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Type of clinical outcomes used by healthcare professionals to evaluate health-related quality of life domains to inform clinical decision making for chronic pain management

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Abstract

Purpose To evaluate the health-related quality of life (HRQoL) domains currently assessed by healthcare professionals (HCPs) in secondary and tertiary hospital-based chronic pain clinics and the type of clinical outcomes (CO) used.

Methods Electronic cross-sectional survey (May to September 2016) based on domains of HRQoL included in the Patient-Reported Outcomes Measurement Information System (PROMIS) framework.

Results HCPs response rate was 53% (36/68). Their mean clinical experience was 14.8 years (± 11.1), and their mean experience treating chronic pain (CP) population was 10.2 years (± 7.8). All PROMIS-HRQoL domains were assessed by HCPs (range 28–97%, mean = 64%) with a preponderance of domains related to physical health (mean = 82%). Standardized outcome measures (OMs) including performance outcomes and patient-reported outcomes (PROs) were not frequently used (mean 0.5% and 3%, respectively) for assessing HRQoL domains compared to clinician reported outcomes (patient interviews, patient observation) (mean = 87%). Forty different OMs for assessing HRQoL domains were reported, and 30% of OMs were used by more than one HCP. HCPs expressed a need (range from 2.3 to 26.3%) for using more than one type of CO for assessing most domains of HRQoL (range from 2.3 to 26.3%) with a preference of using more PROs combined with CROs.

Conclusions All domains of HRQoL are assessed by at least some HCPs for chronic pain management. Standardized OMs including performance-based measures and PROs were not frequently used, and there was no consistent use of the same OM across HCPs. A consensus among different stakeholders in chronic pain management on core domains of HRQoL and their associated OMs to promote a more evidence-based assessment is needed.

Keywords Chronic pain · Clinical outcomes · Evaluation · Health-related quality of life · Healthcare professionals · Survey

Background

Chronic pain (CP) is recognized as a complex condition that has a profound impact on the physical, psychological, social, and economic dimensions of the lives of sufferers and their families [1]. CP is prevalent affecting ~ 10% to 20% of the world's population [2, 3], and as much as 11% of the adult population has severe CP which seriously affects their quality of life [4]. In the USA, direct and indirect costs of CP are estimated between $560 and $635 billion annually [1] and in Europe it is more than €200 billion annually [2]. Estimates are expected to rise with an aging population in developed countries and chronic conditions associated with CP (e.g., osteoarthritis, diabetes, cancer, etc.), ultimately increasing the burden on the healthcare system [5].

CP has numerous negative consequences affecting all aspects of life. Regarding psychological health, CP sufferers reported feelings of hopelessness, helplessness, sorrow, solitude, despair, and low self-esteem [6, 7] that may be associated with anxiety and depression [8]. Furthermore, CP may contribute to drug and alcohol abuse [7] and increase the risk of suicide [9]. CP also contributes to general physical deterioration by affecting sleep, and the ability to exercise

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and perform basic daily activities such as walking or doing household chores [6, 7]. Recurrent flare-ups impact work ability, with persons suffering from CP describing the struggle to retain work, fear of job loss, and future financial insecurity [10]. Family relationships were also reported to be disturbed, with sufferers reporting feeling inadequate as a spouse or partner [6] leading to marital strain and breakdown [10].

Because CP affects all dimensions of health-related quality of life (HRQoL) (i.e., physical, psychological, and social), interdisciplinary, patient centered, and biopsychosocial approaches are recommended for treating persons with CP [1, 11]. A comprehensive and appropriate assessment is the first step to the development of a coordinated and effective patient management plan tailored to meet the specific needs of the person with CP [12–14].

Numerous studies have [13–16] described the important factors that should be considered to evaluate and manage patients with different CP conditions using a biopsychosocial perspective. Common assessment factors reported as important in the literature include the severity, location, duration, and likely causes of pain as well as questions related to patient health status, medical history, comorbidities, prior and current medications and interventions [13, 14]. Other key psychosocial and behavioral domains of HRQoL that should be considered for assessment are emotional state (e.g., anxiety, depression), coping resources, expectations, sleep quality, physical function, and pain-related interference with daily activities [13, 16].

To assess these domains of HRQoL, different types of clinical outcomes (COs) can be used that provide different types of information depending on the source of information. For example, the patient is the best source of information for certain domains of pain (e.g., pain intensity or pain interference) which cannot be observed and can only be assessed by asking the person; therefore, patient-reported outcome measures (PROMs) should be used. Some other domains may only be assessed using expert examination by a clinician. For instance, when performing a physical and neurologic examination, the clinician will apply his/her professional expertise and judgment to the observations or conversations with the patient to guide diagnostic and treatment decisions. These types of outcomes are referred to as clinician-reported outcomes (CROs). Performance outcomes (PerfOs) are another type of outcomes with which clinicians can assess the patient's performance by administrating standardized tests, for example measures of gait speed or balance [17, 18].

Because of the complexity and multidimensional nature of CP, it is recommended to use different types of COs and sources of information to assess the above-mentioned domains affected by CP to gain a comprehensive and holistic understanding of all potential social, emotional, cognitive, environmental, and behavioral factors that can impact the persons' HRQoL [12, 19]. The information obtained from the assessment must then be integrated to guide treatment decision making [20]. Despite this, to our knowledge, there are no previous studies that have investigated what domains of HRQoL are currently assessed by healthcare professionals (HCPs) working with individuals suffering from CP in their day to day clinical practice and how these domains are being assessed (i.e., type of COs used).

The objective of this study was to evaluate the HRQoL domains currently assessed by HCPs in CP programs and the type of COs used to assess these domains. These findings will inform the gaps in HRQoL domains and standardized COs used to measure these domains, with a focus on PROMs.

Methods

Study design

An electronic cross-sectional survey study was conducted from May to September 2016 using closed-ended and open-ended questions.

Context of the study

In Quebec, as in other countries, CP care is hierarchical, with the patient moving from primary care to secondary and tertiary care as increased specialization and multidisciplinary care is needed. The patient's first contact with healthcare services for CP is a family physician in primary care. For more complex patients, the family physician may refer the patient to secondary or tertiary care for access to a pain specialist and pain clinics which provide rehabilitation services using multidisciplinary teams comprised of physicians, psychologists, nurses, physical therapists, occupational therapists, social workers, and other specialists.

Participants and setting

Sixty-eight HCPs with a minimum of 6-month experience in CP and working in three hospital-based pain clinics in Montreal, Quebec, Canada, providing secondary and tertiary care to individuals suffering from CP were invited to participate. The invitation was sent by email and comprised a link to a secure online survey software (www. fluidsurveys. com). Email addresses were obtained from the manager of each pain clinic. Invited HCPs included all clinicians working in the multidisciplinary CP teams (physicians, physical therapists, occupational therapists, psychologists, social workers, kinesiologists and special education technicians). Participants consented to participate by completing the

survey. Non-respondents were sent up to two reminders at two-week intervals.

Survey development

A survey was developed to evaluate which HRQoL domains were assessed by HCPs for CP management and to explore HCPs interest as well as the perceived advantages, barriers, and facilitators to the implementation of PROMs (see Appendix 1 for an extract from survey). The present study reports only the results pertaining to HRQoL domains assessed by HCPs. This section of the survey was developed based on the 19 domains of HRQoL included in the Patient-Reported Outcomes Measurement Information System (PROMIS) framework. PROMIS is a National Institutes of Health initiative launched in 2004 with the goal to create and validate item banks to measure key symptoms and health concepts relevant across a range of chronic conditions [21]. The PROMIS framework was developed based on the World Health Organization (WHO) physical, mental, and social framework. HRQoL domains included in the PROMIS framework were developed through independent literature reviews and a consensus-building Delphi process [21]. For each of the 19 domains of HRQoL, HCPs were asked: (1) if they usually assess this domain in their regular clinical practice and if not, the reason for not assessing it; (2) when assessed, with whom this information was shared; (3) the type of outcomes used to assess the domain (standardized measures such as PROMs or PerfOs; CROs such as patient observation or patient interview;) and (4) their perception of the ideal type of outcome to assess the domain. Nominal measurement scales were used for most of the questions (except for questions asking to name outcome measure used when a domain was reported as being assessed). The survey also included a section with questions about demographics and professional characteristics such as age, profession, and years of experience working with the CP population. The survey was pilot tested with three HCPs for clarity and comprehensiveness.

Data analysis

Descriptive statistics were used to report HRQoL domains assessed by HCPs. For other questions with a nominal scale, categorical variables were summarized as counts and percentages.

The study was approved by the Ethics Committee of the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal.

Results

Participants

From 68 eligible HCPs invited to participate in the survey, 36 HCPs completed the survey resulting in a response rate of 53% (36/68). All questions were completed by all respondents. Table 1 summarizes the demographic and professional characteristics of the responding HCPs. Most respondents were female (63%). Their mean clinical experience was 15 years (range from 2 to 35 years since licence), and their mean experience treating a CP population was 10 years (range from 1 to 31 years).

HRQoL domains assessed

Figure 1 shows the percentage of HCPs that reported usually assessing each of the 19 domains of HRQoL in their clinical practice. All HRQoL domains were assessed (range 28–97%, mean = 64%), with a higher percentage of clinicians assessing physical health (range 61–97%; mean = 82%), followed by mental health (range 47–69%; mean = 58%) and social health (range 28–81%; mean = 54%). The physical health domains that were assessed by a higher proportion of HCPs were pain intensity (94%), pain interference (97%), and sleep disturbance (92%). Anxiety and self-efficacy were the two domains of mental health that were assessed by a higher proportion of HCPs, respectively, 69% and 61%. Social support, including informational (28%), instrumental (39%), and emotional support (42%), was less frequently assessed. The most frequent reason for not assessing a domain in physical health and social health was that it was not perceived as being relevant by participants in their clinical practice. For mental health, the main reason reported for not assessing a domain was the perception that the domain was not part of the field of practice of the HCP. Approximately 10% of HCPs reported the absence of available outcome measures (Fig. 2) as a main reason for not assessing a HRQoL domain. When HCPs reported assessing a HRQoL domain, the clinical information obtained was mostly shared with patients and other members of the clinical team and rarely with caregivers or the referring physician (Fig. 3).

Clinical outcomes used and ideal clinical outcomes to assess HRQoL domains

HCPs reported assessing domains of HRQoL by mostly using CROs which include patient interviews and patient observation. In order of importance, CROs alone were mainly used to assess mental health domains (94.3%), followed by social health domains (94%), and physical health domains (73.6%) (Table 2). Use of PROMs or PerfOs

Table 1 Demographics and professional characteristics of participants

Characteristic	$n=36$	Frequency (%)
Sex		
Female	23	63
Profession		
Physical therapist	6	17
Occupational therapist	7	19
Psychologist	10	28
Social worker	1	3
Kinesiologist	3	8
Special education technician	1	3
Nurse	3	8
Doctor	5	14
Highest degree of education		
Baccalaureate	12	33
Masters	12	33
Doctorate	9	25
Other	3	9
	Mean ± SD	Range
Age (years)	42 ± 13	25–75
Years licensed	15 ± 11	2–35
Years of experience with chronic pain population	10 ± 8	1–31

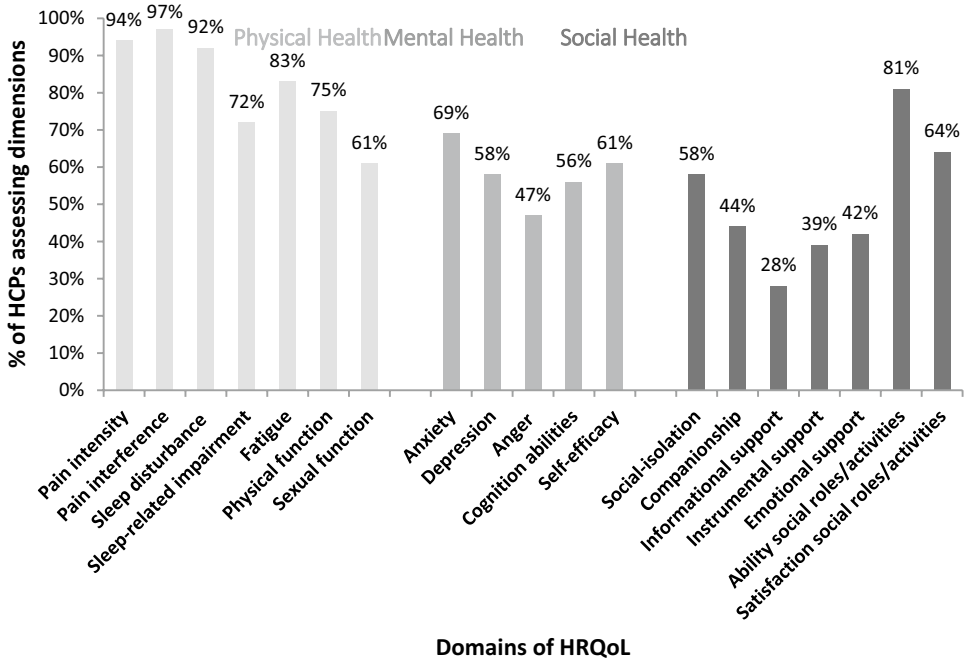

Fig. 1 HRQoL domains assessed by HCPs

only for assessing domains was seldom used. As shown in Table 3, there was a great variability in the reported outcome measures (OMs) for assessing HRQoL domains (i.e., 40 different OMs) with only 30% of OMs (12/40 OMs) used by more than one HCP. Of the 40 different OMs used, 70% ($n=28$) were PROMs and 30% ($n=12$) were PerfOs. The OMs more frequently used were PROMs, more specifically, the McGill Pain Questionnaire ($n=8$) and the Visual Analogue Scale ($n=7$) to assess *pain intensity*. Other frequently used OMs included the Pain Disability Index ($n=8$) to

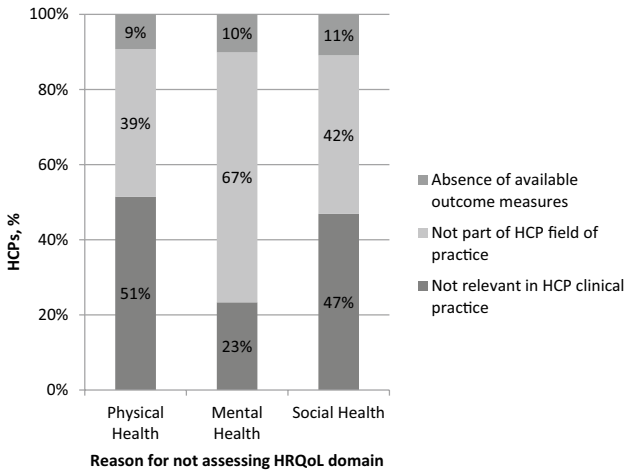

Fig. 2 HCPs' reasons for not assessing a HRQoL domain

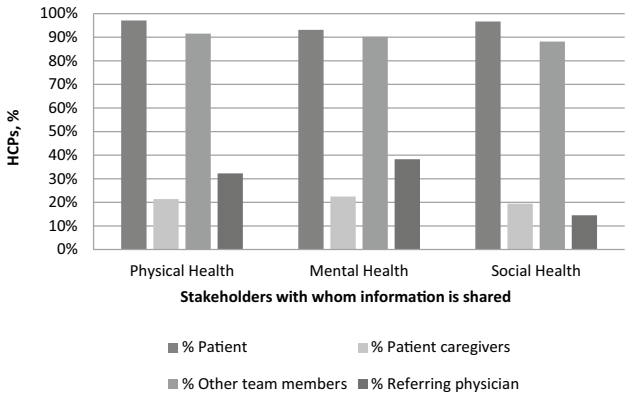

Fig. 3 Stakeholders with whom HCPs share clinical information of assessed HRQoL domains

assess domains of physical and social health, and the Hospital Anxiety and Depression Scale ($n=5$) to assess domains of mental health. There were no reported OMs for assessing five out of the seven domains included in social health, namely *social isolation, companionship, informational support, instrumental support,* and *emotional support*.

Regarding HCPs' perceptions of the ideal type of COs for assessing HRQoL domains, use of CROs only was still preferred with 54.2, 35.7 and 28% for social health, physical health, and mental health domains, respectively (Table 2). However, there was a perception that using more standardized OMs (PROs and/or PerfOs) may be preferable than the actual preponderant use of CROs. In addition, HCPs expressed a preference of using more PROs combined with CROs for assessing all domains of health. This preference was greater for social health domains (24.3% difference between reported use and ideal use of PROs combined with CROs), followed by mental health domains (19.7%) and physical health domains (2.8%).

Discussion

This is the first study to report the domains of HRQoL assessed by HCPs in multidisciplinary pain programs in their day to day practice and the types of outcomes used to measure these domains. HCPs reported assessing all domains of HRQoL with a higher proportion evaluating physical health, followed by mental health and social health. This agrees with the recommendations made by the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT), an international consortium of pain experts, that identified six core domains to be assessed for CP outcomes in clinical trials. Among these were pain, physical, and emotional functioning [22]. More importantly, this comprehensive and multidimensional assessment of CP patients is in accordance with the rationale that multidisciplinary pain programs should provide holistic biopsychosocial care that identifies and addresses physical, mental, and social needs [1, 11].

We also found out in our study a low use of standardized OMs (PROs and/or PerfOs) compared to CROs for CP management, which is not unique to our sample of HCPs and has been reported in several studies [23–25]. Indeed, many barriers to the routine use of OMs in diverse clinical settings were reported [26] and efforts to understand the specific barriers in each clinical setting to inform implementation strategies to address these should continue to be a research priority. Many elements can facilitate use of standardized assessments. There are a variety of OMs available that allow assessment of wide range of symptoms, behaviors, impairments, and disability [24, 27]. Several of these tools are freely available, and most are easy and inexpensive to administer [27].

Best practice in CP assessment [1, 12, 19] recommends using CROs, which include patient observation and interview, use of PerfOs which include administration of standardized tests [28], and PROs which provide unique insight from the patient about HRQoL domains affected by CP without the clinician's interpretation of her/his responses [29]. Given that pain is a multidimensional individual experience [30], PROMs have become the gold standard for the assessment of CP as they reflect the person's perception of his main HRQoL concerns and priorities for treatment [12, 31–34].

It is also important that HCPs share PROMs information with patients as this could promote patient-centered care where the patient is actively involved in his care and effectively collaborates in the decisions making process [34, 35]. Besides the potential to improve clinicians and patients'

Table 2 Outcomes measures used by HCPs for each HRQoL domain assessed

HRQoL domains	Outcomes measures	% of HCPs that reported using OMs to assess a domain[a]
Physical health		
Pain intensity	• McGill Pain Questionnaire	• 47% ($n=8/17$)
	• Visual analogue scale	• 41% ($n=7/17$)
	• Numeric rating scale	• 235% ($n=6/17$)
Pain interference	• Pain Disability Index	• 40% ($n=2/5$)
	• Multidimensional Pain Inventory	• 40% ($n=2/5$)
	• Oswestry Disability Index	• 20% ($n=1/5$)
	• Neck Disability Index	• 20% ($n=1/5$)
	• Lower extremity functional scale	• 20% ($n=1/5$)
	• Neck and Upper Limb Index (NULI)	• 20% ($n=1/5$)
	• Brief Pain Inventory	• 20% ($n=1/5$)
	• Disabilities of the Arm, Shoulder and Hand (DASH)	• 20% ($n=1/5$)
	• Canadian Occupational Performance Measure (COPM)	• 20% ($n=1/5$)
Sleep disturbance	• Brief Pain Inventory (BPI)	• 100% ($n=1/1$)
Sleep related impairment	• Epworth Sleepiness Scale	• 100% ($n=1/1$)
Fatigue	• Fatigue impact scale	• 66% ($n=2/3$)
	• Borg scale	• 33% ($n=1/3$)
	• Multidimensional Assessment of Fatigue	• 33% ($n=1/3$)
	• Fatigue Severity Scale (FSS)	• 33% ($n=1/3$)
Physical function	• Multidimensional Pain Inventory	• 17% ($n=1/6$)
	• Evaluation form of physical abilities	• 17% ($n=1/6$)
	• Berg Balance Scale	• 17% ($n=1/6$)
	• Muscle strength	• 17% ($n=1/6$)
	• Range of motion	• 17% ($n=1/6$)
	• Prehension force	• 17% ($n=1/6$)
	• Oswestry Disability Index	• 17% ($n=1/6$)
	• Neck Disability Index	• 17% ($n=1/6$)
	• Lower extremity functional scale	• 17% ($n=1/6$)
	• Neck and Upper Limb Index (NULI)	• 17% ($n=1/6$)
	• Brief Pain Inventory	• 17% ($n=1/6$)
	• Pain Disability Index	• 17% ($n=1/6$)
	• Standardized form for assessing fitness	• 17% ($n=1/6$)
Sexual function	• Pain Disability Index	• 75% ($n=3/4$)
	• Form for identifying rehabilitation goals	• 25% ($n=1/4$)
Mental health		
Anxiety	• Hospital Anxiety and Depression Scale (HADS)	• 27% ($n=3/11$)
	• Millon Clinical Multiaxial Inventory (MCMI-III)	• 9% ($n=1/11$)
	• Generalized Anxiety Disorder 7-item (GAD-7)	• 18% ($n=2/11$)
	• Tampa Scale of Kinesiophobia	• 27% ($n=3/11$)
	• Pain Catastrophizing Scale	• 18% ($n=2/11$)
	• Penn State Worry Questionnaire	• 9% ($n=1/11$)
	• Worry and anxiety questionnaire (WAQ)	• 9% ($n=1/11$)
Depression	• Beck's Depression Inventory	• 40% ($n=4/10$)
	• Hospital Anxiety and Depression Scale (HADS)	• 20% ($n=2/10$)
	• Millon Clinical Multiaxial Inventory (MCMI-III)	• 10% ($n=1/10$)
	• Patient Health Questionnaire (PHQ-9)	• 20% ($n=2/10$)

Table 2 (continued)

HRQoL domains	Outcomes measures	% of HCPs that reported using OMs to assess a domain[a]
Anger	• Injustice Experience Questionnaire	• 100% ($n=3/3$)
	• Tampa Scale of Kinesiophobia	• 33% ($n=1/3$)
	• Pain Catastrophizing Scale	• 33% ($n=1/3$)
Cognition abilities	• Test of Everyday Attention (TEA)	• 25% ($n=1/4$)
	• Montreal Cognitive Assessment (MoCA)	• 50% ($n=2/4$)
	• Mini Mental State Examination (MMSE)	• 25% ($n=1/4$)
Self-efficacy	• Prochaska' stages of change	• 100% ($n=1/1$)
	• Pain Catastrophizing Scale	• 100% ($n=1/1$)
Social health		
Social isolation	No OMs used	
Companionship	No OMs used	
Informational support	No OMs used	
Instrumental support	No OMs used	
Emotional support	No OMs used	
Ability social roles/activities	• Canadian Occupational Performance Measure	• 50% ($n=1/2$)
	• Brief Pain Inventory (BPI)	• 50% ($n=1/2$)
	• Pain Disability Index	• 50% ($n=1/2$)
	• Arthritis Impact Measurement Scales (AIMS) (brief version)	• 50% ($n=1/2$)
Satisfaction social roles/activities	• Canadian Occupational Performance Measure	• 100% ($n=1/1$)
	• Pain Disability Index	• 100% ($n=1/1$)
	• Assessment of life habits (LIFE-H)	• 100% ($n=1/1$)

[a]Some HCPs reported using more than one OM for assessing a given HRQoL domain

Table 3 Type of clinical outcomes (COs) used by HCPs and perceived type of ideal clinical outcomes to assess HRQoL domains

Type of COs	Physical health		Mental health		Social health	
	COs used (%)	Ideal COs (%)	COs used (%)	Ideal COs (%)	COs used (%)	Ideal COs (%)
PRO only	4.3	14.4	2.4	13	2	8.5
PerfO only	0.0	2.4	0.5	2	1	0.0
CRO only	73.6	35.7	94.3	28	94	54.2
PRO and PerfO	0.5	6.3	0.0	7	0	3.3
PRO and CRO	19.1	21.9	2.3	22	2	26.3
PerfO and CRO	2.1	9.6	0.4	10	0	2.8
PRO and PerfO and CRO	0.4	9.8	0.0	17	0	4.8

satisfaction, measuring meaningful outcomes for patients may promote patient-clinical team communication further enhancing self-management support and patient's engagement in treatment planning [35]. Our study results showed that more than 95% of HCPs shared assessment information with patients.

In contrast, only 28% of HCPs communicated assessment information to the referring GP. Sharing of assessment information with the GP is important given that CP is a chronic condition for which the patient will require consistent and lifelong management that will likely be provided and coordinated in primary care by a GP. Providing GPs with outcome information will allow them to more effectively monitor the evolution of the patient during and after every episode of care. Communication of patient outcomes between different clinical settings (primary and secondary or tertiary care) is essential as it could contribute to improved coordinated and integrated care that will be better aligned with patient's needs and thereby improving the quality of care [36, 37].

Overcoming common challenges of implementing PROMs will facilitate the implementation of comprehensive assessments for CP that include PROMs. The first is the sheer number of available tools that makes it difficult for clinicians to make an informed choice to select the best

tool based on psychometric properties, usefulness for clinical decision making and applicability in the clinical context while considering patient burden [31]. For instance, Deckert et al. [38] identified more than 140 outcome definitions with a high heterogeneity in the measurement instruments used for assessing CP in multidisciplinary settings. Our results also showed that there was great variability in the choice of OMs and particularly PROMs used among HCPs. Indeed, only 30% (12/40) of the 40 different OMs reported to be used by HCP are used by more than one HCP.

One solution is to develop a core set of OMs for each HRQoL domain, or to develop a core set grounded on the most important domains of HRQoL to be assessed, based on a consensus among different stakeholders including HCPs, persons suffering from CP, decision makers, experts, and researchers in CP [22, 24, 32, 33, 38–40]. Such initiatives have already been ongoing for several years (see Kaiser and al., 2016 for detailed description); however, currently there is no consensus for either the domains or the OMs to be used in a clinical context. Furthermore, the focus of these initiatives is mostly to identify HRQoL domains and OMs pertinent for assessing the effectiveness of CP interventions in clinical trials and less consideration is given to the feasibility of implementing OMs in a clinical context.

The second challenge is that most OMs are too long to be able to cover each relevant domain and achieve precise estimates. One interesting avenue could be to use PROMs from the item banks developed by the PROMIS initiative that cover different domains of physical, mental and social health, [21] instead of using legacy OMs that may be lengthy. PROMIS PROMs can be administered in a variety of formats including short forms and computerized adaptive tests (CAT). A big advantage of CAT is that items are automatically selected from the item bank based on the person's responses to previous items. This tailored measurement to functioning of the individual respondent allows for very precise assessment with only 4–6 items that are enough to assess many HRQoL domains which reduces considerably time of completion and patient's burden [41, 42]. Furthermore, in accordance with our results, using PROMIS will allow clinicians to assess multiple domains of HRQoL, as they do, but more efficiently. Although psychometric testing of PROMIS items banks is ongoing in different CP populations (e.g., [43, 44]), more studies are needed to assess the measurement properties of PROMIS items in specific CP populations such as low back pain, neck pain, fibromyalgia, or osteoarthritis.

Finally the implementation of PROMs is a complex enterprise because it often requires the use of multiple implementation strategies (e.g., audit and feedback, interactive training, clinical champions) to overcome the numerous barriers that can impede implementation and also because the implementation process occurs in contexts which are themselves complex because of the interaction of multiple levels (e.g., patients, HCP, multidisciplinary teams, departments) [45]. Given these reasons, the implementation of PROMs and its sustained use could benefit from the use of principles and methods of implementation science which focus both on the impact of the implementation strategy on the use of the new intervention (in our case PROMs) and on the health impact of the new intervention itself [45, 46]. We have applied this approach to the development of implementation strategies and training for chronic pain [47].

Strength and limitations

This study established current HCPs practices in the assessment of domains of HRQoL in multidisciplinary pain settings and the types of COs used. This study has some limitations that should be considered when interpreting the results. First, our response rate was only 53% so it may limit the ability to generalize our findings. Those with an interest toward the evaluation of HRQoL domains using different types of COs may be overrepresented in our sample. Second, the study population was derived from one Canadian province and from urban and university affiliated health care organizations, so the findings might not be representative of HCPs in other geographical regions or working in other types of organizations. In addition, not all multidisciplinary teams are composed of the same type of HCPs, so this might limit the generalizability of the study findings.

Conclusion

The findings of our study show that all domains of HRQoL are measured by at least some HCPs in multidisciplinary CP settings by mostly using CROs with a preponderance of patient interview and patient observation as a method of assessment. Standardized OMs including PROMs and PerfOs are not frequently used, and when used, very few are consistently used across HCPs. However, HCPs express an interest in using more standardized OM which suggests a need for a consensus among different stakeholders in CP management, including patients, on core domains of HRQoL and their associated OMs to promote a more evidence-based assessment and patient-centered care that addresses physical, mental, and social needs of CP sufferers.

Funding No funding was received for this study.

Compliance with ethical standards

Conflict of interest The authors report no conflicts of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

Appendix 1: Extract from the survey: sample question for one from the 19 dimensions of HRQoL

I. PHYSICAL HEALTH

Dimension 1: Pain intensity: Assesses the level of pain perceived by a person.

1. In your clinical practice, do you assess pain intensity?

○ Yes

○ No

2. What are the reasons for not assessing pain intensity?

☐ Not relevant to my clinical practice

☐ Not relevant for the patient

☐ Lack of appropriate standardized measurement tools / questionnaires for patients

☐ Other, please explain: _____

3.How do you assess pain intensity?

☐ With a standardized questionnaire, please name it: _____

☐ By patient interview

☐ Other means, please specify: _____

4.With whom do you share the information about the assessment and evolution of pain intensity?

☐ With the patient

☐ With the patient caregivers (if authorized by the latter)

☐ With other team members

☐ With the referring physician

☐ Other, please specify: _____

5. What would you consider the ideal method to assess pain intensity?

☐ With a standardized Patient reported outcome measure

☐ With a standardized measurement tool / questionnaire administered by the therapist

☐ By interview (administered by the therapist)

☐ Other method, please specify: _____

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