

Canadian Journal of Neurological Sciences
Journal Canadien des Sciences Neurologiques

Original Article

Quality of Life in Patients with Subjective Cognitive Impairment Referred to a Rural and Remote Memory Clinic

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ABSTRACT: ***Background:*** We sought to compare whether quality of life (QOL) in patients with subjective cognitive impairment (SCI) who performed normally on a neuropsychological battery significantly differed from those diagnosed with mild cognitive impairment (MCI), Alzheimer's disease (AD) or non-Alzheimer's dementia (non-AD) at initial assessment in a Rural and Remote Memory Clinic (RRMC). ***Methods:*** 610 patients referred to our RRMC between 2004 and 2019 were included in this study. We compared self-reported and caregiver-reported patient QOL scores in those with SCI ($n = 166$) to those diagnosed with MCI ($n = 98$), AD ($n = 228$) and non-AD ($n = 118$). ***Results:*** Patients with SCI self-reported significantly lower QOL compared to patients with AD. Interestingly, the reverse was seen in caregivers: SCI caregivers rated patient QOL higher than AD caregivers. Patients with SCI also reported lower QOL than patients with MCI. SCI caregivers reported higher patient QOL than their non-AD counterparts. Caregiver-rated patient QOL was higher in those with MCI compared to AD. Patients with MCI self-reported higher QOL scores compared to patients with non-AD dementias. Similarly, MCI caregivers reported higher patient QOL than non-AD caregivers. No other comparisons were statistically significant. ***Conclusion:*** Although they lacked clinically significant cognitive deficits, patients with SCI self-reported significantly lower QOL than patients with MCI and AD. Conversely, caregiver-reported patient QOL was higher for patients with SCI than for patients with AD and non-AD. This shows that SCI seriously impacts QOL. More research is needed on how we can better support patients with SCI to improve their QOL.

RÉSUMÉ : Évaluation de la qualité de vie de personnes faisant état de troubles cognitifs subjectifs, dirigées vers un centre de soins axés sur la mémoire, en milieu rural et éloigné. ***Contexte :*** L'étude visait à déterminer si la qualité de vie (QV) des personnes qui faisaient état de troubles cognitifs subjectifs (TCS) mais qui obtenaient des résultats normaux à la batterie de tests neuropsychologiques différait sensiblement de celle des patients chez qui un diagnostic de troubles cognitifs légers (TCL), de la maladie d'Alzheimer (MA) ou de démence de type non-Alzheimer (D non-MA) avait été posé au moment de l'évaluation initiale, dans une clinique de soins axés sur la mémoire, en région rurale et éloignée. ***Méthode :*** Au total, 610 patients dirigés vers le centre de soins Rural and Remote Memory Clinic (RRMC), entre 2004 et 2019, ont été retenus dans l'étude. Les scores relatifs à la QV, autodéclarés et déclarés par les aidants et les aidantes, obtenus par les personnes faisant état de TCS ($n = 166$) ont été comparés avec ceux obtenus par les patients chez qui un diagnostic de TCL ($n = 98$), de MA ($n = 228$) et de D non-MA ($n = 118$) avait été posé. ***Résultats :*** Les personnes souffrant de TCS autodéclarés ont fait état d'une QV passablement moins bonne que celle indiquée par les patients atteints de la MA. Point digne de mention, le contraire a été observé chez les aidants de personnes touchées par des TCS, qui ont accordé une cote plus élevée de QV que les aidants de patients atteints de la MA. Les personnes souffrant de TCS ont aussi fait mention d'une QV inférieure à celle indiquée par les sujets présentant des TCL. Par ailleurs, les aidants de personnes touchées par des TCS ont jugé la QV de leurs proches supérieure à celle indiquée par les aidants de patients atteints de D non-MA. La QV notée par les aidants s'est montrée meilleure chez les sujets souffrant de TCL que chez les patients atteints de la MA. Les personnes touchées par des TCL ont fait mention d'une QV autodéclarée meilleure que celle déclarée par les malades souffrant de D non-MA. Les aidants de sujets présentant des TCL ont également déclaré meilleure la QV de ces derniers que ceux prenant soin de patients atteints de D non-MA. Enfin, il n'y avait pas d'écart statistiquement significatif entre les autres comparaisons. ***Conclusion :*** Malgré l'absence de déficits cognitifs importants sur le plan clinique, les personnes touchées par des TCS ont fait état d'une QV passablement moins bonne que celle notée par les patients atteints de TCL ou de la MA. À l'inverse, la QV cotée par les aidants de sujets souffrant de TCS était supérieure à celle accordée par les aidants de patients touchés par la MA ou de D non-MA. Les résultats montrent bien que les TCS ont des répercussions importantes sur la QV. Aussi faudrait-il poursuivre la recherche afin d'apporter un meilleur soutien aux personnes atteintes de TCS afin d'améliorer leur QV.

Keywords: Dementia; quality of life; cognitive impairment

(Received 3 May 2024; final revisions submitted 22 December 2024; date of acceptance 23 December 2024)

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Cite this article: Sun G, Kirk A, Karunanayake C, O'Connell ME, and Morgan DG. Quality of Life in Patients with Subjective Cognitive Impairment Referred to a Rural and Remote Memory Clinic. *The Canadian Journal of Neurological Sciences*, https://doi.org/10.1017/cjn.2024.368

Highlights

- Patients with subjective cognitive impairment (SCI) reported worse quality of life (QOL) compared to patients with mild cognitive impairment and Alzheimer's disease (AD).
- Caregiver-reported QOL for patients with SCI was better than caregivers of patients with AD and non-Alzheimer's dementia.
- SCI significantly affects QOL, warranting further research and clinical consideration.

Introduction

The prevalence of dementia is on the rise, a reflection of both an aging population and improved public awareness of dementia symptoms and disease burden. Consequently, dementia is a common worry for older adults,[1] and perceived cognitive impairment can be a significant source of anxiety for many people.[2,3] As awareness of dementia grows, a new group of patients has emerged: those with subjective cognitive impairment (SCI). These are patients who are concerned they have dementia but are neurologically normal, with a neuropsychological profile that is within normal limits once adjustments for age and demographic factors are accounted for.

Concerns around declining cognitive function have a deleterious effect on psychological well-being [4], and these concerns are pervasive among middle-aged and older adults.[5] Dementia, particularly Alzheimer's disease (AD), is an especially dreaded condition because it is considered to be irreversible.[6] These concerns are well-documented in the literature as "anticipatory dementia" and "dementia worry."[7,8]

The prognosis of SCI is variable. Earlier work by our group showed that the likelihood of progression of SCI to measurable neurological decline is low, although a small proportion of people studied did go on to develop pathology.[9] SCI is of growing interest now because it may herald abnormal cognitive decline and may be a risk factor for dementia.[2,9–12] Thus, some patients with SCI are at risk of disease progression, some will remain as the "worried well" and some patients' SCI represents early pathology.

Methods

610 patients were seen at the Rural and Remote Memory Clinic (RRMC) between March 2004 and June 2019. These people were categorized into four diagnostic groups. 166 patients were neurologically and neuropsychologically normal and diagnosed with SCI, 98 were diagnosed with mild cognitive impairment (MCI), 228 were diagnosed with AD and 118 were diagnosed with non-Alzheimer's dementia (non-AD).

The University of Saskatchewan's RRMC is a centralized interdisciplinary clinic dedicated to assessing and caring for patients with memory concerns from rural Saskatchewan. Patients can be referred by primary care providers such as a family physician or nurse practitioner. At the initial visit, the patient sees a neurologist, physiotherapist and nurse and undergoes neuropsychological testing. A neuropsychology team assesses premorbid ability, attention, speeded mental processing, receptive and expressive language, visuospatial abilities, executive function and verbal and visual memory. The patient also undergoes a standard workup for causes of dementia including blood tests and neuroimaging. Other data collected at the initial visit include age, sex, years of formal education, Mini-Mental Status Exam (MMSE), Center for Epidemiologic Studies Depression Scale (CES-D), Functional Activities Questionnaire (FAQ), alcohol consumption, marital status, hours per week of work, past medical history, sleep concerns, possession of a driver's license and family history of memory concerns. Assessments take one full day. At the end of the day, patients are given a diagnosis as agreed upon by the multidisciplinary team. More details about the RRMC can be found in previous publications.[9,13–23]

A diagnosis of SCI is given if patients meet the following criteria: no clinical evidence of neurologic disease; normal neuroimaging; and normal performance on neuropsychological testing relative to normative comparison standards that are adjusted for demographic

variables, which include age and for some tests, biological sex and level of formal education.

For this study, the main measure we assessed was the Quality of Life of the Patient Scale (QOLPT),[24] which patients complete upon their initial visit to the RRMC. The QOLPT scale is a brief assessment of patient quality of life (QOL) as determined through self-report and caregiver-report. Both the patient and their caregiver complete a version of the scale to evaluate the patient's QOL. The QOLPT is comprised of 13 items, each scored between 1and 4, with overall scores ranging from 13 to 52. Higher scores indicate higher patient QOL. Self-reported and caregiver-reported patient QOLPT scores were compared across the four diagnostic groups: SCI, MCI, AD and non-AD.

Participants were eligible to participate in this study if they presented to the RRMC within the timeframe of data collection and completed the necessary testing. We avoided potential bias by analyzing data without patient identifiers. In addition, those involved in data analysis were not involved in seeing the patients in the clinic. Descriptive analyses were completed using frequencies, measures of central tendencies and variability. The QOLPT scores of different diagnostic groups were compared using the analysis of variance test. Statistical analyses were completed using SPSS version 27. Ethics approval was obtained from the University of Saskatchewan Biomedical Research Ethics Board.

Table 1. Total number of patients and caregivers by diagnostic grouping

Diagnostic group	Patient ($n = 464$)	Caregiver ($n = 537$)
SCI	148	129
MCI	77	89
AD	167	209
Non-AD dementia	72	110

SCI = subjective cognitive impairment; MCI = mild cognitive impairment; AD = Alzheimer's disease.

Results

In total, 464 patients and 537 caregivers had complete data and were therefore included in the analysis. Within the population of patients, 148 were diagnosed with SCI, 77 were diagnosed with MCI, 167 were diagnosed with AD and 72 were diagnosed with non-AD dementia. In the caregiver group, 129 cared for patients with SCI, 89 cared for patients with MCI, 209 cared for patients with AD and 110 cared for patients with non-AD dementia. Table 1 summarizes the groupings for patients and caregivers.

A summary of the demographic characteristics of the patients at the time of their initial clinic visit can be found in Table 2.

https://doi.org/10.1017/cjn.2024.368

Table 2. Demographic characteristics of patients on clinic day

Group	Mean age ± SD	Male sex (%)	Female sex (%)
SCI	60.90 ± 11.98	75 (45.20%)	91 (54.80%)
MCI	71.74 ± 9.86	47 (48.00%)	51 (52.00%)
AD	75.50 ± 8.07	70 (30.70%)	158 (69.30%)
Non-AD dementia	71.17 ± 10.69	58 (49.20%)	60 (50.80%)

SCI = subjective cognitive impairment; MCI = mild cognitive impairment; AD = Alzheimer's disease.

Table 3. Quality of Life of the Patient Scale (QOLPT) scores (mean ± SD)

Diagnostic group	Patient	Caregiver
SCI	34.55 ± 6.26	34.61 ± 6.90
MCI	36.97 ± 5.24	34.52 ± 6.88
AD	35.96 ± 5.78	31.72 ± 5.82
Non-AD dementia	34.81 ± 6.29	31.17 ± 5.64

SCI = subjective cognitive impairment; MCI = mild cognitive impairment; AD = Alzheimer's disease.

Mean patient QOL scores as determined by self-report and caregiver-report on the QOLPT scale are summarized in Table 3.

Despite being neurologically and neuropsychologically normal, patients with SCI self-reported significantly lower QOLPT scores compared to patients with AD (mean 34.55 vs 35.96, $p < 0.05$). However, caregivers reported the opposite pattern, as SCI caregivers rated patient QOL higher than AD caregivers (mean 34.61 vs 31.72, $p < 0.001$).

Patients with SCI self-reported lower QOL than patients with MCI (mean 34.55 vs 36.97, $p < 0.05$). Caregivers of these two groups did not significantly differ in their ratings of patient QOL (mean 34.61 vs 34.52, $p = 0.912$).

Caregivers of patients with SCI reported higher patient QOL than caregivers of patients with non-AD dementia (mean 34.61 vs 31.17, $p < 0.001$). However, patients with SCI did not have significantly different QOL scores from those with non-AD dementia (mean 34.55 vs 34.81, $p = 0.768$).

Caregivers of patients with MCI also rated higher patient QOL than their AD counterparts (mean 34.52 vs 31.72, $p < 0.001$), but there were no differences between these two groups in the patient ratings (mean 36.97 vs 35.96, $p = 0.215$).

Patients with MCI self-reported higher QOL compared to patients with non-AD dementia (mean 36.97 vs 34.81, $p < 0.05$). Caregivers in these two groups responded similarly: caregivers of patients with MCI also reported higher patient QOL than caregivers of patients with non-AD (mean 34.52 vs 31.72, $p < 0.001$).

There were no statistically significant differences between the AD and non-AD groups for patients (mean 35.96 vs 34.81, $p = 0.169$) nor caregivers (mean 31.72 vs 31.17, $p = 0.459$). Table 4 summarizes these findings.

The results of patient results for the MMSE, FAQ and CES-D are summarized in Table 5.

CES-D scores were significantly higher in patients with SCI compared to patients with MCI (mean 16.77 vs 13.61, $p = 0.023$). CES-D scores were also significantly higher in SCI patients than in AD patients (mean 16.77 vs 12.47, $p < 0.001$). There were no significant differences in CES-D scores between patients with SCI vs non-AD, MCI vs AD, MCI vs non-AD and AD vs non-AD.

Table 4. Comparison of QOLPT scores between patient and caregiver reports for SCI, MCI AD and non-AD groups at initial assessment using ANOVA

	Patient-reported QOLPT score		Caregiver-reported QOLPT score	
Comparison group	Mean difference	*p*-value	Mean difference	*p*-value
SCI vs MCI	−2.42	0.004*	0.10	0.912
SCI vs AD	−1.40	0.037*	2.90	<0.001*
SCI vs non-AD	−0.25	0.768	3.44	<0.001*
MCI vs AD	1.02	0.215	2.80	<0.001*
MCI vs non-AD	2.17	0.026*	3.34	<0.001*
AD vs non-AD	1.15	0.169	0.55	0.459

**= significant when $p < 0.05$. QOLPT = Quality of Life of the Patient Scale; SCI = subjective cognitive impairment; MCI = mild cognitive impairment; AD = Alzheimer's disease.*

Table 5. MMSE, FAQ and CES-D scores by patient grouping

	MMSE		FAQ		CES-D	
Group	N	Mean ± SD	N	Mean ± SD	N	Mean ± SD
SCI	127	27.74 ± 2.49	117	4.20 ± 5.04	139	16.77 ± 10.25
MCI	71	26.46 ± 2.53	73	6.84 ± 5.68	74	13.61 ± 8.59
AD	146	21.66 ± 3.75	167	15.59 ± 7.42	152	12.47 ± 10.09
Non-AD dementia	65	23.70 ± 4.50	72	12.83 ± 7.58	69	14.12 ± 8.39

MMSE = Mini-Mental Status Exam; FAQ = Functional Activities Questionnaire; CES-D = Center for Epidemiologic Studies Depression Scale; SCI = subjective cognitive impairment; MCI = mild cognitive impairment; AD = Alzheimer's disease.

Discussion

The goal of this study was to elucidate the QOL in patients with SCI living in rural and remote Saskatchewan. We assessed this by comparing self-reported and caregiver-reported measures of patient QOL and compared it to scores for patients diagnosed with MCI, AD and non-AD dementia.

Patients with SCI self-reported significantly worse QOL than patients diagnosed with MCI and AD, despite patients with SCI lacking clinically significant cognitive deficits. Interestingly, the opposite trend was found in caregivers. Caregiver-rated patient QOL was higher for patients with SCI compared to patients with AD and non-AD. We also found that patients with MCI self-reported better QOL than patients with non-AD and that caregivers of patients with MCI reported better patient QOL compared to their AD and non-AD counterparts.

It is possible that depressive symptoms contribute to the lower QOL scores seen in patients with SCI. This is in keeping with previous work done by our group, which characterized increased depressive symptomatology in this population,[16] and the relationship between depression, memory concerns and QOL is multifaceted. Depression can be an independent contributor to memory concerns, particularly given that our subset of patients

https://doi.org/10.1017/cjn.2024.368

with SCI tended to be younger; depression can also be an early symptom of dementia, and these two entities also have some behavioral overlap such as apathy. Furthermore, the psychological distress from heightened awareness of memory lapses could also contribute to these mood symptoms. Ultimately, these findings still underscore that patients with SCI have worse QOL, even if depression is a contributing factor, which is important to bear in mind when providing comprehensive care to these patients. Therefore, screening for and treating depression could be part of the interventions offered to patients with SCI.

SCI is a common and distressing experience for older adults. Despite not being diagnosed with a disease, our results demonstrate that SCI is an important condition for clinicians to be aware of because of its impact on QOL despite patients being perceived as clinically well. That SCI has a negative impact on QOL is consistent with other findings in the literature.[2–4,25,26] Many mechanisms have been proposed for why this occurs. SCI can negatively affect patient QOL through patients worrying about their memory and forgetfulness.[27] For some patients, SCI represents feelings of loss of control and meaning in life.[28,29] The reduced ratings in QOL could reflect that patients with SCI experience increased affective symptoms.[30]. SCI can also result in decreased engagement in activities[31] and more functional problems.[32,33] The societal and economic toll of SCI will only increase as the population ages.

Assessments for SCI can be difficult due to the variability and challenges in identifying it.[4] In one study, older adults ranked subjective memory impairment as more concerning than angina, asthma, hypertension or previous myocardial infarction, even though medical help-seeking through raising their concerns with their family physician was very low.[34] This suggests that SCI may even be underreported. Many factors can impact help-seeking behaviors for patients with SCI such as personal concern about symptoms, perceived attitudes of their primary care providers and the availability of resources that can provide reassurance.[34,35] Lack of interest by clinicians has also been identified as a contributor as to why SCI is underreported.[2] The patients in our study sought help by obtaining a referral to the RRMC, so it is possible that our sample does not capture the breadth of experience of patients living with SCI, especially in terms of their QOL.

Interventions for SCI have been a growing area of need, which our findings in this study support. Some work has been done around interventions such as "memory fitness" training[36,37] and nutrition,[38] but the evidence for these interventions is not robust, and not much is known about their efficacy. One study showed that an intervention consisting of educational materials on cognitive aging and compensatory skills and behavior improved patients' negative emotional reactions to their cognition compared to controls.[39]

Overall, QOL in patients with SCI has been insufficiently studied to date and therefore represents an important gap in the field. In conjunction with our findings that patients with SCI self-report worse QOL than patients with MCI and AD, this demonstrates the need for future work on how patients with SCI can be supported to improve their QOL.

Acknowledgments. Thank you to the RRMC at the University of Saskatchewan for the support of this research.

Author contributions. All authors contributed in preparing and editing the final manuscript. GS wrote the manuscript under AK's guidance. AK and GS developed the study design and AK oversaw data collection. CK performed the statistical analysis. DM participated in the conception of the RRMC clinical model and managed data entry. MEO and AK oversaw clinical assessments and performed the diagnosis. MEO administered and oversaw neuropsychological testing, depression testing and function testing.

Funding statement. AK has received an honorarium from Lilly for a speaking engagement and has participated in advisory boards for Lilly, Elsai, Roche and Paladin. The other authors have no conflicts to disclose. We did not receive funding for this project.

Competing interests. None to declare.

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