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Measuring Shared Decision-Making and Collaborative Goal-Setting in Community Rehabilitation: A Focused Ethnography Using a Prospective Cohort

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Title: Measuring Shared Decision-Making and Collaborative Goal-Setting in Community Rehabilitation: A Focused Ethnography Using a Prospective Cohort

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ABSTRACT (250 words)

Objective: To measure shared decision-making (SDM) experience from the perspective of patients and providers in diverse community-rehabilitation settings.

Design: Prospective, longitudinal surveys

Setting: 13 primary level-of-care community-rehabilitation sites in diverse areas varying in geography, patient population, and provider discipline

Subjects: 341 adult, English-speaking patient-participants, and 66 provider-participants

Measures: ASK-MI (dyadic tool measuring SDM), WatLX^{TM} (outpatient rehabilitation experience), and demographic questionnaire. Survey packages distributed at two time-points (T0=recruitment; T1=3-months-later)

Results: We found that amongst 341 patient-provider dyads, 26.4% agreed that the appointment at recruitment involved high-quality SDM. Patient perceptions of goal-setting suggested that 19.6% of patients did not set a goal for their care, and only 11.4% set goals in functional language that tied directly to an activity/role/responsibility that was meaningful to their life. Better SDM was clinically associated with higher total family income (p=0.045), more privacy during the appointment (p=0.070), regional-urban settings (p=0.068), and provider participation in person-centred behaviour-change training (p=0.091).

Conclusions: These findings clarify that there is a need to improve the consistency and quality of SDM and goal-setting in community rehabilitation. For patients, lower ratings of SDM corresponding to less recognition of their preferences, which is the heart of SDM. Actionable strategies include privacy promotion, person-centred training, and developing strategies to identify and support financially-vulnerable patients. Study limitations include recall bias, the Hawthorne effect, acquiescence and social desirability bias. We recommend more research into strategies that advance highly-functional goal-setting with patients, and that lessen survey ceiling effects.

Article Summary: Strengths and limitations of the study

- One strength is that this study has a significant sample size, with 341 patient participants completing surveys.
- Another strength is that participant diversity allows for statistically-appropriate comparisons based on geography, level of privacy, patient demographics, and provider training.
- Study limitations include that the survey measuring shared decision-making is novel, has a floor effect, and may be subject to acquiescence and social desirability biases.

Keywords: shared decision-making, community, rehabilitation, patient perspectives, provider perspectives, survey, goal-setting

Introduction

Measurement of shared decision-making (SDM) remains challenging, but necessary [1–3]. Internationally, mandates call for greater patient engagement in healthcare and health research [4–8]. Accurate measurement of SDM is necessary to confirm the realization of such mandates. Shared decision-making (SDM) is a decision-making process wherein provider(s) and patient contribute and collaborate by sharing best available evidence as well as patient values, preferences and lived experience [9, 10].

The plethora of SDM definitions have contributed to many different tools being developed [1, 11, 12]. To date, SDM measurement tools do not correlate with SDM teaching. No universally-accepted standard outcome or experience measure exists to assess SDM [1], particularly for non-physician interactions. A 2015 review found that only four of 13 SDM tools involved patients during their development [3], bringing into question content validity. Potentially inaccurate presumptions remain that patients are aware of 'decision points' and that only one decision point exists per consult [3].

The conceptualization and operationalization of SDM has further challenged understanding, and measurement, of SDM. Some approaches to SDM have become quite technical, tokenistic and rote; these often involve checklists and expectations met in theory, but lack full collaboration [13]. Humanistic approaches to SDM are more collaborative, engaging and transparent; it requires "…understanding of the person and their human situation and working together to discuss and form ways forward that make sense for each person and their situation" [13]. A systematic review (n=154 studies) revealed that prospective studies assessing SDM in clinical settings rarely examined the humanistic aspects of patient-clinician communication such as respect, compassion, integrity, empathy: only 9% of 154 studies contained any remark on humanistic communication [13].

Qualitative research by team members revealed challenges with a previously-published SDM tool (SDM-Q-9) in primary care and mental health settings [14]. Challenges included inability to capture the SDM phase when problems are discussed and prioritized; the lack of a "not applicable" option; an over-emphasis on medical conditions; a lack of relevance for non-pharmacological interventions; and, the lack of recognition that SDM is valuable in goal-setting, investigations, as well as (as opposed to exclusively for) exploring treatment options [Olson K, et al. "Development of the Alberta Shared Decision-Making Measurement Instrument" *Under Review*].

A novel, dyadic SDM tool was developed: the Alberta Shared decision-maKing Measurement Instrument (ASK-MI) (Figure 1 is the patient version; provider version is same except language transposed to address provider). Using a 6-point Likert Scale (with not-applicable option), patients and providers independently describe the appointment experience from a SDM-process perspective. This process involves patients and providers agreeing on the main concern; working together to make a plan that considers patients' wishes; and, ensuring the provider confirms patient understanding and next steps. The ASK-MI was developed and piloted in primary care and mental health clinics in Alberta [14].

This research program used this tool in community rehabilitation, an under-studied context regarding SDM [15]. For patients and providers of diverse community-rehabilitation sites across a single province in an industrialized country, we aimed to:

(a) measure the prevalence of high-quality SDM experiences using the ASK-MI tool;
(b) measure goal-setting perceptions by patients;
(c) determine any associations between SDM experience (ASK-MI score) and demographic and contextual factors (e.g. geography, patient and provider age, gender, discipline).

This study complements another in this population that used qualitative interviews to explore SDM experiences [16]. While the dyadic ASK-MI moves towards illuminating the humanistic communication, or lack thereof, in SDM, the complementary qualitative study explored this concept in great detail. The research team included two patient-co-investigators who consulted on the research design, implementation and results dissemination.

Methods

We used focused ethnography in this research program [17]. Ethnography involves making cultural inferences "(1) from what people say; (2) from the way people act; and (3) from the artifacts people use" [18]. We focused on the communities of patients and professionals composing diverse community-rehabilitation sites across a provincial geography. Focused ethnography features a problem-focused and context-specific approach; a focus on a discrete phenomenon; the conceptual orientation of a single researcher; involvement of limited participants; episodic participant observation; participants with specific knowledge; and an emphasis on academic and healthcare settings [19, 20]. We met all criteria save participant observation due to feasibility constraints.

Participant Population

We captured diverse rehabilitation settings that saw outpatients including both public and private provider sites, as well as three geographic types (rural (population < 10000), regional-urban (population between 10000 and 100000), and metropolitan-urban (where population > 100000)).

Participants included current patients and providers visiting and working, respectively, at study sites. Provider inclusion criterion was employment at the site at recruitment. Patient inclusion criteria included ≥ 18 years of age; their provider was participating; able to consent without proxy; and can understand and speak English. There were no exclusion criteria.

Recruitment

Site leadership informed provider recruitment. Tactics included email introductions followed by study presentations (by webinar, in-person, or one-on-one). After discussions, informed consent was procured.

Convenience sampling directed patient recruitment. Management identified onsite recruiters from clerical and therapy-assistant staff. Researchers trained recruiters to identify eligible patients, discuss participation, and record those patients accepting take-home study packages. While provider-participants may have mentioned the study to patients, only onsite recruiters distributed surveys. Recruitment was bounded by a four-week site maximum and a 20-patient limit per provider to minimize site and provider burden. Patient consent was implied by the mailed return of surveys; written consent was required for future data sharing and future research contact.

Data Collection

We used validated surveys to measure SDM (ASK-MI tool), quality of life and patient experience (WatLX^{TM} survey) over two time-points (T0=baseline at recruitment; T1=3-months post-baseline). Demographic and contextual data was collected from participants at T0. Survey completion took 5-7 minutes per time-point.

The dyadic ASK-MI tool requires patient and provider to independently rate six facets of the SDM experience; lower numeric scores reflect higher quality SDM. Individual scores are summed; the two sum scores are compared to determine the final rating score: Excellent, Acceptable, or Unacceptable. When both patient and provider rate SDM highly, an Excellent rating score is reached. Disparity between parties would lead to a lower ASK-MI rating score. Full agreement on SDM Excellence equates to patient and provider both giving the best, lowest numeric score on each ASK-MI item. Using self-report, we collected contextual (e.g. group or individual appointment; were goals set with provider) and participant demographic data (e.g. age, gender, marital status).

The WatLX™ is a 2-page outpatient rehabilitation care patient experience survey meant for post-completion of rehabilitation care. The WatLX™ consists of 10 questions, where respondents can respond either not applicable or on a 7-point Likert scale. Psychometric testing of the WatLX™ involved 1174 cognitively-intact, English-speaking, adult outpatients who had completed a program of cardiac, musculoskeletal, neurologic, stroke, pulmonary, or speech language rehabilitative care in Ontario [21]. Reliability analyses compared the use of a 7-point to 5-point Likert scale in the WatLX™. Cronbach's alphas were 0.863 and 0.957 for the 5 and 7-point scale, and the ICC = 0.827 and 0.880, respectively [21]. Generally, the higher the score, the more positive the patient experience. There is evidence of ceiling effects with the WatLX™.

The T0 take-home study package included a consent form and directions, the ASK-MI survey, a patient demographic form including their communication preference for the 3-month follow-up (T1) surveys (which included WatLX™). All envelopes were pre-addressed and stamped to support convenient, confidential return to the researchers. Patients were directed to complete the surveys within 24 hours, so their appointment was fresh in their mind.

When a patient took a study package, the recruiter logged the date, envelope number, patient's initials, and provider name. Daily, this recruitment information was sent to the lead researcher, who emailed the ASK-MI (provider version) tool to the named provider, along with the patient initials via personalized email link to REDCAP at the University of Alberta. Providers received one email per patient and had 48 hours to complete the survey.

The second time-point (T1), for patients only, was exactly three months post-recruitment. T1 data collection was by mail or email per patient-participant preference. Participants received email or phone reminders 1-week prior to T1, and at 7-days post-T1.

To ensure the accuracy of data entry of paper surveys, a randomly-selected 30% of the study sample was assessed at the close of data collection. If more than 10% of the data was incorrectly entered, then another random 30% of the study sample would have been checked. Errors were rectified immediately.

Data Analysis

After cleaning and coding the T0 and T1 data, we completed descriptive and exploratory analyses to address the research questions. The ASK-MI Score was collapsed into two different binary categorical variables: (a) Excellent versus Acceptable/Unacceptable; and (b) Full Agreement on SDM Excellence versus Not Full Agreement on SDM Score. The secondary variable was overall rehabilitative care experience (WatLX^{TM}). Independent variables included age, gender, patient income range, geographical area, and other demographic and contextual variables.

The distribution of interval and ratio type survey data (e.g. age) was checked for whether it is normally distributed. Test selection was based upon the results of these analysis (e.g. non-normally-distributed data was analyzed using non-parametric tests). We analyzed the questionnaire data descriptively, with means, standard deviations, both overall in community rehabilitation and based on contextual differences. For categorical data, chi-square tests directed comparisons between high versus low quality SDM; sub-analyses using tests of proportions considered this ratio of experiences in different demographic and organizational settings based on the size and quality of independent variable data collected. For the three surveys, where missing data was less than 5% across population, then used the 20% as the threshold for missing items: if ≤ 20% items missing, then median response used in place of the missing item to then score the survey; if > 20% of items missing, then the entire record was deleted from the analysis [22]. Univariate correlations were studied between each independent variables (age, gender, income, geographical area, provider discipline) and the ASK-MI score.

Results

Participant Information

Thirteen community-rehabilitation sites distributed 606 take-home survey packages; 341 patients returned them and thus implied consent to participate (response rate 56.2%). At T1, 209 patients returned surveys (response rate 61.3%, the remainder lost to follow-up).

Table 1 describes the patient-participant population. The patient-participants' mean (SD) age was 57.5 (16.4) years. Most patient-participants were female (58.9%), married (68.9%), Caucasian (90.9%), had some post-secondary education (70.4%), were at a 1:1 appointment with providers (90.9%), were neither at the first nor last appointment at recruitment (66.9%), and were receiving physiotherapy (68.6%). Participants varied in where they received their care: 46.3% were in an open exercise area, 48.4% were in a private area (either behind a privacy curtain or in private room), and 3.8% described their area as unique. The demographic profile was similar between T0 and T1 patient-participants.

	N (%)
Patient Population	341 (100%)
Mean Age in years (SD)	57.5 (16.4)
Missing	3 (0.9%)
Gender	
Male	138 (40.5%)
Female	201 (58.9%)
Missing	2 (0.6%)
Marital Status	
Single	48 (14.1%)
Married (legal/common law)	235 (68.9%)
Separated or Divorced	32 (9.4%)
Widowed	21 (6.2%)
Missing	5 (1.5%)
Geographical Location	
Metropolitan-Urban	145 (42.5%)
Regional-Urban	161 (47.2%)
Rural	35 (10.3%)
Education	
High school diploma or less	96 (28.1%)
Any post-secondary education	240 (70.4%)
Missing	5 (1.5%)
Employment Status	
Employed	141 (41.3%)
Unemployed	61 (17.9%)
Retired	135 (39.6%)
Missing	4 (1.2%)
Ethnicity	
European Origins	310 (90.9%)
Indigenous (e.g. Inuk, Métis)	10 (2.9%)
Non-European Origins	21 (6.2%)
Supplementary Insurance	
Yes	144 (42.2%)

No	160 (46.9%)
Prefer not to answer	37 (10.9%)
Total Family Income	
Less than $59999	106 (31.1%)
$60000 to 99999	75 (22.0%)
$100000 or More	78 (22.9%)
Prefer not to answer	82 (24%)

Table 1. Patient-Participant Demographics

Table 2 describes the provider-participant population. The provider-participants' mean (SD) age was 41.8 (9.86) years. Experience-wise, providers had a mean (SD) of 15.1 (10.3) years of experience. Providers represented six rehabilitation disciplines, with physiotherapy (53.0%) and occupational therapy (19.7%) being most prevalent. Most providers were female (60.6%), Caucasian (60.6%), trained in Canada (66.7%), and had primarily clinical provider roles (vs. management) (71.2%).

Provider Participant Characteristics	N (%) or Mean (SD)
Population	66
Age (years)	41.83 (9.86)
Missing	13 (19.7%)
Gender	
Male	13 (19.7%)
Female	40 (60.6%)
Missing	13 (19.7%)
Provider Discipline	
Occupational Therapy	13 (19.7%)
Physiotherapy	35 (53.0%)
Other	5 (7.5%)
Missing	13 (19.7%)
Country of Training	
Canada	44 (66.7%)
Outside of Canada	9 (13.6%)
Missing	13 (19.7%)
Ethnicity	
European Ethnic Origins	40 (60.6%)
Non-European Ethnic Origins	8 (12.1%)
Missing	18 (27.2%)
Geographical Location	
Metropolitan-Urban	36 (54.5%)
Regional-Urban	24 (36.4%)
Rural	6 (9.1%)

Table 2. Provider-Participant Demographics

Table 3 describes the provider-participants' work settings. Providers worked a mean (SD) of 31.8 (9.0) hours/week in direct patient care, and saw a mean (SD) of 28.8 (17.6) patients per week. The outpatient clinical settings varied for providers, including community-based (31.8%) and hospital-based (45.5%) clinics. The clinical populations included at least 10 diverse populations, including general adults (25.8%), musculoskeletal (16.7%), and neurorehabilitation (13.6%). Providers were evenly split on participation in a person-centred behaviour-change course (HealthChange® Methodology [23]): 39.4% said they had taken it, 40.9% said they had not taken it, and 19.7% responses were missing herein. Of the providers who had taken HealthChange®, most providers perceived that it influenced their patient interactions to some degree (76.9%) (vs. to a great degree (15.4%)). The perceived influence of HealthChange® on site processes was less clear: 42.3% of providers saw no influence, while 53.8% saw some degree of influence.

Provider Participant Characteristics	N (%) or Mean (SD)
Setting	
Community-Based Clinic	21 (31.8%)
Hospital, outpatient Clinic	30 (45.5%)
Primary Patient Population	
Complex Adults	2 (3.0%)
Hand/Foot/Cardiac	4 (6.0%)
General Adults	17 (25.8%)
Musculoskeletal (MSK)	11 (16.7%)
Neuro	9 (13.6%)
Ortho/Surgery	3 (4.5%)
Seniors	4 (6.1%)
Missing	16 (24.2%)
Average Waitlist (days) for Clinic	16.59 (17.59)
Missing	18 (27.3%)
HealthChange® Completion	
Yes	26 (39.4%)
No	27 (40.9%)
Missing	13 (19.7%)
HealthChange® Influenced Patient Interactions?	
No Influence	1 (3.8%)
To Some Degree	20 (76.9%)
To a Great Degree	4 (15.4%)
Missing	1 (3.8%)
HealthChange® Influenced Site Processes?	
No Influence	11 (42.3%)
To Some Degree	14 (53.8%)
To a Great Degree	0 (0%)
Missing	1 (3.8%)

Table 3. Provider-Participants' Clinical Setting

SDM and Goal-Setting Prevalences in Community Rehabilitation

Using current ASK-MI scoring guidelines, 78.9% of T0 patient-provider appointments rated Excellent (Table 4). Given the evident floor effect of the ASK-MI (i.e. more than 15% of respondents have the lowest score, which is the best value [24]), the survey developers will re-assess the scoring algorithm (incomplete at time of manuscript submission).

Shared Decision-Making Experience	N (%) or Mean (SD)
ASK-MI Score	
Excellent	269 (78.9%)
Acceptable	37 (10.9%)
Unacceptable	2 (0.6%)
Missing/Unable to Calculate	14 (4.1%)
Patient and Provider had Full Agreement on SDM Excellence	
Full Agreement	90 (26.4%)
Less Than Full Agreement	218 (63.9%)
Missing/Unable to Determine	14 (4.1%)
Was a Goal Set with Provider?	
Yes	270 (79.2%)
No	67 (19.6%)
Missing	4 (1.2%)
Level of Functionality of the Patient-Stated Goal	
Highly Functional, focused on everyday activity (i.e.	39 (11.4%)
patient language)	140 (41.1%)
Moderately Functional, focused on general mobility	76 (22.3%)
Not Functional, focused on treatment plan (i.e.	86 (25.2%)
provider language)	
Not Applicable, no goal was set or goal not provided	

Table 4. Prevalence of Shared Decision-Making and Goal-Setting

Looking at full agreement on SDM excellence or not, at T0, 26.4% of patient-provider encounters involved full agreement on SDM excellence. Figures 2 and 3 display the frequency of responses across the 6-item Likert scale for each ASK-MI question for patients and providers, respectively. These two graphs reveal that, across the six items, providers agreed less often about SDM excellence (i.e. relatively fewer responses at 'strongly agree').

For patients, there was less agreement that the patient and provider planned together to address the patient's preferences and that the plan considered the patient's wishes and abilities. Patients more often strongly agreed that the provider checked the patient's understanding of the plan and that there was agreement on the plan created.

For providers, there was less agreement that the patient and provider worked together to make a plan that addressed patient preferences. Providers more often strongly agreed that there was clarity and agreement on the visit's main focus; that the provider checked that patient understanding; and that the patient and provider agreed on the plan created.

Table 5 compares the three geographical settings on prevalence of high quality SDM (i.e. full agreement on SDM excellence) in patient-provider encounters, which demonstrates clinically significant differences in the quality of SDM experiences between geographical areas: metropolitan areas (19.9%) and regional areas (33.8%) (p=0.068).

Variable	**Geography**			F statistic Value (df)	P-value
	Metropolitan Urban Mean (SD) [95% CI] OR %	Regional Urban Mean (SD) 95% CI	Rural Mean (SD) 95% CI		
Patient Age	53.36 (17.29) [50.51-56.21]	61.08 (14.88) [58.74,63.41]	57.97 (15.14) [52.77-63.17]	8.824 (df 2)	< 0.001
Months Knew Provider Before Recruitment	8.40 (14.91) [5.54,11.26]	24.64 (2.39) [5.03,14.52]	51.76 (63.95) [25.36-78.16]	25.88	<0.001
% Appointments with Excellent ASK-MI Score	84.2%	89.0%	90.9%	1.91 (df 2)	0.384
% of Appointments with Full Agreement on SDM Excellence	19.9%	33.8%	26.7%	11.73 (df 6)	0.068
% Patients Perceived that Goals were Set	81.3%	79.1%	80.0%	0.22 (df 2)	0.90
% Perceived Goals were Functional	16.4%	6.3%	14.3%	8.627	0.196
% Providers Took HealthChange® Before	20.7%	56.7%	40.0%	37.05 (df 4)	< 0.001
% Appointments in Private Area	31.7%	69.2%	68.6%	46.25	< 0.001
Income				43.09	< 0.001
Less than $59999	26.1%	40.9%	20.6%		
$60000 to 99999	26.8%	21.4%	14.7%		
$100000 or More	37.0%	12.3%	23.5%		
Prefer not to answer	10.1%	25.3%	41.2%		
Rehabilitation Patient Received				14.07 (df 4)	0.007
Physiotherapy	69.7%	87.2%	74.3%		
Occupational Therapy	27.0%	10.6%	25.7%		

Other	3.3%	2.1%	0%		

Table 5. Comparison of Three Geographical Areas on SDM, Demographic and Contextual Variables

At T0, 19.4% of patients stated that they had not set a goal for their rehabilitation care (Figure 4). When patients had set a goal, they were asked to describe the goal. We categorized the patient-perceived goals based on level of functionality (Table 4). Functional goals speak to participation in a role, responsibility or activity that is important to the person. Less-functional goals relate solely to treatment plans or lack specificity. Only 11.4% of patients stated goals that met the RMoC definition of functionality. A broader definition of functionality includes goals that aim for general improvements in, for example, mobility or strength. Under this broad definition, 42.6% of patients perceive their rehabilitation goals as aimed towards achievements or activities important to their life (Figure 5). Some 22.3% of patients perceived goals as equal to the treatment plan (e.g. doing home exercises, coming to appointments).

SDM, Goal-Setting, and Associated Factors

The only patient characteristic associated with SDM was total family income wherein the lowest income bracket had less instances of full agreement on SDM excellence (p=0.045). SDM experience quality was not associated with whether patients' perceived that goals were set or whether patients' perceived goals that were functional. SDM experience was not associated with other immutable patient characteristics (e.g. gender, education, employment status, insurance access) or appointment type (Table 6).

Variable	**Patient & Provider Full Agreement on SDM Excellence?**		Pearson Chi-Square Value (df)	P-value
	Yes Count (%)	No Count (%)		
Seen Provider Before Recruitment?			0.313 (df 2)	0.855
Yes	76.9%	74.4%		
No	23.1%	25.6%		
Appointment Timing at Recruitment			13.57 (df 6)	0.035
First Appointment	27.9%	22.6%		
Near Start of Care	37.2%	35.4%		
Near End of Care	30.2%	38.7%		
Last Appointment	4.7%	3.3%		
Appointment Type				

Group	6.6%	9.5%	0.734 (df 2)	0.693
Individual	93.4%	90.5%		
Where in Facility				
Open Area	39.8%	49.3%	7.05 (df 3)	0.070
Private Area or Other	60.2%	50.7%		
Patient Perceived Goals Set?				
Yes	80.2%	81.7%	2.567 (df 2)	0.277
No	19.8%	18.3%		
Perceived Goals were Functional?				
Yes	14.3%	10.9%	0.793 (df 2)	0.673
No	85.7%	89.1%		
Female Gender	58.2%	58.6%	0.015 (df 2)	0.993
Marital Status				
Married (incl common law)	72.5%	69.9%	3.08 (df 3)	0.379
Not, or No Longer, Married	27.5%	30.1%		
Education				
High school diploma or less	30.8%	26.5%	2.68 (df 3)	0.443
Any post-secondary education	69.2%	73.5%		
Employment				
Employed	41.8%	42.9%	3.50 (df 6)	0.743
Unemployed	16.5%	17.8%		
Retired	41.8%	39.3%		
Insurance				
Yes	45.1%	43.8%	7.515 (df 6)	0.276
No	41.8%	48.4%		
Prefer not to answer	13.2%	7.8%		
Income				
Less than $59999	33.7%	62.3%	17.269 (df 9)	0.045
$60000 to 99999	21.3%	24.5%		
$100000 or More	30.3%	21.7%		
Prefer not to answer	14.6%	22.6%		
Provider Discipline				
Physiotherapy	74.4%	81.3%	12.69 (df 6)	0.048
Occupational Therapy	25.6%	15.5%		
Other	0%	3.1%		
Provider Took HealthChange?			11.11 (df 6)	0.085
Yes	73.9%	41.2%		
No	26.1%	58.8%		
Provider Trained in Canada	85.3%	83.2%	0.264 (df 2)	0.877

Table 6. Relationship between Full Agreement on SDM (High Quality SDM) and Other Demographic or Contextual Factors

Clinically-significant higher levels of SDM experience were associated with earlier timing of the rehabilitation appointment (65.1% high-quality-SDM vs. 58.0% less-quality-SDM, p=0.035), more privacy during the appointment (60.2% high-quality-SDM vs. 50.7% in low-quality-SDM, p=0.070), non-physiotherapy (74.4% physiotherapy in high-quality-SDM vs. 81.3% physiotherapy in low-quality-SDM, p=0.091) and if the provider had taken HealthChange® (73.9% in high-quality-SDM vs. only 41.2% high-quality-SDM if not taken, p=0.085). SDM experience was not associated with the providers' experience (in years since graduation) or the time since the provider took HealthChange®.

SDM and goal-setting varied across the three geographical areas (Table 5). In regional-urban settings, patients experienced higher levels of SDM experience (p=0.068) but less functional goals were set (p=0.066). More providers had taken HealthChange® (p<0.001) in regional settings compared to rural and metropolitan settings. There was no difference in the proportion of patients with functional goals across geographies. Demographically, more patients had lower total family income in regional areas (40.9% lowest-income-bracket vs. 26.1% (metropolitan) or 20.6% (rural), p<0.001). Contextually, metropolitan-urban areas were unique in that fewer appointments were in private areas (31.7% vs. 69.2% in regional and 68.6% in rural, p<0.001) and fewer providers had taken person-centred behaviour-change training (HealthChange®) (20.7% vs. 56.7% in regional and 40.0% in rural, p<0.001). Finally, occupational therapy was represented least often in regional-urban appointments (10.6% vs. 27.0% (metropolitan) and 25.7% (rural), p=0.007).

Patients who perceived that a goal was set for their care saw a higher proportion of occupational therapists (35.5% vs. 14.7%, p=0.001). It appears that the clinically-relevant impact of behaviour-change training (HealthChange®), provider discipline and level of privacy had opposite relationships with goal-setting and SDM (e.g. providers who took HealthChange® were associated with more high-quality SDM experiences, but FEWER experiences of patients setting goals).

While the time a provider knew the patient before T0 was associated with whether a goal was set (p=0.054), the variance was high. Few other patient or provider characteristics were associated with patient perceptions of goal-setting. Patient perceptions of goal-setting for their rehabilitation did not differ by geographical setting, patient gender, marital status, education, employment status, or total family income (Table 7). Provider experience was not associated with patients' perceptions of goal-setting. Provider HealthChange® participation was not associated with patients' perception of goals setting or the functionality of the goal set.

Variable	**Did Patient Perceive that a Goal was Set for Rehabilitation Care?**		Test Statistic Valude (df)	P-value
	Yes Mean (SD) OR %	No Mean (SD) OR %		
WatLX™ Overall Rehabilitation Experience	9.034 (1.251)	8.717 (1.953)	F=1.47 (df 1)	0.227
Patient Age at T0	57.23 (15.92)	57.30 (18.14)	F=0.001 (df 1)	0.974
Provider's Experience	14.05 (10.67)	13.91 (10.17)	F=0.008 (df 1)	0.930
Time Patient Knew Provider	11.51 (24.63)	21.93 (51.61)	F=3.760 (df 1)	0.054
Months Since Provider Took HealthChange®	11.87 (19.86)	19.65 (26.73)	F=2.546 (df 1)	0.113
% Patients with Female Gender	59.6%	54.0%	x^2=0.666 (df 1)	0.414
% Providers took HealthChange®	39.2%	42.6%	x^2=0.474 (df 2)	0.789
Where in Facility			x^2= 2.780 (df 1)	0.095
Open Area	49.1%	37.5%		
Private Area or Other	50.9%	62.5%		
Marital Status			x^2=0.910 (df 1)	0.34
Married (incl common law)	190 (71.2%)	43 (65.2%)		
Not, or No Longer, Married	77 (28.8%)	23 (34.8%)		
Education			x^2=1.612 (df 1)	0.204
High school diploma or less	72 (27.0%)	23 (34.8%)		
Any post-secondary education	195 (73.0%)	43 (65.2%)		
Employment			x^2=2.316 (df 2)	0.314
Employed	118 (44.2%)	23 (34.3%)		
Unemployed	46 (17.2%)	15 (22.4%)		
Retired	103 (38.6%)	29 (43.3%)		
Income			x^2=2.458 (df 3)	0.483
Less than $59999	80 (30.7%)	25 (40.3%)		

$60000 to 99999	63 (24.1%)	11 (17.7%)		
$100000 or More	64 (24.5%)	14 (22.6%)		
Prefer not to answer	54 (20.7%)	12 (19.4%)		
Provider Discipline			x^2=13.79 (df 2)	0.001
Physiotherapy	192 (82.8%)	39 (62.9%)		
Occupational Therapy	34 (14.7%)	22 (35.5%)		
Other	6 (2.6%)	1 (1.6%)		

Table 7. Clinically Relevant Differences Between Whether Patient Set a Goal or Not During Care and Other Variables

Finally, the mean (SD) overall WatLX™ rating of patient experience was 8.97 (1.39), where 10 was the highest rating. Item mean (SD) ratings ranged from 5.65 (1.35) to 6.79 (0.579) (7 was highest rating). Figure 6 demonstrates the distribution of responses along the 7-point Likert scale for these 10 items. The item with the greatest use of not applicable was having chosen family or friend given information that they needed about the patient's care, which suggests this question may be relevant for many patients. The lowest rated items were for achieving treatment goals and controlling physical pain as much as possible. The highest rated items were for being treated with courtesy, feeling safe during treatment activities and would recommend to others.

The mean (SD) overall rehabilitation experience when patients' experienced high-quality SDM experiences was 9.07 (1.57), and was not different from the experience of participants who reported "not high-quality" SDM (8.94 (1.41), p=0.735). Similarly, patient perceptions of a goal being set was not associated with patients' overall rehabilitation experience rating (9.03 (1.25) vs. 8.72 (1.95), p=0.227).

Discussion

These findings correspond with current literature but also provide a foundation for expansion [15, 25–28]. Previous literature reviews suggested very negative and limited SDM experiences in rehabilitation [15]. A narrative synthesis (n=15 studies) revealed that in-patient rehabilitation goal-setting did not permit patient input, was overly-controlled by staff, was challenging for time and patient-load reasons, and involved parties lacking SDM knowledge [15]. While our findings reveal much room to improve SDM quality and consistency in community rehabilitation, our data suggest that many patients and providers rate SDM-quality high even though some providers do take a leading (or controlling) role. For patients, the lowest ratings relate to the recognition of patient preferences, which is at the heart of SDM. Providers were more critical than patients on SDM experiences, which suggests a receptivity to strategies to improve SDM.

While the literature in rehabilitation often conflates goal-setting and SDM [15, 29], our findings suggest that may be inappropriate. Patient-participant perceptions of whether goals were set, and the connection (or not) between set goals and patient lives, is concerning. Nearly 1 in 5 patients in this provincial health-system are not setting goals for their rehabilitation care. If goal functionality is modestly measured to include general and specific connections to patients' everyday activities, roles and responsibilities, then only every other patient is setting a goal in language that is meaningful to them. Patient engagement and SDM are strategies to support movement towards meaningful goal-setting, which itself supports patients in working on treatment plans that motivate them and move them in the direction that they would like to go [30].

Our findings suggest actionable items that could promote more experiences of high quality SDM in community rehabilitation, and possibly goal-setting. First, provider training, especially person-centred behaviour change training (HealthChange®), are associated with better-quality SDM encounters ($p=0.086$). Most providers felt that HealthChange® influenced their patient interactions and site processes to some degree (76.9% and 53.8%, respectively). This identifies an alternative, more impactful training process versus the train-the-trainer SDM-development activities completed previously in Europe that did not yield increased patient involvement in decision-making [26, 28].

Second, providers should facilitate the feeling of privacy during appointments, whether using available private rooms or a privacy curtain as both options significantly improved SDM experiences. The latter would be particularly useful in urban settings, where private rooms are less available and there are frequently other people in the rehabilitation area.

Third, most non-modifiable patient characteristics (including age) were not significantly associated with the quality of SDM or goal-setting. Only total family income was associated with SDM experience. These findings corroborate the literature that SDM is a skill that can be taught and not an innate trait of an individual [31]. Total family income is a marker of socioeconomic status and relative vulnerability; it is not about capacity or education because education level was not associated with SDM experience. Further strategies and training are required to support providers and organizations in identifying, then approaching and empowering, more economically-vulnerable patients in SDM.

Finally, as different disciplines seem to have varying success with SDM, there may be an opportunity to promote greater transdisciplinary learning, practice and sharing in community-rehabilitation sites. This would support the development of a community of practice, which would also sustain learnings from person-centred training (e.g. HealthChange®) through ongoing discussion.

Based on participant demographics, these findings confidently apply to diverse community rehabilitation settings across Alberta. The patient population was fairly distributed amongst different family incomes, insurance access, and employment. These findings were not as highly represented from patients originating from rural communities, ethnocultural communities, and less-educated populations (i.e. less than high school).

Participating providers were mostly fairly experienced. The findings apply to hospital-based and community-based settings. These findings may not apply to new-graduates or providers trained outside of Canada. Most providers represented two rehabilitation disciplines: occupational therapy and physiotherapy. While several other disciplines were present to a lesser degree, it may be useful to examine these research questions where these other disciplines are more populous.

Limitations

We recognize several study limitations. First, we tried to minimize recall (memory) bias by placing a 24-hour limit on participants to complete surveys, so the appointment is fresh in their minds. We recognize that patients may not have completed the survey on-time with take-home packages since it was outside the supervision of researchers and recruiters.

Second, we tried to lessen the risk of loss at 3-month follow-up using several tactics from Dillman et al. [32]. These tactics included allowing participant preference to dictate the form of follow-up (email or paper); using a mix of email and phone reminders both pre- and post- T1. We lost about 40% of patients at T1. Demographically, the patient-participants at recruitment and follow-up did not differ significantly on any patient characteristics.

Third, Phase-1 learnings suggested that there may be a selection bias and non-response bias. Patients with extreme experiences (either good or bad) could have been more interested in participation, which could differ significantly from the general patient-population experience. It was unlikely, given the difficulty in patient recruitment generally, to recruit non-responders to participate in a non-responder survey. This study prioritized significant recruitment using convenience sampling to lessen the influence of these biases.

Fourth, there may have been a Hawthorne effect on providers wherein their knowledge of a study assessing their communication altered their communicative behaviours. A previous feasibility study demonstrated that rehabilitation professionals were accustomed to being observed during practice given their own training, the multidisciplinary players, and trainee presence at many sites. For patients, they would generally not know of the study until after their appointment, so their actions likely would not be influenced by reactive effects.

Fifth, there may have been acquiescence and social desirability bias whereby participants frequently endorsed positive statements and where participants wished to present themselves at their best, including being fully engaged in SDM. Historically, this has been shown to have a small but pervasive effect. To minimize this, we aimed to recruit until a high survey sample size and diversity of population were recruited.

Sixth, for feasibility, survey tools were used differently from their original validation process. The WatLX^{TM} was completed 3-months after recruitment which corresponded differently across patients' rehabilitation journey; not all patients completed the WatLX^{TM} within the two weeks after care ended. Most patients stated at recruitment that they were neither at the first nor last appointment. Only 4.4% of patients were on their last appointment at recruitment. The most egregious difference in WatLX^{TM} completion (i.e. 3 months after last appointment) was only possible for a rarity of participants. The gains made in data collection compared to the feasibility study suggest that this compromise in data collection was worthwhile. The resonance and corroboration of findings across methods and studies confirms that the tools remained valid.

Seventh, we cannot guarantee that ASK-MI survey completion was based on assessments of the recruitment-date appointment only rather than on the totality of experience with that patient, provider or clinic. Many participating patient comments in the ASK-MI referred to the entirety of their rehabilitation care. Patients may have felt that there was commonality or consistency in interactions across appointments, so it was then appropriate to assess SDM across the rehabilitation journey. Further research is required to understand when and how patients judge SDM in rehabilitation along the different points in the rehabilitation journey.

Conclusions

While we recognize several study limitations, we believe our forethought and planning to consider and address these limits ensures the methodological rigour of this study. This study complements our qualitative findings,[16], that SDM is complex not monolithic in community rehabilitation. There is room to improve upon patient and provider practices of SDM and collaborative goal-setting in these settings, and we offer strategies such as further person-centred training, enhancing privacy during appointments, and building transdisciplinary communities of practice around how rehabilitation providers can approach SDM with patients. Further research is required to determine whether novel scoring of the ASK-MI influences SDM prevalence, which tactics to identify and redress the vulnerability of low-family-income patients are useful to advance SDM for this vulnerable group. This study suggests that SDM experience and goal-setting are not associated with longitudinal perceptions of rehabilitation experience and treatment goals being met, using a tool with high ceiling effects. We recommend more research into strategies that advance highly-functional goal-setting with patients, and to re-examine these relationships with tools without (or with less prominent) ceiling effects.

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Author Contributions:

KPM helped contribute to the study's conceptualization and design. KPM implemented the study methodology, managed resources, and developed all manuscript drafts.

KO helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (SV, TW) regarding its methods, conduct, analysis, and manuscript development.

KC helped contribute to the study's operationalization; provided ongoing support on conduct, analysis, and manuscript development; and, reviewed and edited this manuscript.

SV helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (KO, TW) regarding its methods, conduct, analysis, and manuscript development.

TW helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (KO, SV) regarding its methods, conduct, analysis, and manuscript development.

Competing Interests: none

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Ethics Approval: Research ethics board approval was secured for this study.

Provenance, Peer Review: Not commissioned; externally peer reviewed.

Data Sharing Statement: Availability of data and materials. For the data wherein patients consented to future data sharing, the de-identified data is currently being prepared for deposit in a secure data repository for data sharing upon application.

Patient Consent: Patient-participants provided consent to share aggregated data in peer-reviewed publications.

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Figure 1

215x279mm (200 x 200 DPI)

Figure 2. Patient Responses on the Six ASK-MI Items on SDM Experience

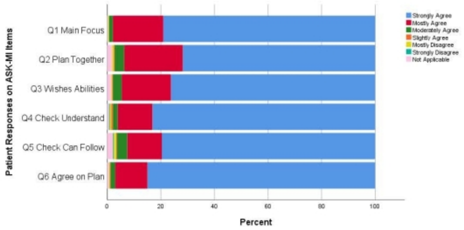

Figure 2

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Figure 3. Provider Responses on the Six ASK-MI Items on SDM Experience

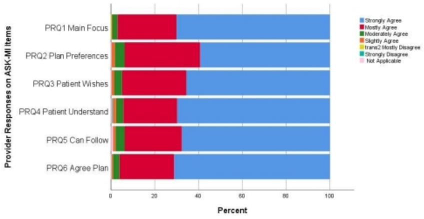

Figure 3

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Figure 4. Patient Perceptions of Goal Setting Occurrence

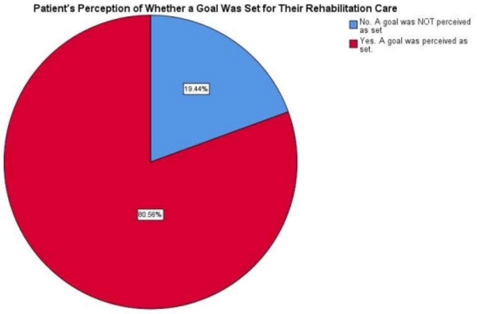

Figure 4

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Figure 5. Level of Functionality of Patient-Stated Goals

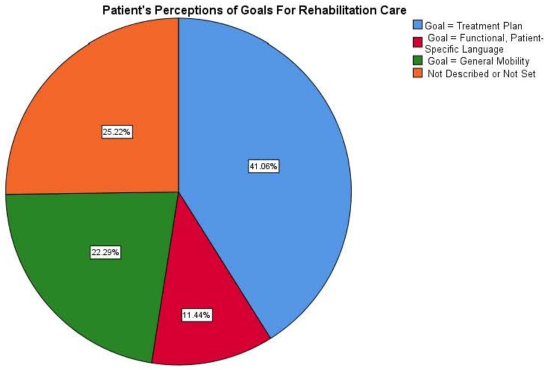

Figure 5

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Figure 6. Patient Ratings of Experience on Individual WatLX™ Items

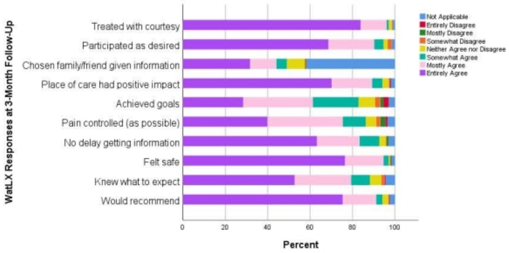

Figure 6

215x279mm (153 x 182 DPI)

COMMUNITY REHABILITATION PATIENT – Information and Consent Form

Title of Research Study: ASK-MI Community Rehabilitation PHASE 2 - Measuring the Impact of Shared Decision-making in Community Rehabilitation in Alberta

Lead Investigators:
Tracy Wasylak, Alberta Health Services & University of Calgary, 403-943-1256
Kiran Manhas, University of Alberta & Alberta Health Services, 403-478-8598

This consent form is only part of the informed consent process. It should give you the basic idea of what the research is about and what taking part will involve. If you want more detail, please ask. Please read this carefully and ensure you understand any add-on information. This copy is for your records; we will imply your consent to the survey study if you send this form back.

WHAT IS THE PURPOSE OF THE STUDY?

This study is looking at what promotes or hinders shared decision-making between patients and providers in community rehabilitation (rehab). Shared decision-making involves using evidence and patient preferences to make healthcare decisions.

WHAT WOULD I HAVE TO DO?

We are asking patients and providers at this site to take part in this study:

- You will be asked to complete a set of surveys at a two different times. The questions will focus on you and your experiences with community rehab and making decisions. Each individual survey is 1 to 2 pages long.

Time-point	# of Surveys	Time Required	Format
Today	4	5-10 min	• Take-home paper-based surveys • Base on today's appointment • Return by mail
In 3 months	3	5-10 min	• By email or mail • You will get a phone call reminder 1-week before the survey is sent to you. • You will have two weeks to complete and return it. • You may receive email or phone reminders if you have not completed the survey.

- You agree that your rehab provider will complete a survey about shared decision-making based on your appointment. The provider may also talk about your appointments in an interview.
- You MAY be invited to take part in an interview (30-60 minutes) to discuss your experience with shared decision-making. The interview could be in-person, phone or Skype, based on what you prefer.

WHAT ARE THE RISKS AND BENEFITS?

There are no physical risks to study participation. The study has no to minimal risks. Some people may find it upsetting to talk about their experience. If you feel upset, some resources are available for free including:

- In-person: AHS Mental Health Walk-in Service (located at South Calgary Health Centre 31 Sunpark Plaza SE, 403-943-9374).

- Telephone: AB Mental Health HelpLine 1-877-303-2642
- Online: The Distress Centre website that offers online resources (incl. confidential chat option) (www.distresscentre.com).

DO I HAVE TO PARTICIPATE?

Your participation is completely voluntary. You may withdraw at any time with no effect on your care or job. You can refuse to answer any question(s). If you withdraw, you may choose what happens with the data you contributed so far unless the study data collection period is done. There may or may not be a direct benefit to you. The information we get from this study may help us to provide better care experiences, through better shared decision-making, in the future for patients visiting community rehab.

WILL MY RECORDS BE KEPT PRIVATE?

All data collected will be kept strictly confidential. Only the study team will see it (not your providers, patients or employers). All study documents will be kept in a locked cabinet for a minimum of 5 years prior to being destroyed. We will store interview and survey data on password-protected, encrypted AHS computer(s) and an approved research data repository (REDCAP). No information that contains personal information will be released to anyone else without a court order, so we will maintain your confidentiality unless legally required not to. We will use a study ID, not your name, to link your data together. Data from all study participants from this clinic will be summarized and all identifying-information removed, before it is shared with stakeholders (e.g. clinic and managerial staff).

Quotes from interviews may be used in research reports to help explain study results. Names and identifying information will not be included. Site-level data may be shared within AHS to support continued learning and improvement. We will submit a final report for publication in a peer- reviewed journal. At study end, where you consent, de-identified quantitative data may be shared with a secure research data repository for future research by approved researchers.

By signing this consent form you are agree to the study team to collect, use and disclose information about you including personally identifiable information, but this information will remain confidential and will not be identifiable to you.

WHAT IF SOMETHING NEW COMES UP DURING THE STUDY THAT AFFECTS PARTICIPATION IN THE RESEARCH?

We will let you know of any significant changes that could affect your decision to participate. You can withdraw from the study at any time, for any reason, with no explanation.

WILL I BE PAID FOR PARTICIPATING?

No, you will not be paid for taking part. But **everyone who completes the three month surveys will be eligible for a draw at the end of the study to win a FitBit**. This draw is to recognize your time and contributions. We will pay parking costs during study interviews.

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. This consent form has been given to you to keep for your records and reference. If you have further questions concerning matters related to this research, please contact: **Ms. Tracy Wasylak (403) 943-1256 OR Dr. Kiran Pohar Manhas (403) 478-8598.** If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care.

Reporting checklist for cohort study.

Based on the STROBE cohort guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cohortreporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

		Reporting Item	Page Number
Title and abstract			
Title	#1a	Indicate the study’s design with a commonly used term in the title or the abstract	1
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	#3	State specific objectives, including any prespecified hypotheses	4
Methods			

Study design	#4	Present key elements of study design early in the paper	4
Setting	#5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up.	5
Eligibility criteria	#6b	For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	5
Bias	#9	Describe any efforts to address potential sources of bias	13
Study size	#10	Explain how the study size was arrived at	5
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	7
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	7
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	7
Statistical methods	#12c	Explain how missing data were addressed	7
Statistical methods	#12d	If applicable, explain how loss to follow-up was addressed	7
Statistical methods	#12e	Describe any sensitivity analyses	n/a

Results

Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	7
Participants	#13b	Give reasons for non-participation at each stage	7
Participants	#13c	Consider use of a flow diagram	n/a
Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	8
Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	8-11, Tables
Descriptive data	#14c	Summarise follow-up time (eg, average and total amount)	6
Outcome data	#15	Report numbers of outcome events or summary measures over time. Give information separately for exposed and unexposed groups if applicable.	8-11, Tables
Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8-11, Tables
Main results	#16b	Report category boundaries when continuous variables were categorized	8-11, Tables
Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	7

Discussion

Key results	#18	Summarise key results with reference to study objectives	11-12

Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	13-14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12-13
Generalisability	#21	Discuss the generalisability (external validity) of the study results	13
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

None The STROBE checklist is distributed under the terms of the Creative Commons Attribution License CC-BY. This checklist can be completed online using https://www.goodreports.org/, a tool made by the EQUATOR Network in collaboration with Penelope.ai

BMJ Open

Measuring Shared Decision-Making and Collaborative Goal Setting in Community Rehabilitation: A Focused Ethnography Using Cross-Sectional Surveys in Canada

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Title: Measuring Shared Decision-Making and Collaborative Goal-Setting in Community Rehabilitation: A Focused Ethnography Using Cross-Sectional Surveys in Canada

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ABSTRACT (250 words)

Objective: To describe and measure the shared decision-making (SDM) experience, including goal-setting experiences, from the perspective of patients and providers in diverse community-rehabilitation settings.

Design: Prospective, longitudinal surveys

Setting: 13 primary level-of-care community-rehabilitation sites in diverse areas varying in geography, patient population, and provider discipline

Subjects: 341 adult, English-speaking patient-participants, and 66 provider-participants

Measures: ASK-MI (dyadic tool measuring SDM), WatLX^{TM} (outpatient rehabilitation experience), and demographic questionnaire. Survey packages distributed at two time-points (T0=recruitment; T1=3-months-later)

Results: We found that amongst 341 patient-provider dyads, 26.4% agreed that the appointment at recruitment involved high-quality SDM. Patient perceptions of goal-setting suggested that 19.6% of patients did not set a goal for their care, and only 11.4% set goals in functional language that tied directly to an activity/role/responsibility that was meaningful to their life. Better SDM was clinically associated with higher total family income (p=0.045).

Conclusions: These findings provide evidence for the importance of SDM and goal-setting in community rehabilitation. Among patients, lower ratings of SDM corresponded with less recognition of their preferences. Actionable strategies include supporting financially-vulnerable patients in realizing SDM through training of providers to make extra space for such patients to share their preferences and better preparing patients to articulate their preferences. We recommend more research into strategies that advance highly-functional goal-setting with patients, and that lessen survey ceiling effects.

Article Summary: Strengths and limitations of the study

- One strength is that this study has a significant sample size, with 341 patient participants completing surveys.
- Another strength is that participant diversity allows for statistically-appropriate comparisons based on geography, level of privacy, patient demographics, and provider training.
- Study limitations include that the survey measuring shared decision-making is novel, has a floor effect, and may be subject to acquiescence and social desirability biases.

Keywords: shared decision-making, community, rehabilitation, patient perspectives, provider perspectives, survey, goal-setting

Introduction

Many public policies aim to better empower patients in their health and healthcare, [1–7]. Patient-centred care, which emphasizes shared decision-making (SDM) and patient engagement, is one strategy to empower patients [5]. SDM is an interpersonal decision-making process where provider(s) and patient make treatment choices collaboratively using best available evidence, patient values and preferences [8, 9].

SDM meets an ethical imperative to enable patient autonomy [10, 11]. Research suggests that SDM increases patient knowledge and satisfaction [12–14], enhances realization of treatment goals [15], moderately reduces inappropriate service utilization [16], and improves patient-reported outcomes [12, 17]. SDM is neither routinely utilized nor taught in healthcare [11, 18, 19].

SDM is multi-faceted [20]. Based on a systematic review (n=418 studies), Makoul & Clayman (2006) describe an SDM model with nine essential elements: problem-definition; presenting and discussing options; discussing patient values and abilities; discussing provider knowledge; clarifying understanding; decision-making; and arranging follow-up. This SDM model overlaps with conceptualizations, and practices, of collaborative goal-setting in rehabilitation [21, 22].

SDM literature emphasizes patient-physician interactions. Less research examines the impacts of SDM on other professionals, teams and organizations [10]; on the appropriate policy types for building SDM capacity within organizations [9]; and on SDM in rehabilitation involving primarily allied-health providers [21]. Authors of a narrative synthesis (n=15 studies) revealed that in-patient rehabilitation goal-setting did not permit patient input, was overly-controlled by staff, and involved parties lacking knowledge about SDM [21]. Five further studies evaluated a “train-the-trainer” program to promote SDM in inpatient rehabilitation using focus groups, surveys and a cluster-randomized controlled study, but did not fully elaborate the SDM experience in rehabilitation [23–27]. Other research theorizes on SDM in rehabilitation, positing on technology, ethics and collaboration [28–32]. The transferability of these findings to community contexts is unclear [21]. Inpatient and outpatient needs and resources vary, impacting communication and care [33, 34].

The measurement of SDM-related constructs remains challenging [35–37]. A plethora of SDM definitions contributed to many different SDM measurement tools being developed [35, 38, 39]. No universally-accepted standard outcome or experience measure exists to assess SDM [35], particularly for non-physician interactions. A 2015 review found that only four of 13 SDM tools involved patients during their development [37], bringing into question content validity. Potentially inaccurate presumptions remain that patients are aware of 'decision points' and that only one decision point exists per consult [37].

While the OPTION GRID is a commonly-used tool to measure SDM [40, 41], its use of a third-party observer is not universally feasible in resource-constrained healthcare settings (as in our study context). Qualitative research by team members revealed challenges with a previously-published SDM tool (SDM-Q-9) in primary care and mental health settings(manuscript under review). Challenges included inability to capture the SDM phase when problems are discussed and prioritized; the lack of a "not applicable" option; an over-emphasis on medical conditions; a lack of relevance for non-pharmacological interventions; and, the lack of recognition that SDM is valuable in goal-setting, investigations, as well as (as opposed to exclusively for) exploring treatment options [Olson K, et al. "Development of the Alberta Shared Decision-Making Measurement Instrument" *Under Review*].

In this context, the provincial health system sought to understand the experience of shared decision-making and collaborative goal-setting at diverse community rehabilitation sites across the province. This health system is the longest-running provincial health system in Canada and serves more than 4 million people. This work would form the baseline data to eventually evaluate the implementation of a novel model of care seeking to promote patient centred-care and collaborative goal-setting in community rehabilitation. In this study, for patients and providers of diverse community-rehabilitation sites across a single province in an industrialized country, we aimed to:

(a) measure the prevalence of high-quality SDM experiences (compared to less than high quality SDM experiences);
(b) measure goal-setting perceptions by patients;
(c) determine any associations between SDM experience or goal-setting perceptions and demographic and contextual factors (e.g. geography, patient and provider age, gender, discipline).

This study included a small pilot feasibility study in this population to understand the reliability of the SDM tool and recruitment logistics. This study complements another in this population that used qualitative interviews to explore SDM experiences (manuscript under review). The research team included two patient-co-investigators who consulted on the research design, implementation and results dissemination.

Methods

We used focused ethnography in this research program [42]. Ethnography involves making cultural inferences "(1) from what people say; (2) from the way people act; and (3) from the artifacts people use" [43]. We focused on the communities of patients and professionals composing diverse community-rehabilitation sites across a provincial geography. Focused ethnography features a problem-focused and context-specific approach; a focus on a discrete phenomenon; the conceptual orientation of a single researcher; involvement of limited participants; episodic participant observation; participants with specific knowledge; and an emphasis on academic and healthcare settings [44, 45]. We met all criteria save participant observation due to feasibility constraints. While this paper emphasizes the survey findings, this paper is part of a broader study that included qualitative interviews, focus groups, and patient-led data collection (manuscripts under review). Together, this research program followed an ethnographic methodology that underpinned its theoretical approach to data collection and analysis, which carried into this survey work equally. The surveys allowed a population-level perspective to inform the in-depth qualitative work (described elsewhere).

Participant Population

We captured diverse rehabilitation settings that saw outpatients including both public and private provider sites, as well as three geographic types (rural (population < 10000), regional-urban (population between 10000 and 100000), and metropolitan-urban (where population > 100000)).

Participants included current patients and providers visiting and working, respectively, at study sites. Provider inclusion criterion was employment at the site at recruitment. Providers included allied-health professionals who were members of the rehabilitation team (e.g. physical therapists, occupational therapists, speech-language pathologists). Patient inclusion criteria included ≥ 18 years of age; their provider was participating; able to consent without proxy; and can understand and speak English. There were no exclusion criteria.

Recruitment

Site leadership informed provider recruitment. Tactics included email introductions followed by study presentations (by webinar, in-person, or one-on-one). After discussions, informed consent was procured.

Convenience sampling directed patient recruitment. Management identified onsite recruiters from clerical and therapy-assistant staff. Researchers trained recruiters to identify eligible patients, discuss participation, and record those patients accepting take-home study packages. While provider-participants may have mentioned the study to patients, only onsite recruiters distributed surveys. Recruitment was bounded by a four-week site maximum and a 20-patient limit per provider to minimize site and provider burden. Patient consent was implied by the mailed return of surveys; written consent was required for future data sharing and future research contact.

Data Collection

We used validated surveys to measure SDM, goal-setting, quality of life and patient experience: at baseline (T0) we captured SDM (ASK-MI tool), perceptions on goal-setting, quality of life, demographic and contextual data; at 3-months post-baseline (T1) we captured quality of life and overall patient-reported rehabilitation experience (WatLX™ survey). The patient demographic and contextual data captured self-reported age, gender, education, income, medical conditions, and their perceptions of their health journey (i.e. where they were in their rehabilitation, whether they perceived a goal was set for their rehabilitation, and if so what that goal was). The provider demographic and contextual data included self-reported age, gender, professional discipline, years of experience. Providers were also asked if they completed the HealthChange® Methodology workshop through their organization, which aims to educate providers in helping patients make the behaviour changes needed to promote health; such training impacts provider-patient interactions and could impact SDM as patient-centred communication is discussed [46]. Survey completion took 5-7 minutes per time-point.

In a pilot feasibility study, we completed the following data collection strategies at two community rehabilitation sites with the modification that T1 would be at 6-weeks after recruitment (versus 3-months). The data collected was used to determine study logistics feasibility and the reliability of the ASK-MI results (via Cronbach's alpha determination).

A novel, dyadic SDM tool was used given the infeasibility of using a 3rd-party reviewer, and the challenges in using the SDM-Q-9 in similar Alberta populations: the Alberta Shared decision-maKing Measurement Instrument (ASK-MI) (Figure 1 is the patient version; provider version is same except language transposed to address provider). Using a 6-point Likert Scale (with not-applicable option), patients and providers independently describe the appointment experience from a SDM-process perspective. This process involves patients and providers agreeing on the main concern; working together to make a plan that considers patients' wishes; and, ensuring the provider confirms patient understanding and next steps. The ASK-MI was developed and piloted in primary care and mental health clinics in Alberta (manuscript under review).

The dyadic ASK-MI tool requires patient and provider to independently rate six facets of the SDM experience; lower numeric scores reflect higher quality SDM. Individual scores are summed; the two sum scores are compared to determine the final rating score: Excellent, Acceptable, or Unacceptable. When both patient and provider rate SDM highly, an Excellent rating score is reached. Disparity between parties would lead to a lower ASK-MI rating score. Full agreement on SDM Excellence equates to patient and provider both giving the best, lowest numeric score on each ASK-MI item. Using self-report, we collected contextual (e.g. group or individual appointment; were goals set with provider) and participant demographic data (e.g. age, gender, marital status).

The WatLX™ is a 2-page outpatient rehabilitation care patient experience survey meant for post-completion of rehabilitation care. The WatLX™ consists of 10 questions, where respondents can respond either not applicable or on a 7-point Likert scale. Psychometric testing of the WatLX™ involved 1174 cognitively-intact, English-speaking, adult outpatients who had completed a program of cardiac, musculoskeletal, neurologic, stroke, pulmonary, or speech language rehabilitative care in Ontario [47]. Reliability analyses compared the use of a 7-point to 5-point Likert scale in the WatLX™. Cronbach's alphas were 0.863 and 0.957 for the 5 and 7-point scale, and the ICC = 0.827 and 0.880, respectively [47]. Generally, the higher the score, the more positive the patient experience. There is evidence of ceiling effects with the WatLX™.

The T0 take-home study package included a consent form and directions, the ASK-MI survey, a patient demographic form including their communication preference for the 3-month follow-up (T1) surveys (which included WatLX^{TM}). All envelopes were pre-addressed and stamped to support convenient, confidential return to the researchers. Patients were directed to complete the surveys within 24 hours, so their appointment was fresh in their mind.

When a patient took a study package, the recruiter logged the date, envelope number, patient's initials, and provider name. Daily, this recruitment information was sent to the lead researcher, who emailed the ASK-MI (provider version) tool to the named provider, along with the patient initials via personalized email link to REDCAP at the University of Alberta. Providers received one email per patient and had 48 hours to complete the survey.

The second time-point (T1), for patients only, was exactly three months post-recruitment. T1 data collection was by mail or email per patient-participant preference. Participants received email or phone reminders 1-week prior to T1, and at 7-days post-T1.

To ensure the accuracy of data entry of paper surveys, a randomly-selected 30% of the study sample was assessed at the close of data collection. If more than 10% of the data was incorrectly entered, then another random 30% of the study sample would have been checked. Errors were rectified immediately.

At the close of data collection, the research team developed a coding rubric by consensus to capture the presence, and level, of function in the rehabilitation goals perceived by patient participants (as described in the self-reported patient sociodemographic form). Level of functionality was informed by the Alberta Health Services definition that the goal "consider[ed] the whole person – individual context, personal factors, and how a health condition impacts participation in life… work, school, play, relationships, roles and any activities that the person loves to do" [48]. A goal was functional, if it related to participation in a role, responsibility or activity important to the person; the language of the goal spoke to activity and participation in life not the rehabilitation treatment plan. A goal was not functional if it did not speak to such a role, responsibility or activity important to the person (e.g. language focused on the treatment plan or general alleviation of symptoms). While one researcher (KPM) coded all patient-participant self-reported perceptions, the team discussed and practiced the coding together to ensure consensus on approaches to described goals.

Data Analysis

After cleaning and coding the T0 and T1 data, we completed descriptive and exploratory analyses to address the research questions. The ASK-MI Score was collapsed into two different binary categorical variables: (a) Excellent versus Acceptable/Unacceptable; and (b) Full Agreement on SDM Excellence versus Not Full Agreement on SDM Score. The secondary variable was overall rehabilitative care experience (WatLX^{TM}). Independent variables included age, gender, patient income range, geographical area, and other demographic and contextual variables.

The distribution of interval and ratio type survey data (e.g. age) was checked for whether it is normally distributed. Test selection was based upon the results of these analysis (e.g. non-normally-distributed data was analyzed using non-parametric tests). We analyzed the questionnaire data descriptively, with means, standard deviations, both overall in community rehabilitation and based on contextual differences. For categorical data, chi-square tests directed comparisons between high versus low quality SDM; sub-analyses using tests of proportions considered this ratio of experiences in different demographic and organizational settings based on the size and quality of independent variable data collected. For the three surveys, where missing data was less than 5% across population, then used the 20% as the threshold for missing items: if ≤ 20% items missing, then median response used in place of the missing item to then score the survey; if > 20% of items missing, then the entire record was deleted from the analysis [49]. Univariate correlations were studied between each independent variables (age, gender, income, geographical area, provider discipline) and the ASK-MI score. A binary regression was completed to ascertain the effects of training (i.e. HealthChange participation), level of privacy during appointment, geographical setting, and timing of appointment (relative to patient's rehabilitation care journey). This model used a binomial distribution with log link function to obtain relative risks. We used backward elimination with the Akaike Information Criterion (AIC) to reduce the model. At each step, the variables with the largest associated decrease in the AIC at removal was deleted from the model. The steps continued until the removal of remaining variable resulted in an increase in the AIC.

Results

Pilot Feasibility Study Results

Phase 1 involved two community rehabilitation sites in an urban-metropolitan area in Alberta between March and May 2018 (n=24 patients and n=6 providers). The mean (range) participant age for patients and providers was 48.3 (22-71) and 37.4 (26-56) years, respectively. Most participants were White (87.5% patients; 80% providers) and female (66.7% patients; 60% providers). Fifty percent of patient-participants were employed, while 20.8% were retired. Patient-participants' total family income varied with 37.5% being affluent (≥ $150000) and a combined 20.8% being less affluent (<$35000). On average (range), provider-participants had 12 (3-30) years of experience and worked 31.7 (10-70) hours weekly.

Because only four patients completed follow-up surveys that included the WatLX^{TM}, we only assessed the reliability of the EQ-5D-5L and ASK-MI surveys in this population. Table 1 describes the tools' means, standard deviations and internal consistency assessments using Cronbach's alpha. Given the small sample, the reliability of these measures appear appropriate and related to estimates during tool development [50]. Field notes support the validity of the EQ-5D-5L and ASK-MI tools for participants. The ASK-MI scores were clustered in the excellent range, which is common to many patient-reported experience measures. The ASK-MI was completed by 24 patient-provider dyads. The scores obtained from these dyads scoring the SDM experience as Excellent (70.8%), Acceptable (29.2%), or Unacceptable (0%). Because complementary studies by study co-authors (manuscript under review) detail the psychometric validity of the instrument, we do not present further findings in that regard.

Tool	Mean	Standard Deviation	Internal Consistency Measurement Tool	Internal Consistency Measurement
ASK-MI	6.96 (patients) 10 (providers)	1.93 (patients) 4.07 (providers)	Cronbach's Alpha	0.82
EQ-5D-5L	73.6% (VAS) 0.760 (EQ-5D Index score)	13.7 (VAS) 0.104 (EQ-5D Index score)	Cronbach's Alpha	0.648

Table 1. Internal Consistency of Surveys in Pilot Feasibility Study

Participant Information (Full Study)

Thirteen community-rehabilitation sites distributed 606 take-home survey packages; 341 patients returned them and thus implied consent to participate (response rate 56.2%). At T1, 209 patients returned surveys (response rate 61.3%, the remainder lost to follow-up).

Table 2 describes the patient-participant population. The patient-participants' mean (SD) age was 57.5 (16.4) years. Most patient-participants were female (58.9%), married (68.9%), Caucasian (90.9%), had some post-secondary education (70.4%), were at a 1:1 appointment with providers (90.9%), were neither at the first nor last appointment at recruitment (66.9%), and were receiving physiotherapy (68.6%). Participants varied in where they received their care: 46.3% were in an open exercise area, 48.4% were in a private area (either behind a privacy curtain or in private room), and 3.8% described their area as unique. The demographic profile was similar between T0 and T1 patient-participants.

	N (%)
Patient Population	341 (100%)
Mean Age in years (SD)	57.5 (16.4)
Missing	3 (0.9%)
Gender	
Male	138 (40.5%)
Female	201 (58.9%)
Missing	2 (0.6%)
Marital Status	
Single	48 (14.1%)
Married (legal/common law)	235 (68.9%)
Separated or Divorced	32 (9.4%)
Widowed	21 (6.2%)
Missing	5 (1.5%)
Geographical Location	
Metropolitan-Urban	145 (42.5%)

Regional-Urban	161 (47.2%)
Rural	35 (10.3%)
Education	
High school diploma or less	96 (28.1%)
Any post-secondary education	240 (70.4%)
Missing	5 (1.5%)
Employment Status	
Employed	141 (41.3%)
Unemployed	61 (17.9%)
Retired	135 (39.6%)
Missing	4 (1.2%)
Ethnicity	
European Origins	310 (90.9%)
Indigenous (e.g. Inuk, Métis)	10 (2.9%)
Non-European Origins	21 (6.2%)
Supplementary Insurance	
Yes	144 (42.2%)
No	160 (46.9%)
Prefer not to answer	37 (10.9%)
Total Family Income	
Less than $59999	106 (31.1%)
$60000 to 99999	75 (22.0%)
$100000 or More	78 (22.9%)
Prefer not to answer	82 (24%)

Table 2. Patient-Participant Demographics

Table 3 describes the provider-participant population. The provider-participants' mean (SD) age was 41.8 (9.86) years. Experience-wise, providers had a mean (SD) of 15.1 (10.3) years of experience. Providers represented six rehabilitation disciplines, with physiotherapy (53.0%) and occupational therapy (19.7%) being most prevalent. Most providers were female (60.6%), Caucasian (60.6%), trained in Canada (66.7%), and had primarily clinical provider roles (vs. management) (71.2%).

Provider Participant Characteristics	N (%) or Mean (SD)
Population	66
Age (years)	41.83 (9.86)
Missing	13 (19.7%)
Gender	
Male	13 (19.7%)
Female	40 (60.6%)
Missing	13 (19.7%)
Provider Discipline	
Occupational Therapy	13 (19.7%)
Physiotherapy	35 (53.0%)
Other	5 (7.5%)
Missing	13 (19.7%)

Country of Training	
Canada	44 (66.7%)
Outside of Canada	9 (13.6%)
Missing	13 (19.7%)
Ethnicity	
European Ethnic Origins	40 (60.6%)
Non-European Ethnic Origins	8 (12.1%)
Missing	18 (27.2%)
Geographical Location	
Metropolitan-Urban	36 (54.5%)
Regional-Urban	24 (36.4%)
Rural	6 (9.1%)

Table 3. Provider-Participant Demographics

Table 4 describes the provider-participants' work settings. Providers worked a mean (SD) of 31.8 (9.0) hours/week in direct patient care, and saw a mean (SD) of 28.8 (17.6) patients per week. The outpatient clinical settings varied for providers, including community-based (31.8%) and hospital-based (45.5%) clinics. The clinical populations included at least 10 diverse populations, including general adults (25.8%), musculoskeletal (16.7%), and neurorehabilitation (13.6%). Providers were evenly split on participation in a person-centred behaviour-change course (HealthChange® Methodology [51]): 39.4% said they had taken it, 40.9% said they had not taken it, and 19.7% responses were missing herein. Of the providers who had taken HealthChange®, most providers perceived that it influenced their patient interactions to some degree (76.9%) (vs. to a great degree (15.4%)). The perceived influence of HealthChange® on site processes was less clear: 42.3% of providers saw no influence, while 53.8% saw some degree of influence.

Provider Participant Characteristics	N (%) or Mean (SD)
Setting	
Community-Based Clinic	21 (31.8%)
Hospital, outpatient Clinic	30 (45.5%)
Primary Patient Population	
Complex Adults	2 (3.0%)
Hand/Foot/Cardiac	4 (6.0%)
General Adults	17 (25.8%)
Musculoskeletal (MSK)	11 (16.7%)
Neuro	9 (13.6%)
Ortho/Surgery	3 (4.5%)
Seniors	4 (6.1%)
Missing	16 (24.2%)
Average Waitlist (days) for Clinic	16.59 (17.59)

Missing	18 (27.3%)
HealthChange® Completion	
Yes	26 (39.4%)
No	27 (40.9%)
Missing	13 (19.7%)
HealthChange® Influenced Patient Interactions?	
No Influence	1 (3.8%)
To Some Degree	20 (76.9%)
To a Great Degree	4 (15.4%)
Missing	1 (3.8%)
HealthChange® Influenced Site Processes?	
No Influence	11 (42.3%)
To Some Degree	14 (53.8%)
To a Great Degree	0 (0%)
Missing	1 (3.8%)

Table 4. Provider-Participants' Clinical Setting

SDM and Goal-Setting Prevalence in Community Rehabilitation

Using current ASK-MI scoring guidelines, 78.9% of T0 patient-provider appointments rated Excellent (Table 5). Given the evident floor effect of the ASK-MI (i.e. more than 15% of respondents have the lowest score, which is the best value [52]), the survey developers will re-assess the scoring algorithm (incomplete at time of manuscript submission).

Shared Decision-Making Experience	N (%) or Mean (SD)
ASK-MI Score	
Excellent	269 (78.9%)
Acceptable	37 (10.9%)
Unacceptable	2 (0.6%)
Missing/Unable to Calculate	14 (4.1%)
Patient and Provider had Full Agreement on SDM Excellence	
Full Agreement	90 (26.4%)
Less Than Full Agreement	218 (63.9%)
Missing/Unable to Determine	14 (4.1%)
Was a Goal Set with Provider?	
Yes	270 (79.2%)
No	67 (19.6%)
Missing	4 (1.2%)
Level of Functionality of the Patient-Stated Goal	
Highly Functional, focused on everyday activity (i.e. patient language)	39 (11.4%) 140 (41.1%)
Moderately Functional, focused on general mobility	76 (22.3%)

Not Functional, focused on treatment plan (i.e. provider language)	86 (25.2%)
Not Applicable, no goal was set or goal not provided	

Table 5. Prevalence of Shared Decision-Making and Goal-Setting

Looking at full agreement on SDM excellence or not, at T0, 26.4% of patient-provider encounters involved full agreement on SDM excellence. Figures 2 and 3 display the frequency of responses across the 6-item Likert scale for each ASK-MI question for patients and providers, respectively. These two graphs reveal that, across the six items, providers agreed less often about SDM excellence (i.e. relatively fewer responses at 'strongly agree').

For patients, there was less agreement that the patient and provider planned together to address the patient's preferences and that the plan considered the patient's wishes and abilities. Patients more often strongly agreed that the provider checked the patient's understanding of the plan and that there was agreement on the plan created.

For providers, there was less agreement that the patient and provider worked together to make a plan that addressed patient preferences. Providers more often strongly agreed that there was clarity and agreement on the visit's main focus; that the provider checked for patient understanding; and that the patient and provider agreed on the plan created.

Table 6 compares the three geographical settings on prevalence of high quality SDM (i.e. full agreement on SDM excellence) in patient-provider encounters, which demonstrates no statistically significant differences in the quality of SDM experiences between geographical areas: metropolitan areas (19.9%) and regional areas (33.8%) (p=0.068).

Variable	**Geography**			F statistic Value (df)	P-value
	Metropolitan Urban Mean (SD) [95% CI] OR %	Regional Urban Mean (SD) 95% CI	Rural Mean (SD) 95% CI		
Patient Age	53.36 (17.29) [50.51-56.21]	61.08 (14.88) [58.74,63.41]	57.97 (15.14) [52.77-63.17]	8.824 (df 2)	< 0.001
Months Knew Provider Before Recruitment	8.40 (14.91) [5.54,11.26]	24.64 (2.39) [5.03,14.52]	51.76 (63.95) [25.36-78.16]	25.88	<0.001
% Appointments with Excellent ASK-MI Score	84.2%	89.0%	90.9%	1.91 (df 2)	0.384

% of Appointments with Full Agreement on SDM Excellence	19.9%	33.8%	26.7%	11.73 (df 6)	0.068
% Patients Perceived that Goals were Set	81.3%	79.1%	80.0%	0.22 (df 2)	0.90
% Perceived Goals were Functional	16.4%	6.3%	14.3%	8.627	0.196
% Providers Took HealthChange® Before	20.7%	56.7%	40.0%	37.05 (df 4)	< 0.001
% Appointments in Private Area	31.7%	69.2%	68.6%	46.25	< 0.001
Income				43.09	< 0.001
Less than $59999	26.1%	40.9%	20.6%		
$60000 to 99999	26.8%	21.4%	14.7%		
$100000 or More	37.0%	12.3%	23.5%		
Prefer not to answer	10.1%	25.3%	41.2%		
Rehabilitation Patient Received				14.07 (df 4)	0.007
Physiotherapy	69.7%	87.2%	74.3%		
Occupational Therapy	27.0%	10.6%	25.7%		
Other	3.3%	2.1%	0%		

Table 6. Comparison of Three Geographical Areas on SDM, Demographic and Contextual Variables

At T0, 19.4% of patients stated that they had not set a goal for their rehabilitation care (Figure 4). When patients had set a goal, they were asked to describe the goal. We categorized the patient-perceived goals based on level of functionality (Table 5). Only 11.4% of patients stated goals that met the Alberta Health Services' definition of functionality. A broader definition of functionality includes goals that aim for general improvements in, for example, mobility or strength. Under this broad definition, 42.6% of patients perceive their rehabilitation goals as aimed towards achievements or activities important to their life (Figure 5). Some 22.3% of patients perceived goals as equal to the treatment plan (e.g. doing home exercises, coming to appointments).

SDM, Goal-Setting, and Associated Factors

In the first phase, we used univariate Chi-square tests of correlation. SDM experience quality was not associated with whether patients' perceived that goals were set or whether patients' perceived goals that were functional. SDM experience was not associated with other immutable patient characteristics (e.g. gender, education, employment status, insurance access, income) or appointment type (Table 7). The only patient-related features associated with SDM timing of appointment (65.1% high-quality-SDM vs. 58.0% less-quality-SDM, p=0.035).

Variable	**Patient & Provider Full Agreement on SDM Excellence?**		Pearson Chi-Square Value (df)	P-value
	Yes Count (%)	No Count (%)		
Seen Provider Before Recruitment?			0.313 (df 2)	0.855
Yes	76.9%	74.4%		
No	23.1%	25.6%		
Appointment Timing at Recruitment			13.57 (df 6)	0.035
First Appointment	27.9%	22.6%		
Near Start of Care	37.2%	35.4%		
Near End of Care	30.2%	38.7%		
Last Appointment	4.7%	3.3%		
Appointment Type			0.734 (df 2)	0.693
Group	6.6%	9.5%		
Individual	93.4%	90.5%		
Where in Facility			7.05 (df 3)	0.070
Open Area	39.8%	49.3%		
Private Area or Other	60.2%	50.7%		
Patient Perceived Goals Set?			2.567 (df 2)	0.277
Yes	80.2%	81.7%		
No	19.8%	18.3%		
Perceived Goals were Functional?			0.793 (df 2)	0.673
Yes	14.3%	10.9%		
No	85.7%	89.1%		
Female Gender	58.2%	58.6%	0.015 (df 2)	0.993
Marital Status			3.08 (df 3)	0.379
Married (incl common law)	72.5%	69.9%		
Not, or No Longer, Married	27.5%	30.1%		
Education			2.68 (df 3)	0.443
High school diploma or less	30.8%	26.5%		
Any post-secondary education	69.2%	73.5%		
Employment			3.50 (df 6)	0.743
Employed	41.8%	42.9%		
Unemployed	16.5%	17.8%		
Retired	41.8%	39.3%		
Insurance				

Yes	45.1%	43.8%	7.515 (df 6)	0.276
No	41.8%	48.4%		
Prefer not to answer	13.2%	7.8%		
Income				
Less than $59999	34.3%	50.0%	5.91 (df 6)	0.43
$60000 to 99999	27.4%	23.5%		
$100000 or More	13.9%	11.8%		
Prefer not to answer	24.3%	14.7%		
Provider Discipline				
Physiotherapy	74.4%	81.3%	12.69 (df 6)	0.048
Occupational Therapy	25.6%	15.5%		
Other	0%	3.1%		
Provider Took HealthChange?			11.11 (df 6)	0.085
Yes	73.9%	41.2%		
No	26.1%	58.8%		
Provider Trained in Canada	85.3%	83.2%	0.264 (df 2)	0.877

Table 7. Relationship between Full Agreement on SDM (High Quality SDM) and Other Demographic or Contextual Factors

SDM experience was not associated with the providers' experience (in years since graduation) or the time since the provider took HealthChange®. SDM was not statistically-significantly associated with other features such as more privacy during the appointment (60.2% high-quality-SDM vs. 50.7% in low-quality-SDM, p=0.070), non-physiotherapy (74.4% physiotherapy in high-quality-SDM vs. 81.3% physiotherapy in low-quality-SDM, p=0.091) and if the provider had taken HealthChange® (73.9% in high-quality-SDM vs. only 41.2% high-quality-SDM if not taken, p=0.085).

SDM and goal-setting varied across the three geographical areas (Table 5). More providers had taken HealthChange® (p<0.001) in regional settings compared to rural and metropolitan settings. There was no difference in the proportion of patients with functional goals across geographies. Demographically, more patients had lower total family income in regional areas (40.9% lowest-income-bracket vs. 26.1% (metropolitan) or 20.6% (rural), p<0.001). Contextually, metropolitan-urban areas were unique in that fewer appointments were in private areas (31.7% vs. 69.2% in regional and 68.6% in rural, p<0.001) and fewer providers had taken person-centred behaviour-change training (HealthChange®) (20.7% vs. 56.7% in regional and 40.0% in rural, p<0.001). Finally, occupational therapy was represented least often in regional-urban appointments (10.6% vs. 27.0% (metropolitan) and 25.7% (rural), p=0.007).

A backwards, stepwise logistic regression was performed to ascertain the effects of appointment timing at recruitment, level of privacy (per location at setting), geographical setting, and whether the provider took HealthChange® on the likelihood that the patient and provider fully agreed on the excellence of the SDM experience. The final model included HealthChange® training and geographical setting, while appointment timing and privacy were removed as not statistically significant. The final model reveals the following relative risks ([95% confidence interval], p-value): 2.463 ([1.650,3.816], p<0.001) for regional vs. metropolitan settings; 1.399 ([0.646,2.652], p=0.329) for rural vs. metropolitan settings; and 0.439 ([0.284,0.649], p<0.001) for taken HealthChange® vs. not taken. Providers who took the training were less likely to rate their interactions with the highest score (37/119 = 31.6%) when compared with providers who did not take the training (82/178 = 47.4%; P < 0.01). Provider training was not associated with patient ratings. Patients with providers who took the training did not rate their interactions as less favorable than patients with providers who did not take the training (69/119 = 61.6% vs 110/178 = 64.7%; P=0.876).

Patients who perceived that a goal was set for their care saw a higher proportion of occupational therapists (35.5% vs. 14.7%, p=0.001). While the time a provider knew the patient before T0 was associated with whether a goal was set (p=0.054), the variance was high. Few other patient or provider characteristics were associated with patient perceptions of goal-setting. Patient perceptions of goal-setting for their rehabilitation did not differ by geographical setting, patient gender, marital status, education, employment status, or total family income (Table 8). Provider experience was not associated with patients' perceptions of goal-setting. Provider HealthChange® participation was not associated with patients' perception of goals setting or the functionality of the goal set.

Variable	**Did Patient Perceive that a Goal was Set for Rehabilitation Care?**		Test Statistic Value (df)	P-value
	Yes Mean (SD) OR %	No Mean (SD) OR %		
WatLX^{TM} Overall Rehabilitation Experience	9.034 (1.251)	8.717 (1.953)	F=1.47 (df 1)	0.227
Patient Age at T0	57.23 (15.92)	57.30 (18.14)	F=0.001 (df 1)	0.974
Provider's Experience	14.05 (10.67)	13.91 (10.17)	F=0.008 (df 1)	0.930

Time Patient Knew Provider	11.51 (24.63)	21.93 (51.61)	F=3.760 (df 1)	0.054
Months Since Provider Took HealthChange®	11.87 (19.86)	19.65 (26.73)	F=2.546 (df 1)	0.113
% Patients with Female Gender	59.6%	54.0%	x^2=0.666 (df 1)	0.414
% Providers took HealthChange®	39.2%	42.6%	x^2=0.474 (df 2)	0.789
Where in Facility Open Area Private Area or Other	 49.1% 50.9%	 37.5% 62.5%	x^2= 2.780 (df 1)	0.095
Marital Status Married (incl common law) Not, or No Longer, Married	 190 (71.2%) 77 (28.8%)	 43 (65.2%) 23 (34.8%)	x^2=0.910 (df 1)	0.34
Education High school diploma or less Any post-secondary education	 72 (27.0%) 195 (73.0%)	 23 (34.8%) 43 (65.2%)	x^2=1.612 (df 1)	0.204
Employment Employed Unemployed Retired	 118 (44.2%) 46 (17.2%) 103 (38.6%)	 23 (34.3%) 15 (22.4%) 29 (43.3%)	x^2=2.316 (df 2)	0.314
Income Less than $59999 $60000 to 99999 $100000 or More Prefer not to answer	 80 (30.7%) 63 (24.1%) 64 (24.5%) 54 (20.7%)	 25 (40.3%) 11 (17.7%) 14 (22.6%) 12 (19.4%)	x^2=2.458 (df 3)	0.483
Provider Discipline Physiotherapy Occupational Therapy Other	 192 (82.8%) 34 (14.7%) 6 (2.6%)	 39 (62.9%) 22 (35.5%) 1 (1.6%)	x^2=13.79 (df 2)	0.001

Table 8. Clinically Relevant Differences Between Whether Patient Set a Goal or Not During Care and Other Variables

Finally, the mean (SD) overall WatLX™ rating of patient experience was 8.97 (1.39), where 10 was the highest rating. Item mean (SD) ratings ranged from 5.65 (1.35) to 6.79 (0.579) (7 was highest rating). Figure 6 demonstrates the distribution of responses along the 7-point Likert scale for these 10 items. The item with the greatest use of not applicable was having chosen family or friend given information that they needed about the patient’s care, which suggests this question may not be relevant for many patients. The lowest rated items were for achieving treatment goals and controlling physical pain as much as possible. The highest-rated items were for being treated with courtesy, feeling safe during treatment activities and would recommend to others.

The mean (SD) overall rehabilitation experience when patients’ experienced high-quality SDM experiences was 9.07 (1.57), and was not different from the experience of participants who reported “not high-quality” SDM (8.94 (1.41), p=0.735). Similarly, patient perceptions of a goal being set was not associated with patients’ overall rehabilitation experience rating (9.03 (1.25) vs. 8.72 (1.95), p=0.227).

Discussion

These findings correspond with current literature but also provide a foundation for expansion [23–25, 53, 54]. Previous literature reviews suggested very negative and limited SDM experiences in rehabilitation [53]. A narrative synthesis (n=15 studies) revealed that in-patient rehabilitation goal-setting did not permit patient input, was overly-controlled by staff, was challenging for time and patient-load reasons, and involved parties lacking SDM knowledge [53]. Our data suggest that many patients and providers rate SDM-quality high even though some providers do take a leading (or controlling) role. For patients, the lowest ratings relate to the recognition of patient preferences, which is at the heart of SDM. Providers were more critical than patients on SDM experiences, which suggests a receptivity to strategies to improve SDM. This critical nature may be expanded by training in patient-centred care principles. Our multivariate analysis revealed that exposure to HealthChange® training decreased the likelihood of full agreement between the patient and provider on SDM excellence during the appointment. Further analyses revealed that provider training was not associated with patient ratings, but providers who took HealthChange® training were less likely to rate their interactions with the best (lowest) score. This finding also suggests that perhaps patients who tended to judge interactions as positive also tended to have providers who had taken the course.

While the literature in rehabilitation often conflates goal-setting and SDM [53, 55], our findings suggest that may be inappropriate. Patient-participant perceptions of whether goals were set, and the connection (or not) between set goals and patient lives, calls for further investigation. Nearly 1 in 5 patients in this provincial health-system did not set goals for their rehabilitation care. If goal functionality is modestly measured to include general and specific connections to patients' everyday activities, roles and responsibilities, then only every other patient set a goal in language that was meaningful to their lives and activities. Patient engagement and SDM are strategies to support movement towards meaningful goal-setting, which itself supports patients in working on treatment plans that motivate them and move them in the direction that they would like to go [6].

While full agreement on SDM excellence was less frequently associated with providers who took HealthChange®, most providers felt that HealthChange® influenced their patient interactions and site processes to some degree (76.9% and 53.8%, respectively). In addition, providers who took the training were less likely to rate their interactions with the highest score (37/119 = 31.6%) when compared with providers who did not take the training (82/178 = 47.4%; $P < 0.01$). Provider training was not associated with patient ratings. Patients with providers who took the training did not rate their interactions as less favorable than patients with providers who did not take the training (69/119 = 61.6% vs 110/178 = 64.7%; $P=0.876$). This suggests that providers who took the training may be more discerning when judging their interactions with patients.

This work, however, may suffer from similar challenges as the train-the-trainer SDM-development activities completed previously in Europe that did not yield increased patient involvement in decision-making [24, 25]. In our study and that in Europe, providers perceive an impact of their training relating to the processual aspects of SDM, but in both cases a statistically-significant positive impacts on SDM is not determined between those with training and those without [24, 25]. More research is required to determine what facets of SDM and patient-centred communication training lead to tangible improvements in SDM experiences.

Most non-modifiable patient characteristics (including age) were not significantly associated with the quality of SDM or goal-setting. Only total family income was associated with SDM experience. These findings corroborate the literature that SDM is a skill that can be taught and not an innate trait of an individual [56]. Total family income is a marker of socioeconomic status and relative vulnerability; it is not about capacity or education because education level was not associated with SDM experience. Further strategies and training are likely required to support providers and organizations in identifying, then approaching and empowering, more economically-vulnerable patients in SDM.

The literature describes SDM, while highly relational (conceptually and practically), is influenced by contextual factors such as time and setting [18, 57, 58]. Our findings do not quantify further details on the contextual factors. Our regression results suggested that geographical settings do vary on quality of SDM. Non-metropolitan areas, which often have more resources but busier clinics, had lower likelihoods of high-quality SDM experiences compared to rural and regional settings. Geographical areas did vary statistically on types of rehabilitation providers, months patient and provider knew each other, and, provider training in patient-centred principles. Finally, as different disciplines seem to have varying success with SDM, there may be an opportunity to promote greater transdisciplinary learning, practice and sharing in community-rehabilitation sites. This would support the development of a community of practice, which would also sustain learnings from person-centred training (e.g. HealthChange®) through ongoing discussion.

Based on participant demographics, these findings confidently apply to diverse community rehabilitation settings across Alberta. The patient population was fairly distributed amongst different family incomes, insurance access, and employment. These findings were not as highly represented from patients originating from rural communities, ethnocultural communities, and less-educated populations (i.e. less than high school).

Participating providers were mostly fairly experienced. The findings apply to hospital-based and community-based settings. These findings may not apply to new-graduates or providers trained outside of Canada. Most providers represented two rehabilitation disciplines: occupational therapy and physiotherapy. While several other disciplines were present to a lesser degree, it may be useful to examine these research questions where these other disciplines are more populous.

Limitations

We recognize several study limitations. First, we tried to minimize recall (memory) bias by placing a 24-hour limit on participants to complete surveys, so the appointment is fresh in their minds. We recognize that patients may not have completed the survey on-time with take-home packages since it was outside the supervision of researchers and recruiters.

Second, we tried to lessen the risk of loss at 3-month follow-up using several tactics from Dillman et al. [59]. These tactics included allowing participant preference to dictate the form of follow-up (email or paper); using a mix of email and phone reminders both pre- and post- T1. We lost about 40% of patients at T1. Demographically, the patient-participants at recruitment and follow-up did not differ significantly on any patient characteristics.

Third, Phase-1 learnings suggested that there may be a selection bias and non-response bias. Patients with extreme experiences (either good or bad) could have been more interested in participation, which could differ significantly from the general patient-population experience. It was unlikely, given the difficulty in patient recruitment generally, to recruit non-responders to participate in a non-responder survey. This study prioritized significant recruitment using convenience sampling to lessen the influence of these biases.

Fourth, there may have been a Hawthorne effect on providers wherein their knowledge of a study assessing their communication altered their communicative behaviours. A previous feasibility study demonstrated that rehabilitation professionals were accustomed to being observed during practice given their own training, the multidisciplinary players, and trainee presence at many sites. For patients, they would generally not know of the study until after their appointment, so their actions likely would not be influenced by reactive effects.

Fifth, there may have been acquiescence and social desirability bias whereby participants frequently endorsed positive statements and where participants wished to present themselves at their best, including being fully engaged in SDM. Historically, this has been shown to have a small but pervasive effect. To minimize this, we aimed to recruit until a high survey sample size and diversity of population were recruited.

Sixth, for feasibility, survey tools were used differently from their original validation process. The WatLX^{TM} was completed 3-months after recruitment which corresponded differently across patients' rehabilitation journey; not all patients completed the WatLX^{TM} within the two weeks after care ended. Most patients stated at recruitment that they were neither at the first nor last appointment. Only 4.4% of patients were on their last appointment at recruitment. The most egregious difference in WatLX^{TM} completion (i.e. 3 months after last appointment) was only possible for a rarity of participants. The gains made in data collection compared to the feasibility study suggest that this compromise in data collection was worthwhile. The resonance and corroboration of findings across methods and studies confirms that the tools remained valid.

Seventh, we cannot guarantee that ASK-MI survey completion was based on assessments of the recruitment-date appointment only rather than on the totality of experience with that patient, provider or clinic. Many participating patient comments in the ASK-MI referred to the entirety of their rehabilitation care. Patients may have felt that there was commonality or consistency in interactions across appointments, so it was then appropriate to assess SDM across the rehabilitation journey. Further research is required to understand when and how patients judge SDM in rehabilitation along the different points in the rehabilitation journey.

Conclusions

While we recognize several study limitations, we believe our forethought and planning to consider and address these limits ensures the methodological rigour of this study. This study complements our qualitative findings,[60], that SDM is complex not monolithic in community rehabilitation. There is room to improve upon patient and provider practices of SDM and collaborative goal-setting in these settings, and we offer strategies such as further person-centred training, enhancing privacy during appointments, and building transdisciplinary communities of practice around how rehabilitation providers can approach SDM with patients. Further research is required to determine whether novel scoring of the ASK-MI influences SDM prevalence, which tactics to identify and redress the vulnerability of low-family-income patients are useful to advance SDM for this vulnerable group. This study suggests that SDM experience and goal-setting are not associated with longitudinal perceptions of rehabilitation experience and treatment goals being met, using a tool with high ceiling effects. We recommend more research into strategies that advance highly-functional goal-setting with patients, and to re-examine these relationships with tools without (or with less prominent) ceiling effects.

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Author Contributions:

KPM helped contribute to the study's conceptualization and design. KPM implemented the study methodology, managed resources, and developed all manuscript drafts.

KO helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (SV, TW) regarding its methods, conduct, analysis, and manuscript development.

KC helped contribute to the study's operationalization; provided ongoing support on conduct, analysis, and manuscript development; and, reviewed and edited this manuscript.

PF helped contribute to data analysis during study implementation, final write-up of the organizational report, and this manuscript's analyses and results and discussion write-up; and, reviewed and edited this manuscript.

SV helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (KO, TW) regarding its methods, conduct, analysis, and manuscript development.

TW helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (KO, SV) regarding its methods, conduct, analysis, and manuscript development.

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Patient Consent: Patient-participants provided consent to share aggregated data in peer-reviewed publications.

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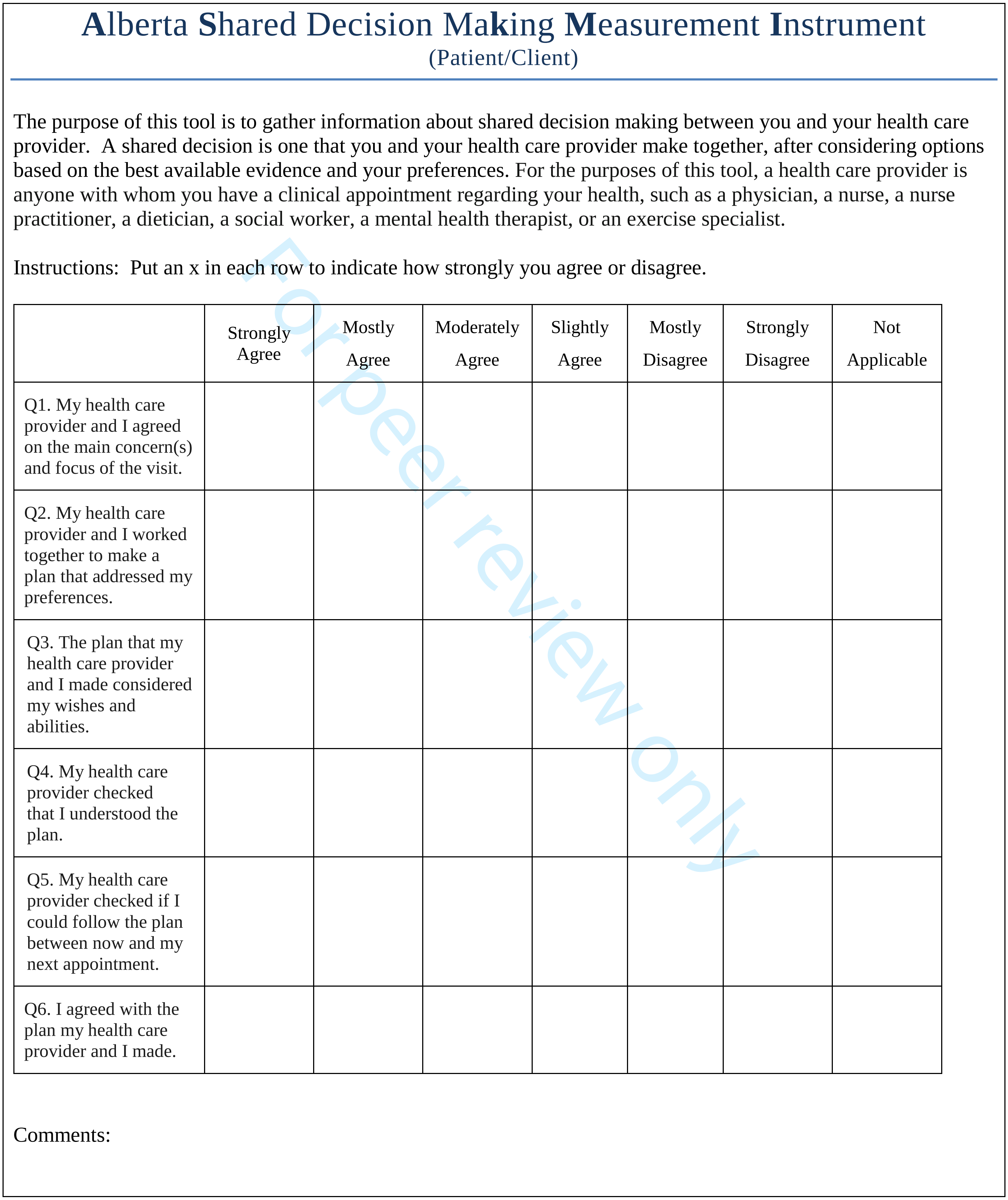
Figure 1. The Alberta Shared Decision-Making Measurement Instrument (ASK-MI)



Alberta Shared Decision Making Measurement Instrument

(Patient/Client)

The purpose of this tool is to gather information about shared decision making between you and your health care provider. A shared decision is one that you and your health care provider make together, after considering options based on the best available evidence and your preferences. For the purposes of this tool, a health care provider is anyone with whom you have a clinical appointment regarding your health, such as a physician, a nurse, a nurse practitioner, a dietician, a social worker, a mental health therapist, or an exercise specialist.

Instructions: Put an x in each row to indicate how strongly you agree or disagree.

	Strongly Agree	Mostly Agree	Moderately Agree	Slightly Agree	Mostly Disagree	Strongly Disagree	Not Applicable
Q1. My health care provider and I agreed on the main concern(s) and focus of the visit.							
Q2. My health care provider and I worked together to make a plan that addressed my preferences.							
Q3. The plan that my health care provider and I made considered my wishes and abilities.							
Q4. My health care provider checked that I understood the plan.							
Q5. My health care provider checked if I could follow the plan between now and my next appointment.							
Q6. I agreed with the plan my health care provider and I made.							

Comments:

Figure 2. Patient Responses on the Six ASK-MI Items on SDM Experience

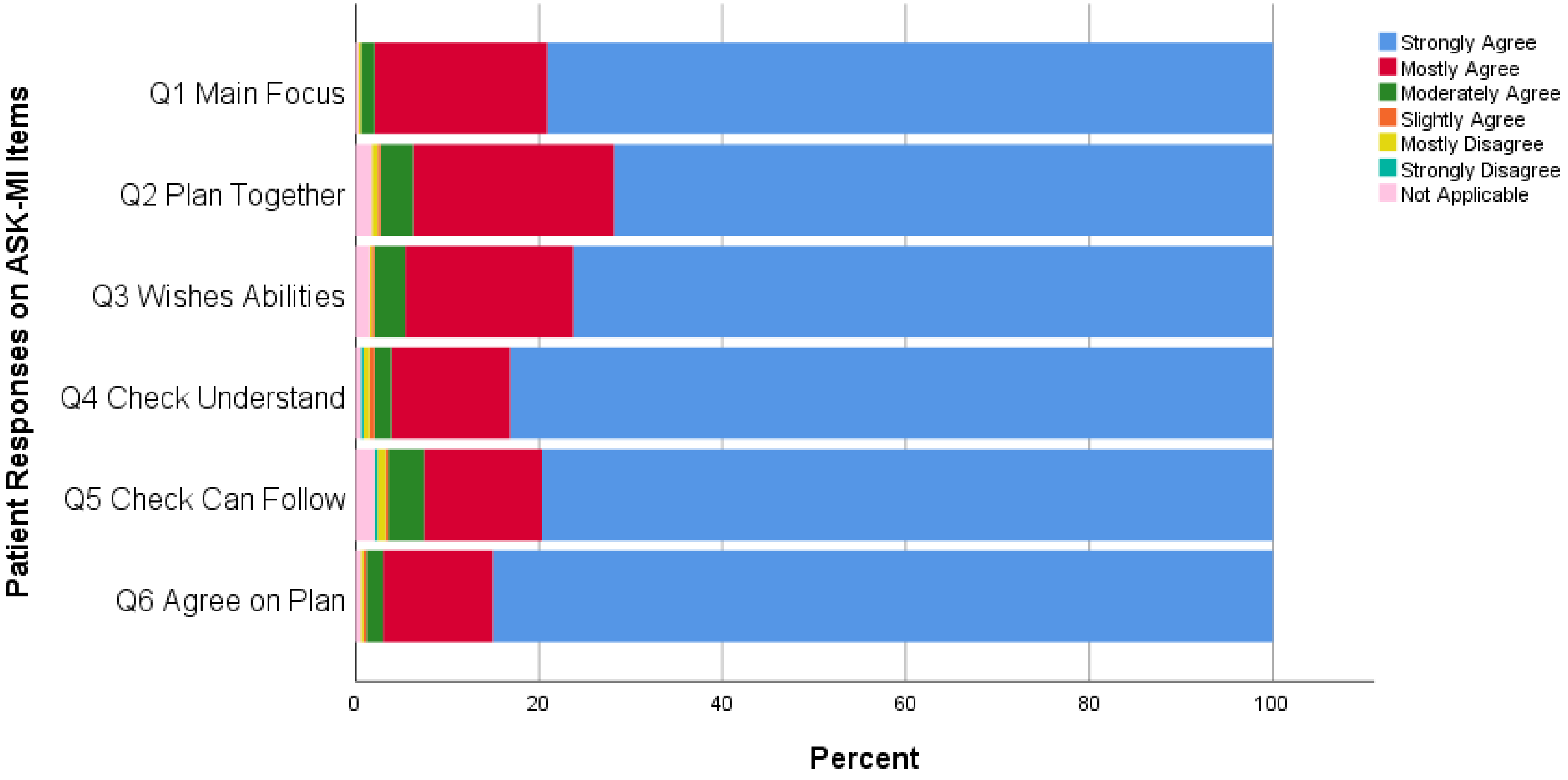


Figure 3. Provider Responses on the Six ASK-MI Items on SDM Experience

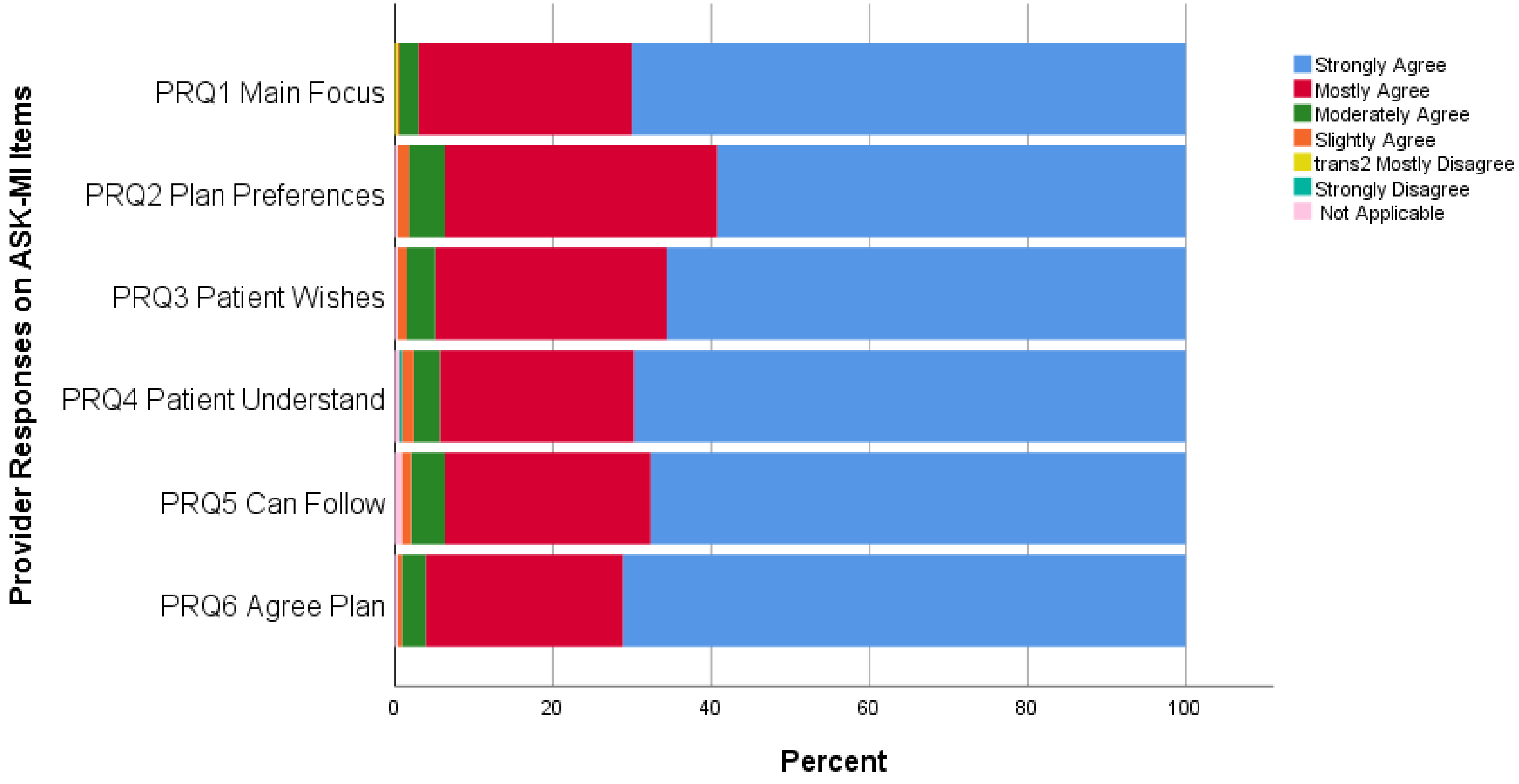


Figure 4. Patient Perceptions of Goal Setting Occurrence

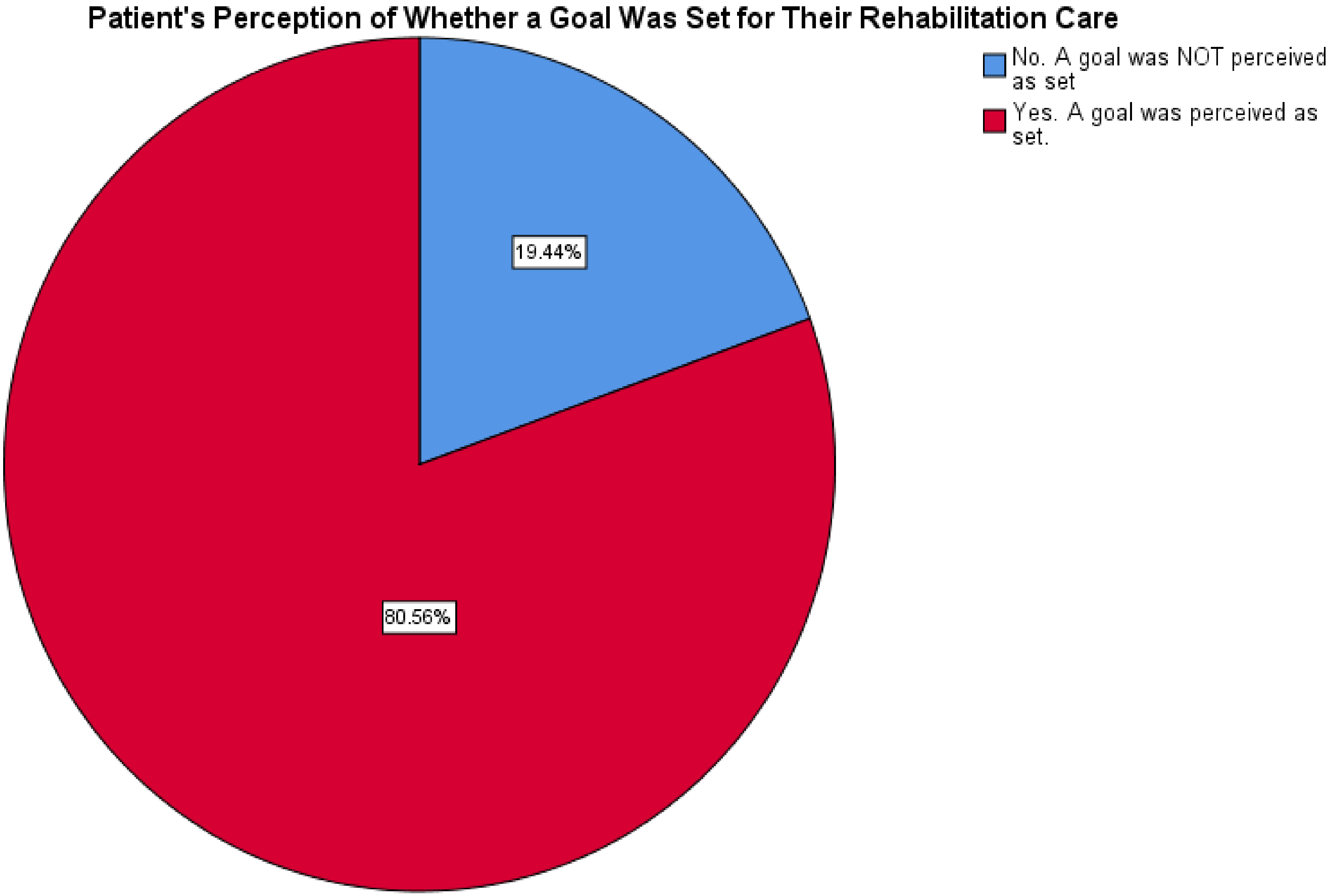


Figure 5. Level of Functionality of Patient-Stated Goals

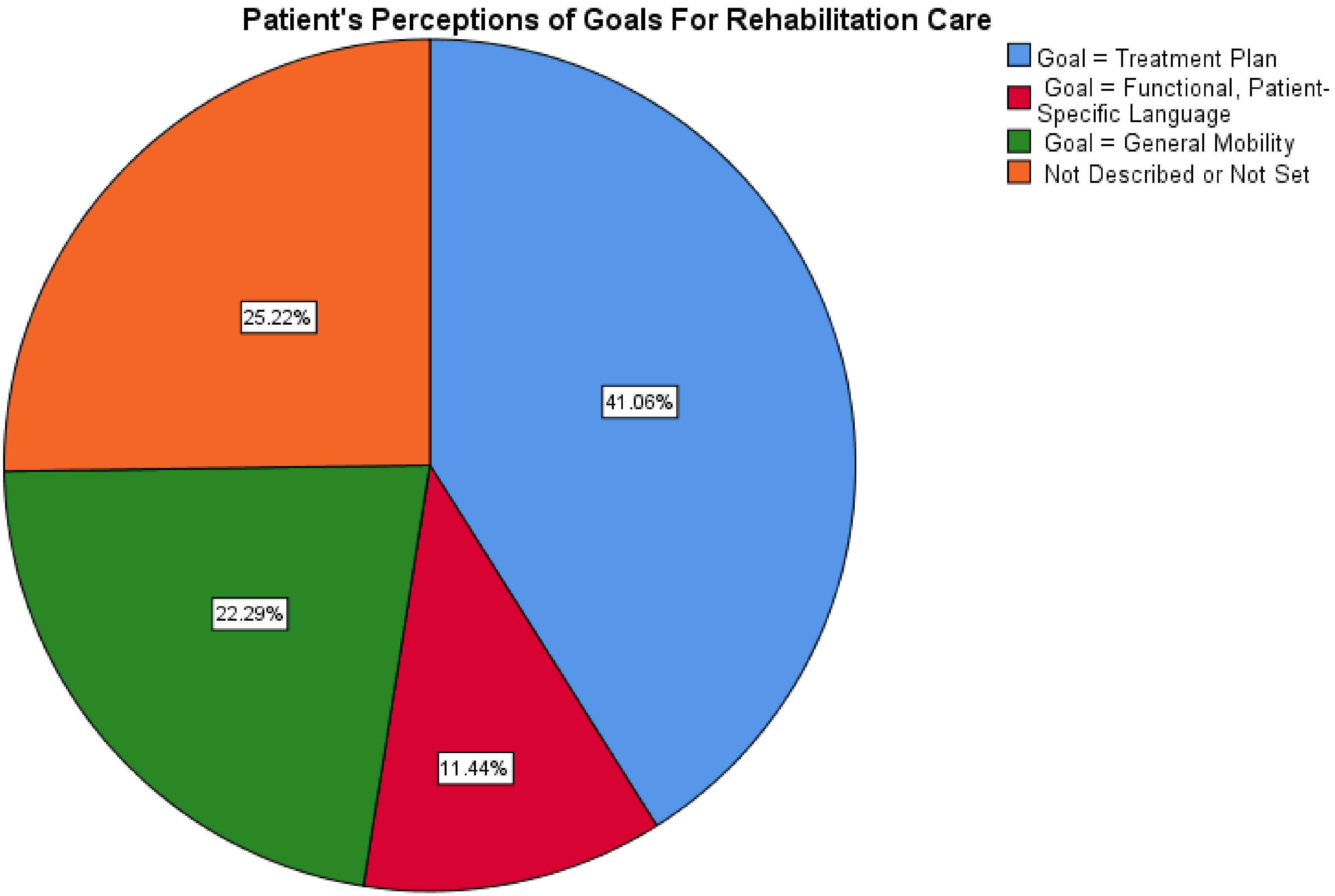
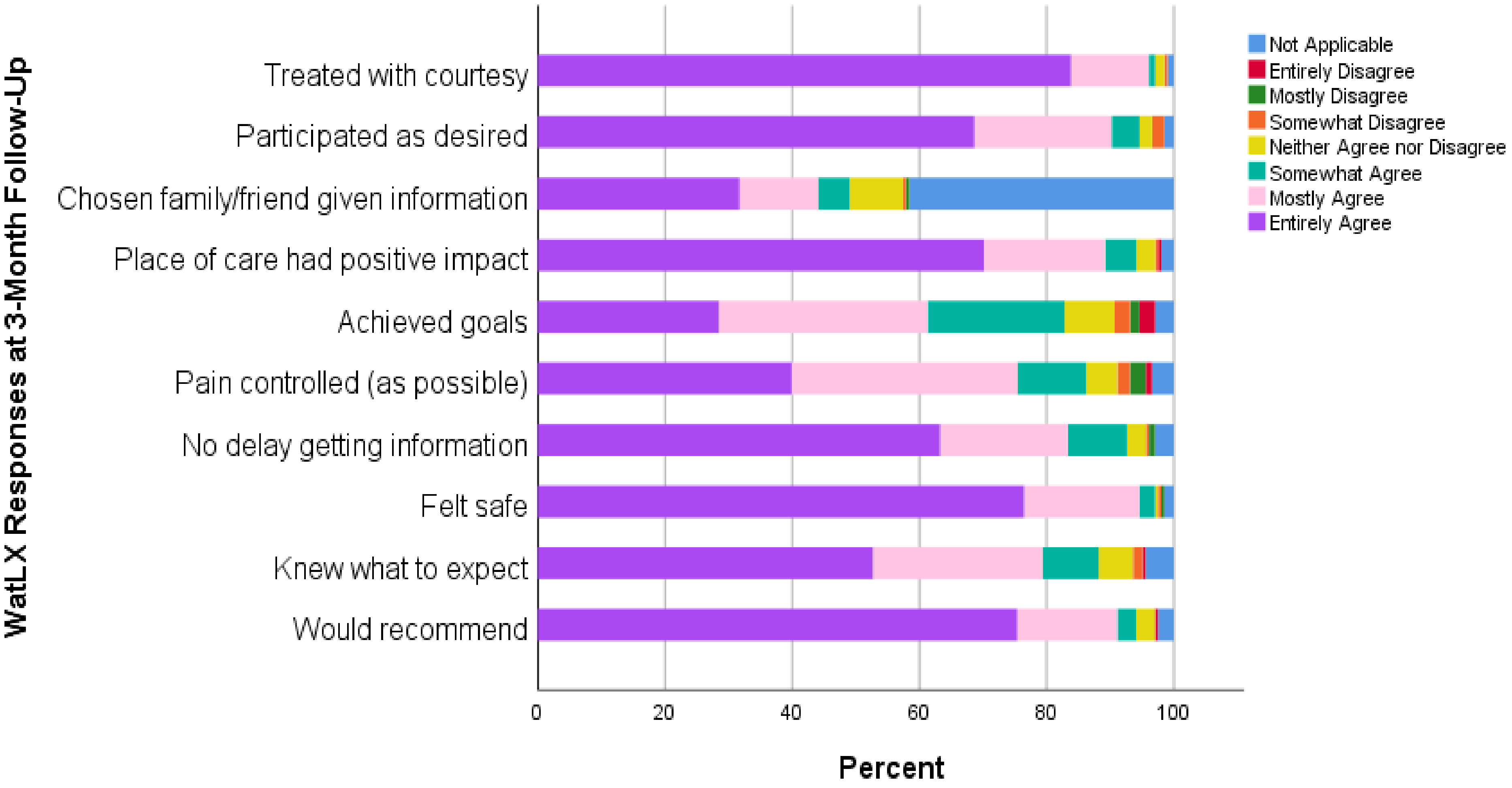


Figure 6. Patient Ratings of Experience on Individual WatLX™ Items



Reporting checklist for cohort study.

Based on the STROBE cohort guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cohortreporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

		Reporting Item	Page Number
Title and abstract			
Title	#1a	Indicate the study’s design with a commonly used term in the title or the abstract	1
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	#3	State specific objectives, including any prespecified hypotheses	4
Methods			

Study design	#4	Present key elements of study design early in the paper	4
Setting	#5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up.	5
Eligibility criteria	#6b	For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	5
Bias	#9	Describe any efforts to address potential sources of bias	13
Study size	#10	Explain how the study size was arrived at	5
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	7
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	7
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	7
Statistical methods	#12c	Explain how missing data were addressed	7
Statistical methods	#12d	If applicable, explain how loss to follow-up was addressed	7
Statistical methods	#12e	Describe any sensitivity analyses	n/a

Results

Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	7
Participants	#13b	Give reasons for non-participation at each stage	7
Participants	#13c	Consider use of a flow diagram	n/a
Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	8
Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	8-11, Tables
Descriptive data	#14c	Summarise follow-up time (eg, average and total amount)	6
Outcome data	#15	Report numbers of outcome events or summary measures over time. Give information separately for exposed and unexposed groups if applicable.	8-11, Tables
Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8-11, Tables
Main results	#16b	Report category boundaries when continuous variables were categorized	8-11, Tables
Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	7

Discussion

Key results	#18	Summarise key results with reference to study objectives	11-12

Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	13-14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12-13
Generalisability	#21	Discuss the generalisability (external validity) of the study results	13
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

None The STROBE checklist is distributed under the terms of the Creative Commons Attribution License CC-BY. This checklist can be completed online using https://www.goodreports.org/, a tool made by the EQUATOR Network in collaboration with Penelope.ai

BMJ Open

Measuring Shared Decision-Making and Collaborative Goal Setting in Community Rehabilitation: A Focused Ethnography Using Cross-Sectional Surveys in Canada

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Title: Measuring Shared Decision-Making and Collaborative Goal-Setting in Community Rehabilitation: A Focused Ethnography Using Cross-Sectional Surveys in Canada

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ABSTRACT (250 words)

Objective: To describe and measure the shared decision-making (SDM) experience, including goal-setting experiences, from the perspective of patients and providers in diverse community-rehabilitation settings.

Design: Prospective, longitudinal surveys

Setting: 13 primary level-of-care community-rehabilitation sites in diverse areas varying in geography, patient population, and provider discipline

Subjects: 341 adult, English-speaking patient-participants, and 66 provider-participants

Measures: ASK-MI (dyadic tool measuring SDM), WatLX^{TM} (outpatient rehabilitation experience), and demographic questionnaire. Survey packages distributed at two time-points (T0=recruitment; T1=3-months-later)

Results: We found that amongst 341 patient-provider dyads, 26.4% agreed that the appointment at recruitment involved high-quality SDM. Patient perceptions of goal-setting suggested that 19.6% of patients did not set a goal for their care, and only 11.4% set goals in functional language that tied directly to an activity/role/responsibility that was meaningful to their life. Better SDM was clinically associated with higher total family income (p=0.045).

Conclusions: These findings provide evidence for the importance of SDM and goal-setting in community rehabilitation. Among patients, lower ratings of SDM corresponded with less recognition of their preferences. Actionable strategies include supporting financially-vulnerable patients in realizing SDM through training of providers to make extra space for such patients to share their preferences and better preparing patients to articulate their preferences. We recommend more research into strategies that advance highly-functional goal-setting with patients, and that lessen survey ceiling effects.

Article Summary: Strengths and limitations of the study

- One strength is that this study has a significant sample size, with 341 patient participants completing surveys.
- Another strength is that participant diversity allows for statistically-appropriate comparisons based on geography, level of privacy, patient demographics, and provider training.
- Study limitations include that the survey measuring shared decision-making is novel, has a floor effect, and may be subject to acquiescence and social desirability biases.

Keywords: shared decision-making, community, rehabilitation, patient perspectives, provider perspectives, survey, goal-setting

Introduction

Many public policies aim to better empower patients in their health and healthcare, [1–7]. Patient-centred care, which emphasizes shared decision-making (SDM) and patient engagement, is one strategy to empower patients [5]. SDM is an interpersonal decision-making process where provider(s) and patient make treatment choices collaboratively using best available evidence, patient values and preferences [8, 9].

SDM meets an ethical imperative to enable patient autonomy [10, 11]. Research suggests that SDM increases patient knowledge and satisfaction [12–14], enhances realization of treatment goals [15], moderately reduces inappropriate service utilization [16], and improves patient-reported outcomes [12, 17]. SDM is neither routinely utilized nor taught in healthcare [11, 18, 19].

SDM is multi-faceted [20]. Based on a systematic review (n=418 studies), Makoul & Clayman (2006) describe an SDM model with nine essential elements: problem-definition; presenting and discussing options; discussing patient values and abilities; discussing provider knowledge; clarifying understanding; decision-making; and arranging follow-up. This SDM model overlaps with conceptualizations, and practices, of collaborative goal-setting in rehabilitation [21, 22].

SDM literature emphasizes patient-physician interactions. Less research examines the impacts of SDM on other professionals, teams and organizations [10]; on the appropriate policy types for building SDM capacity within organizations [9]; and on SDM in rehabilitation involving primarily allied-health providers [21]. Authors of a narrative synthesis (n=15 studies) revealed that in-patient rehabilitation goal-setting did not permit patient input, was overly-controlled by staff, and involved parties lacking knowledge about SDM [21]. Five further studies evaluated a “train-the-trainer” program to promote SDM in inpatient rehabilitation using focus groups, surveys and a cluster-randomized controlled study, but did not fully elaborate the SDM experience in rehabilitation [23–27]. Other research theorizes on SDM in rehabilitation, positing on technology, ethics and collaboration [28–32]. The transferability of these findings to community contexts is unclear [21]. Inpatient and outpatient needs and resources vary, impacting communication and care [33, 34].

The measurement of SDM-related constructs remains challenging [35–37]. A plethora of SDM definitions contributed to many different SDM measurement tools being developed [35, 38, 39]. No universally-accepted standard outcome or experience measure exists to assess SDM [35], particularly for non-physician interactions. A 2015 review found that only four of 13 SDM tools involved patients during their development [37], bringing into question content validity. Potentially inaccurate presumptions remain that patients are aware of 'decision points' and that only one decision point exists per consult [37].

While the OPTION GRID is a commonly-used tool to measure SDM [40, 41], its use of a third-party observer is not universally feasible in resource-constrained healthcare settings (as in our study context). Qualitative research by team members revealed challenges with a previously-published SDM tool (SDM-Q-9) in primary care and mental health settings [42]. Challenges included inability to capture the SDM phase when problems are discussed and prioritized; the lack of a "not applicable" option; an over-emphasis on medical conditions; a lack of relevance for non-pharmacological interventions; and, the lack of recognition that SDM is valuable in goal-setting, investigations, as well as (as opposed to exclusively for) exploring treatment options [43].

In this context, the provincial health system sought to understand the experience of shared decision-making and collaborative goal-setting at diverse community rehabilitation sites across the province. This health system is the longest-running provincial health system in Canada and serves more than 4 million people. This work would form the baseline data to eventually evaluate the implementation of a novel model of care seeking to promote patient centred-care and collaborative goal-setting in community rehabilitation. In this study, for patients and providers of diverse community-rehabilitation sites across a single province in an industrialized country, we aimed to:

(a) measure the prevalence of high-quality SDM experiences (compared to less than high quality SDM experiences);
(b) measure goal-setting perceptions by patients;
(c) determine any associations between SDM experience or goal-setting perceptions and demographic and contextual factors (e.g. geography, patient and provider age, gender, discipline).

This study included a small pilot feasibility study in this population to understand the reliability of the SDM tool and recruitment logistics. This study complements another in this population that used qualitative interviews to explore SDM experiences [42]. The research team included two patient-co-investigators who consulted on the research design, implementation and results dissemination.

Methods

We used focused ethnography in this research program [44]. Ethnography involves making cultural inferences “(1) from what people say; (2) from the way people act; and (3) from the artifacts people use” [45]. We focused on the communities of patients and professionals composing diverse community-rehabilitation sites across a provincial geography. Focused ethnography features a problem-focused and context-specific approach; a focus on a discrete phenomenon; the conceptual orientation of a single researcher; involvement of limited participants; episodic participant observation; participants with specific knowledge; and an emphasis on academic and healthcare settings [46, 47]. We met all criteria save participant observation due to feasibility constraints. While this paper emphasizes the survey findings, this paper is part of a broader study that included qualitative interviews, focus groups, and patient-led data collection [42]. Together, this research program followed an ethnographic methodology that underpinned its theoretical approach to data collection and analysis, which carried into this survey work equally. The surveys allowed a population-level perspective to inform the in-depth qualitative work [43].

Participant Population

We captured diverse rehabilitation settings that saw outpatients including both public and private provider sites, as well as three geographic types (rural (population < 10000), regional-urban (population between 10000 and 100000), and metropolitan-urban (where population > 100000)).

Participants included current patients and providers visiting and working, respectively, at study sites. Provider inclusion criterion was employment at the site at recruitment. Providers included allied-health professionals who were members of the rehabilitation team (e.g. physical therapists, occupational therapists, speech-language pathologists). Patient inclusion criteria included ≥ 18 years of age; their provider was participating; able to consent without proxy; and can understand and speak English. There were no exclusion criteria.

Recruitment

Site leadership informed provider recruitment. Tactics included email introductions followed by study presentations (by webinar, in-person, or one-on-one). After discussions, informed consent was procured.

Convenience sampling directed patient recruitment. Management identified onsite recruiters from clerical and therapy-assistant staff. Researchers trained recruiters to identify eligible patients, discuss participation, and record those patients accepting take-home study packages. While provider-participants may have mentioned the study to patients, only onsite recruiters distributed surveys. Recruitment was bounded by a four-week site maximum and a 20-patient limit per provider to minimize site and provider burden. Patient consent was implied by the mailed return of surveys; written consent was required for future data sharing and future research contact.

Data Collection

We used validated surveys to measure SDM, goal-setting, quality of life and patient experience: at baseline (T0) we captured SDM (ASK-MI tool), perceptions on goal-setting, quality of life, demographic and contextual data; at 3-months post-baseline (T1) we captured quality of life and overall patient-reported rehabilitation experience (WatLX™ survey). The patient demographic and contextual data captured self-reported age, gender, education, income, medical conditions, and their perceptions of their health journey (i.e. where they were in their rehabilitation, whether they perceived a goal was set for their rehabilitation, and if so what that goal was). The provider demographic and contextual data included self-reported age, gender, professional discipline, years of experience. Providers were also asked if they completed the HealthChange® Methodology workshop through their organization, which aims to educate providers in helping patients make the behaviour changes needed to promote health; such training impacts provider-patient interactions and could impact SDM as patient-centred communication is discussed [48]. Survey completion took 5-7 minutes per time-point.

In a pilot feasibility study, we completed the following data collection strategies at two community rehabilitation sites with the modification that T1 would be at 6-weeks after recruitment (versus 3-months). The data collected was used to determine study logistics feasibility and the reliability of the ASK-MI results (via Cronbach's alpha determination).

A novel, dyadic SDM tool was used given the infeasibility of using a 3rd-party reviewer, and the challenges in using the SDM-Q-9 in similar Alberta populations: the

Alberta Shared decision-maKing Measurement Instrument (ASK-MI) (Figure 1 is the patient version; provider version is same except language transposed to address provider). Using a 6-point Likert Scale (with not-applicable option), patients and providers independently describe the appointment experience from a SDM-process perspective. This process involves patients and providers agreeing on the main concern; working together to make a plan that considers patients' wishes; and, ensuring the provider confirms patient understanding and next steps. The ASK-MI was developed and piloted in primary care and mental health clinics in Alberta [43].

The dyadic ASK-MI tool requires patient and provider to independently rate six facets of the SDM experience; lower numeric scores reflect higher quality SDM. Individual scores are summed; the two sum scores are compared to determine the final rating score: Excellent, Acceptable, or Unacceptable. When both patient and provider rate SDM highly, an Excellent rating score is reached. Disparity between parties would lead to a lower ASK-MI rating score. Full agreement on SDM Excellence equates to patient and provider both giving the best, lowest numeric score on each ASK-MI item. Using self-report, we collected contextual (e.g. group or individual appointment; were goals set with provider) and participant demographic data (e.g. age, gender, marital status).

The WatLX™ is a 2-page outpatient rehabilitation care patient experience survey meant for post-completion of rehabilitation care. The WatLX™ consists of 10 questions, where respondents can respond either not applicable or on a 7-point Likert scale. Psychometric testing of the WatLX™ involved 1174 cognitively-intact, English-speaking, adult outpatients who had completed a program of cardiac, musculoskeletal, neurologic, stroke, pulmonary, or speech language rehabilitative care in Ontario [49]. Reliability analyses compared the use of a 7-point to 5-point Likert scale in the WatLX™. Cronbach's alphas were 0.863 and 0.957 for the 5 and 7-point scale, and the ICC = 0.827 and 0.880, respectively [49]. Generally, the higher the score, the more positive the patient experience. There is evidence of ceiling effects with the WatLX™.

The T0 take-home study package included a consent form and directions, the ASK-MI survey, a patient demographic form including their communication preference for the 3-month follow-up (T1) surveys (which included WatLX™). All envelopes were pre-addressed and stamped to support convenient, confidential return to the researchers. Patients were directed to complete the surveys within 24 hours, so their appointment was fresh in their mind.

When a patient took a study package, the recruiter logged the date, envelope number, patient's initials, and provider name. Daily, this recruitment information was sent to the lead researcher, who emailed the ASK-MI (provider version) tool to the named provider, along with the patient initials via personalized email link to REDCAP at the University of Alberta. Providers received one email per patient and had 48 hours to complete the survey.

The second time-point (T1), for patients only, was exactly three months post-recruitment. T1 data collection was by mail or email per patient-participant preference. Participants received email or phone reminders 1-week prior to T1, and at 7-days post-T1.

To ensure the accuracy of data entry of paper surveys, a randomly-selected 30% of the study sample was assessed at the close of data collection. If more than 10% of the data was incorrectly entered, then another random 30% of the study sample would have been checked. Errors were rectified immediately.

At the close of data collection, the research team developed a coding rubric by consensus to capture the presence, and level, of function in the rehabilitation goals perceived by patient participants (as described in the self-reported patient sociodemographic form). Level of functionality was informed by the Alberta Health Services definition that the goal "consider[ed] the whole person – individual context, personal factors, and how a health condition impacts participation in life… work, school, play, relationships, roles and any activities that the person loves to do" [50]. A goal was functional, if it related to participation in a role, responsibility or activity important to the person; the language of the goal spoke to activity and participation in life not the rehabilitation treatment plan. A goal was not functional if it did not speak to such a role, responsibility or activity important to the person (e.g. language focused on the treatment plan or general alleviation of symptoms). While one researcher (KPM) coded all patient-participant self-reported perceptions, the team discussed and practiced the coding together to ensure consensus on approaches to described goals.

Data Analysis

After cleaning and coding the T0 and T1 data, we completed descriptive and exploratory analyses to address the research questions. The ASK-MI Score was collapsed into two different binary categorical variables: (a) Excellent versus

Acceptable/Unacceptable; and (b) Full Agreement on SDM Excellence versus Not Full Agreement on SDM Score. The secondary variable was overall rehabilitative care experience (WatLX^{TM}). Independent variables included age, gender, patient income range, geographical area, and other demographic and contextual variables.

The distribution of interval and ratio type survey data (e.g. age) was checked for whether it is normally distributed. Test selection was based upon the results of these analysis (e.g. non-normally-distributed data was analyzed using non-parametric tests). We analyzed the questionnaire data descriptively, with means, standard deviations, both overall in community rehabilitation and based on contextual differences. For categorical data, chi-square tests directed comparisons between high versus low quality SDM; sub-analyses using tests of proportions considered this ratio of experiences in different demographic and organizational settings based on the size and quality of independent variable data collected. For the three surveys, where missing data was less than 5% across population, then used the 20% as the threshold for missing items: if ≤ 20% items missing, then median response used in place of the missing item to then score the survey; if > 20% of items missing, then the entire record was deleted from the analysis [51]. Univariate correlations were studied between each independent variables (age, gender, income, geographical area, provider discipline) and the ASK-MI score. A binary regression was completed to ascertain the effects of training (i.e. HealthChange participation), level of privacy during appointment, geographical setting, and timing of appointment (relative to patient's rehabilitation care journey). This model used a binomial distribution with log link function to obtain relative risks. We used backward elimination with the Akaike Information Criterion (AIC) to reduce the model. At each step, the variables with the largest associated decrease in the AIC at removal was deleted from the model. The steps continued until the removal of remaining variable resulted in an increase in the AIC.

Results

Pilot Feasibility Study Results

Phase 1 involved two community rehabilitation sites in an urban-metropolitan area in Alberta between March and May 2018 (n=24 patients and n=6 providers). The mean (range) participant age for patients and providers was 48.3 (22-71) and 37.4 (26-56) years, respectively. Most participants were White (87.5% patients; 80% providers) and female (66.7% patients; 60% providers). Fifty percent of patient-participants were employed, while 20.8% were retired. Patient-participants' total family income varied with 37.5% being affluent (≥ $150000) and a combined 20.8% being less affluent (<$35000). On average (range), provider-participants had 12 (3-30) years of experience and worked 31.7 (10-70) hours weekly.

Because only four patients completed follow-up surveys that included the WatLX™, we only assessed the reliability of the EQ-5D-5L and ASK-MI surveys in this population. Table 1 describes the tools' means, standard deviations and internal consistency assessments using Cronbach's alpha. Given the small sample, the reliability of these measures appear appropriate and related to estimates during tool development [52]. Field notes support the validity of the EQ-5D-5L and ASK-MI tools for participants. The ASK-MI scores were clustered in the excellent range, which is common to many patient-reported experience measures. The ASK-MI was completed by 24 patient-provider dyads. The scores obtained from these dyads scoring the SDM experience as Excellent (70.8%), Acceptable (29.2%), or Unacceptable (0%). Because complementary studies by study co-authors detail the psychometric validity of the instrument, we do not present further findings in that regard (for details, please contact co-authors as the manuscript is under review).

Tool	Mean	Standard Deviation	Internal Consistency Measurement Tool	Internal Consistency Measurement
ASK-MI	6.96 (patients) 10 (providers)	1.93 (patients) 4.07 (providers)	Cronbach's Alpha	0.82
EQ-5D-5L	73.6% (VAS) 0.760 (EQ-5D Index score)	13.7 (VAS) 0.104 (EQ-5D Index score)	Cronbach's Alpha	0.648

Table 1. Internal Consistency of Surveys in Pilot Feasibility Study

Participant Information (Full Study)

Thirteen community-rehabilitation sites distributed 606 take-home survey packages; 341 patients returned them and thus implied consent to participate (response rate 56.2%). At T1, 209 patients returned surveys (response rate 61.3%, the remainder lost to follow-up).

Table 2 describes the patient-participant population. The patient-participants' mean (SD) age was 57.5 (16.4) years. Most patient-participants were female (58.9%), married (68.9%), Caucasian (90.9%), had some post-secondary education (70.4%), were at a 1:1 appointment with providers (90.9%), were neither at the first nor last appointment at recruitment (66.9%), and were receiving physiotherapy (68.6%). Participants varied in where they received their care: 46.3% were in an open exercise area, 48.4% were in a private area (either behind a privacy curtain or in private room), and 3.8% described their area as unique. The demographic profile was similar between T0 and T1 patient-participants.

	N (%)
Patient Population	341 (100%)
Mean Age in years (SD)	57.5 (16.4)
Missing	3 (0.9%)
Gender	
Male	138 (40.5%)
Female	201 (58.9%)
Missing	2 (0.6%)
Marital Status	
Single	48 (14.1%)
Married (legal/common law)	235 (68.9%)
Separated or Divorced	32 (9.4%)
Widowed	21 (6.2%)
Missing	5 (1.5%)
Geographical Location	
Metropolitan-Urban	145 (42.5%)
Regional-Urban	161 (47.2%)
Rural	35 (10.3%)
Education	
High school diploma or less	96 (28.1%)
Any post-secondary education	240 (70.4%)
Missing	5 (1.5%)
Employment Status	
Employed	141 (41.3%)
Unemployed	61 (17.9%)
Retired	135 (39.6%)
Missing	4 (1.2%)
Ethnicity	

European Origins	310 (90.9%)
Indigenous (e.g. Inuk, Métis)	10 (2.9%)
Non-European Origins	21 (6.2%)
Supplementary Insurance	
Yes	144 (42.2%)
No	160 (46.9%)
Prefer not to answer	37 (10.9%)
Total Family Income	
Less than $59999	106 (31.1%)
$60000 to 99999	75 (22.0%)
$100000 or More	78 (22.9%)
Prefer not to answer	82 (24%)

Table 2. Patient-Participant Demographics

Table 3 describes the provider-participant population. The provider-participants' mean (SD) age was 41.8 (9.86) years. Experience-wise, providers had a mean (SD) of 15.1 (10.3) years of experience. Providers represented six rehabilitation disciplines, with physiotherapy (53.0%) and occupational therapy (19.7%) being most prevalent. Most providers were female (60.6%), Caucasian (60.6%), trained in Canada (66.7%), and had primarily clinical provider roles (vs. management) (71.2%).

Provider Participant Characteristics	N (%) or Mean (SD)
Population	66
Age (years)	41.83 (9.86)
Missing	13 (19.7%)
Gender	
Male	13 (19.7%)
Female	40 (60.6%)
Missing	13 (19.7%)
Provider Discipline	
Occupational Therapy	13 (19.7%)
Physiotherapy	35 (53.0%)
Other	5 (7.5%)
Missing	13 (19.7%)
Country of Training	
Canada	44 (66.7%)
Outside of Canada	9 (13.6%)
Missing	13 (19.7%)
Ethnicity	
European Ethnic Origins	40 (60.6%)
Non-European Ethnic Origins	8 (12.1%)
Missing	18 (27.2%)
Geographical Location	
Metropolitan-Urban	36 (54.5%)
Regional-Urban	24 (36.4%)
Rural	6 (9.1%)

Table 3. Provider-Participant Demographics

Table 4 describes the provider-participants' work settings. Providers worked a mean (SD) of 31.8 (9.0) hours/week in direct patient care, and saw a mean (SD) of 28.8 (17.6) patients per week. The outpatient clinical settings varied for providers, including community-based (31.8%) and hospital-based (45.5%) clinics. The clinical populations included at least 10 diverse populations, including general adults (25.8%), musculoskeletal (16.7%), and neurorehabilitation (13.6%). Providers were evenly split on participation in a person-centred behaviour-change course (HealthChange® Methodology [53]): 39.4% said they had taken it, 40.9% said they had not taken it, and 19.7% responses were missing herein. Of the providers who had taken HealthChange®, most providers perceived that it influenced their patient interactions to some degree (76.9%) (vs. to a great degree (15.4%)). The perceived influence of HealthChange® on site processes was less clear: 42.3% of providers saw no influence, while 53.8% saw some degree of influence.

Provider Participant Characteristics	N (%) or Mean (SD)
Setting	
Community-Based Clinic	21 (31.8%)
Hospital, outpatient Clinic	30 (45.5%)
Primary Patient Population	
Complex Adults	2 (3.0%)
Hand/Foot/Cardiac	4 (6.0%)
General Adults	17 (25.8%)
Musculoskeletal (MSK)	11 (16.7%)
Neuro	9 (13.6%)
Ortho/Surgery	3 (4.5%)
Seniors	4 (6.1%)
Missing	16 (24.2%)
Average Waitlist (days) for Clinic	16.59 (17.59)
Missing	18 (27.3%)
HealthChange® Completion	
Yes	26 (39.4%)
No	27 (40.9%)
Missing	13 (19.7%)
HealthChange® Influenced Patient Interactions?	
No Influence	1 (3.8%)
To Some Degree	20 (76.9%)
To a Great Degree	4 (15.4%)
Missing	1 (3.8%)

HealthChange® Influenced Site Processes?	
No Influence	11 (42.3%)
To Some Degree	14 (53.8%)
To a Great Degree	0 (0%)
Missing	1 (3.8%)

Table 4. Provider-Participants' Clinical Setting

SDM and Goal-Setting Prevalence in Community Rehabilitation

Using current ASK-MI scoring guidelines, 78.9% of T0 patient-provider appointments rated Excellent (Table 5). Given the evident floor effect of the ASK-MI (i.e. more than 15% of respondents have the lowest score, which is the best value [54]), the survey developers will re-assess the scoring algorithm [43].

Shared Decision-Making Experience	N (%) or Mean (SD)
ASK-MI Score	
Excellent	269 (78.9%)
Acceptable	37 (10.9%)
Unacceptable	2 (0.6%)
Missing/Unable to Calculate	14 (4.1%)
Patient and Provider had Full Agreement on SDM Excellence	
Full Agreement	90 (26.4%)
Less Than Full Agreement	218 (63.9%)
Missing/Unable to Determine	14 (4.1%)
Was a Goal Set with Provider?	
Yes	270 (79.2%)
No	67 (19.6%)
Missing	4 (1.2%)
Level of Functionality of the Patient-Stated Goal	
Highly Functional, focused on everyday activity (i.e.	39 (11.4%)
patient language)	140 (41.1%)
Moderately Functional, focused on general mobility	76 (22.3%)
Not Functional, focused on treatment plan (i.e.	86 (25.2%)
provider language)	
Not Applicable, no goal was set or goal not provided	

Table 5. Prevalence of Shared Decision-Making and Goal-Setting

Looking at full agreement on SDM excellence or not, at T0, 26.4% of patient-provider encounters involved full agreement on SDM excellence. Figures 2 and 3 display the frequency of responses across the 6-item Likert scale for each ASK-MI question for patients and providers, respectively. These two graphs reveal that, across the six items, providers agreed less often about SDM excellence (i.e. relatively fewer responses at 'strongly agree').

For patients, there was less agreement that the patient and provider planned together to address the patient's preferences and that the plan considered the patient's wishes and abilities. Patients more often strongly agreed that the provider checked the patient's understanding of the plan and that there was agreement on the plan created.

For providers, there was less agreement that the patient and provider worked together to make a plan that addressed patient preferences. Providers more often strongly agreed that there was clarity and agreement on the visit's main focus; that the provider checked for patient understanding; and that the patient and provider agreed on the plan created.

Table 6 compares the three geographical settings on prevalence of high quality SDM (i.e. full agreement on SDM excellence) in patient-provider encounters, which demonstrates no statistically significant differences in the quality of SDM experiences between geographical areas: metropolitan areas (19.9%) and regional areas (33.8%) (p=0.068).

Variable	**Geography**			F statistic Value (df)	P-value
	Metropolitan Urban Mean (SD) [95% CI] OR %	Regional Urban Mean (SD) 95% CI	Rural Mean (SD) 95% CI		
Patient Age	53.36 (17.29) [50.51-56.21]	61.08 (14.88) [58.74,63.41]	57.97 (15.14) [52.77-63.17]	8.824 (df 2)	< 0.001
Months Knew Provider Before Recruitment	8.40 (14.91) [5.54,11.26]	24.64 (2.39) [5.03,14.52]	51.76 (63.95) [25.36-78.16]	25.88	<0.001
% Appointments with Excellent ASK-MI Score	84.2%	89.0%	90.9%	1.91 (df 2)	0.384
% of Appointments with Full Agreement on SDM Excellence	19.9%	33.8%	26.7%	11.73 (df 6)	0.068
% Patients Perceived that Goals were Set	81.3%	79.1%	80.0%	0.22 (df 2)	0.90
% Perceived Goals were Functional	16.4%	6.3%	14.3%	8.627	0.196
% Providers Took HealthChange® Before	20.7%	56.7%	40.0%	37.05 (df 4)	< 0.001
% Appointments in Private Area	31.7%	69.2%	68.6%	46.25	< 0.001
Income				43.09	< 0.001
Less than $59999	26.1%	40.9%	20.6%		
$60000 to 99999	26.8%	21.4%	14.7%		
$100000 or More	37.0%	12.3%	23.5%		
Prefer not to answer	10.1%	25.3%	41.2%		

Rehabilitation Patient Received				14.07 (df 4)	0.007
Physiotherapy	69.7%	87.2%	74.3%		
Occupational Therapy	27.0%	10.6%	25.7%		
Other	3.3%	2.1%	0%		

Table 6. Comparison of Three Geographical Areas on SDM, Demographic and Contextual Variables

At T0, 19.4% of patients stated that they had not set a goal for their rehabilitation care (Figure 4). When patients had set a goal, they were asked to describe the goal. We categorized the patient-perceived goals based on level of functionality (Table 5). Only 11.4% of patients stated goals that met the Alberta Health Services' definition of functionality. A broader definition of functionality includes goals that aim for general improvements in, for example, mobility or strength. Under this broad definition, 42.6% of patients perceive their rehabilitation goals as aimed towards achievements or activities important to their life (Figure 5). Some 22.3% of patients perceived goals as equal to the treatment plan (e.g. doing home exercises, coming to appointments).

SDM, Goal-Setting, and Associated Factors

In the first phase, we used univariate Chi-square tests of correlation. SDM experience quality was not associated with whether patients' perceived that goals were set or whether patients' perceived goals that were functional. SDM experience was not associated with other immutable patient characteristics (e.g. gender, education, employment status, insurance access, income) or appointment type (Table 7). The only patient-related features associated with SDM timing of appointment (65.1% high-quality-SDM vs. 58.0% less-quality-SDM, p=0.035).

Variable	**Patient & Provider Full Agreement on SDM Excellence?**		Pearson Chi-Square Value (df)	P-value
	Yes Count (%)	No Count (%)		
Seen Provider Before Recruitment?			0.313 (df 2)	0.855
Yes	76.9%	74.4%		
No	23.1%	25.6%		
Appointment Timing at Recruitment			13.57 (df 6)	0.035
First Appointment	27.9%	22.6%		
Near Start of Care	37.2%	35.4%		

Near End of Care	30.2%	38.7%		
Last Appointment	4.7%	3.3%		
Appointment Type				
Group	6.6%	9.5%	0.734 (df 2)	0.693
Individual	93.4%	90.5%		
Where in Facility				
Open Area	39.8%	49.3%	7.05 (df 3)	0.070
Private Area or Other	60.2%	50.7%		
Patient Perceived Goals Set?				
Yes	80.2%	81.7%	2.567 (df 2)	0.277
No	19.8%	18.3%		
Perceived Goals were Functional?				
Yes	14.3%	10.9%	0.793 (df 2)	0.673
No	85.7%	89.1%		
Female Gender	58.2%	58.6%	0.015 (df 2)	0.993
Marital Status				
Married (incl common law)	72.5%	69.9%	3.08 (df 3)	0.379
Not, or No Longer, Married	27.5%	30.1%		
Education				
High school diploma or less	30.8%	26.5%	2.68 (df 3)	0.443
Any post-secondary education	69.2%	73.5%		
Employment				
Employed	41.8%	42.9%	3.50 (df 6)	0.743
Unemployed	16.5%	17.8%		
Retired	41.8%	39.3%		
Insurance				
Yes	45.1%	43.8%	7.515 (df 6)	0.276
No	41.8%	48.4%		
Prefer not to answer	13.2%	7.8%		
Income				
Less than $59999	34.3%	50.0%	5.91 (df 6)	0.43
$60000 to 99999	27.4%	23.5%		
$100000 or More	13.9%	11.8%		
Prefer not to answer	24.3%	14.7%		
Provider Discipline				
Physiotherapy	74.4%	81.3%	12.69 (df 6)	0.048
Occupational Therapy	25.6%	15.5%		
Other	0%	3.1%		
Provider Took HealthChange?			11.11 (df 6)	0.085
Yes	73.9%	41.2%		
No	26.1%	58.8%		

Provider Trained in Canada	85.3%	83.2%	0.264 (df 2)	0.877

Table 7. Relationship between Full Agreement on SDM (High Quality SDM) and Other Demographic or Contextual Factors

SDM experience was not associated with the providers' experience (in years since graduation) or the time since the provider took HealthChange®. SDM was not statistically-significantly associated with other features such as more privacy during the appointment (60.2% high-quality-SDM vs. 50.7% in low-quality-SDM, p=0.070), non-physiotherapy (74.4% physiotherapy in high-quality-SDM vs. 81.3% physiotherapy in low-quality-SDM, p=0.091) and if the provider had taken HealthChange® (73.9% in high-quality-SDM vs. only 41.2% high-quality-SDM if not taken, p=0.085).

SDM and goal-setting varied across the three geographical areas (Table 5). More providers had taken HealthChange® (p<0.001) in regional settings compared to rural and metropolitan settings. There was no difference in the proportion of patients with functional goals across geographies. Demographically, more patients had lower total family income in regional areas (40.9% lowest-income-bracket vs. 26.1% (metropolitan) or 20.6% (rural), p<0.001). Contextually, metropolitan-urban areas were unique in that fewer appointments were in private areas (31.7% vs. 69.2% in regional and 68.6% in rural, p<0.001) and fewer providers had taken person-centred behaviour-change training (HealthChange®) (20.7% vs. 56.7% in regional and 40.0% in rural, p<0.001). Finally, occupational therapy was represented least often in regional-urban appointments (10.6% vs. 27.0% (metropolitan) and 25.7% (rural), p=0.007).

A backwards, stepwise logistic regression was performed to ascertain the effects of appointment timing at recruitment, level of privacy (per location at setting), geographical setting, and whether the provider took HealthChange® on the likelihood that the patient and provider fully agreed on the excellence of the SDM experience. The final model included HealthChange® training and geographical setting, while appointment timing and privacy were removed as not statistically significant. The final model reveals the following relative risks ([95% confidence interval], p-value): 2.463 ([1.650,3.816], p<0.001) for regional vs. metropolitan settings; 1.399 ([0.646,2.652], p=0.329) for rural vs. metropolitan settings; and 0.439 ([0.284,0.649], p<0.001) for taken HealthChange® vs. not taken. Providers who took the training were less likely to rate their interactions with the highest score (37/119 = 31.6%) when compared with providers who did not take the training (82/178 = 47.4%; P < 0.01). Provider training was not associated with patient ratings. Patients with providers who took the training did not rate their interactions as less favorable than patients with providers who did not take the training (69/119 = 61.6% vs 110/178 = 64.7%; P=0.876).

Patients who perceived that a goal was set for their care saw a higher proportion of occupational therapists (35.5% vs. 14.7%, p=0.001). While the time a provider knew the patient before T0 was associated with whether a goal was set (p=0.054), the variance was high. Few other patient or provider characteristics were associated with patient perceptions of goal-setting. Patient perceptions of goal-setting for their rehabilitation did not differ by geographical setting, patient gender, marital status, education, employment status, or total family income (Table 8). Provider experience was not associated with patients' perceptions of goal-setting. Provider HealthChange® participation was not associated with patients' perception of goals setting or the functionality of the goal set.

Variable	**Did Patient Perceive that a Goal was Set for Rehabilitation Care?**		Test Statistic Value (df)	P-value
	Yes Mean (SD) OR %	No Mean (SD) OR %		
WatLX^{TM} Overall Rehabilitation Experience	9.034 (1.251)	8.717 (1.953)	F=1.47 (df 1)	0.227
Patient Age at T0	57.23 (15.92)	57.30 (18.14)	F=0.001 (df 1)	0.974
Provider's Experience	14.05 (10.67)	13.91 (10.17)	F=0.008 (df 1)	0.930
Time Patient Knew Provider	11.51 (24.63)	21.93 (51.61)	F=3.760 (df 1)	0.054
Months Since Provider Took HealthChange®	11.87 (19.86)	19.65 (26.73)	F=2.546 (df 1)	0.113
% Patients with Female Gender	59.6%	54.0%	x^2=0.666 (df 1)	0.414
% Providers took HealthChange®	39.2%	42.6%	x^2=0.474 (df 2)	0.789
Where in Facility Open Area Private Area or Other	 49.1% 50.9%	 37.5% 62.5%	x^2= 2.780 (df 1)	0.095
Marital Status Married (incl common law) Not, or No Longer, Married	 190 (71.2%) 77 (28.8%)	 43 (65.2%) 23 (34.8%)	x^2=0.910 (df 1)	0.34

Education			x^2=1.612 (df 1)	0.204
High school diploma or less	72 (27.0%)	23 (34.8%)		
Any post-secondary education	195 (73.0%)	43 (65.2%)		
Employment			x^2=2.316 (df 2)	0.314
Employed	118 (44.2%)	23 (34.3%)		
Unemployed	46 (17.2%)	15 (22.4%)		
Retired	103 (38.6%)	29 (43.3%)		
Income			x^2=2.458 (df 3)	0.483
Less than $59999	80 (30.7%)	25 (40.3%)		
$60000 to 99999	63 (24.1%)	11 (17.7%)		
$100000 or More	64 (24.5%)	14 (22.6%)		
Prefer not to answer	54 (20.7%)	12 (19.4%)		
Provider Discipline			x^2=13.79 (df 2)	0.001
Physiotherapy	192 (82.8%)	39 (62.9%)		
Occupational Therapy	34 (14.7%)	22 (35.5%)		
Other	6 (2.6%)	1 (1.6%)		

Table 8. Clinically Relevant Differences Between Whether Patient Set a Goal or Not During Care and Other Variables

Finally, the mean (SD) overall WatLX^{TM} rating of patient experience was 8.97 (1.39), where 10 was the highest rating. Item mean (SD) ratings ranged from 5.65 (1.35) to 6.79 (0.579) (7 was highest rating). Figure 6 demonstrates the distribution of responses along the 7-point Likert scale for these 10 items. The item with the greatest use of not applicable was having chosen family or friend given information that they needed about the patient's care, which suggests this question may not be relevant for many patients. The lowest rated items were for achieving treatment goals and controlling physical pain as much as possible. The highest-rated items were for being treated with courtesy, feeling safe during treatment activities and would recommend to others.

The mean (SD) overall rehabilitation experience when patients' experienced high-quality SDM experiences was 9.07 (1.57), and was not different from the experience of participants who reported "not high-quality" SDM (8.94 (1.41), p=0.735). Similarly, patient perceptions of a goal being set was not associated with patients' overall rehabilitation experience rating (9.03 (1.25) vs. 8.72 (1.95), p=0.227).

Discussion

These findings correspond with current literature but also provide a foundation for expansion [23–25, 55, 56]. Previous literature reviews suggested very negative and limited SDM experiences in rehabilitation [55]. A narrative synthesis (n=15 studies) revealed that in-patient rehabilitation goal-setting did not permit patient input, was overly-controlled by staff, was challenging for time and patient-load reasons, and involved parties lacking SDM knowledge [55]. Our data suggest that many patients and providers rate SDM-quality high even though some providers do take a leading (or controlling) role. For patients, the lowest ratings relate to the recognition of patient preferences, which is at the heart of SDM. Providers were more critical than patients on SDM experiences, which suggests a receptivity to strategies to improve SDM. This critical nature may be expanded by training in patient-centred care principles. Our multivariate analysis revealed that exposure to HealthChange® training decreased the likelihood of full agreement between the patient and provider on SDM excellence during the appointment. Further analyses revealed that provider training was not associated with patient ratings, but providers who took HealthChange® training were less likely to rate their interactions with the best (lowest) score. This finding also suggests that perhaps patients who tended to judge interactions as positive also tended to have providers who had taken the course.

While the literature in rehabilitation often conflates goal-setting and SDM [55, 57], our findings suggest that may be inappropriate. Patient-participant perceptions of whether goals were set, and the connection (or not) between set goals and patient lives, calls for further investigation. Nearly 1 in 5 patients in this provincial health-system did not set goals for their rehabilitation care. If goal functionality is modestly measured to include general and specific connections to patients' everyday activities, roles and responsibilities, then only every other patient set a goal in language that was meaningful to their lives and activities. Patient engagement and SDM are strategies to support movement towards meaningful goal-setting, which itself supports patients in working on treatment plans that motivate them and move them in the direction that they would like to go [6].

While full agreement on SDM excellence was less frequently associated with providers who took HealthChange®, most providers felt that HealthChange® influenced their patient interactions and site processes to some degree (76.9% and 53.8%, respectively). In addition, providers who took the training were less likely to rate their interactions with the highest score (37/119 = 31.6%) when compared with providers who did not take the training (82/178 = 47.4%; P < 0.01). Provider training was not associated with patient ratings. Patients with providers who took the training did not rate their interactions as less favorable than patients with providers who did not take the training (69/119 = 61.6% vs 110/178 = 64.7%; P=0.876). This suggests that providers who took the training may be more discerning when judging their interactions with patients.

This work, however, may suffer from similar challenges as the train-the-trainer SDM-development activities completed previously in Europe that did not yield increased patient involvement in decision-making [24, 25]. In our study and that in Europe, providers perceive an impact of their training relating to the processual aspects of SDM, but in both cases a statistically-significant positive impacts on SDM is not determined between those with training and those without [24, 25]. More research is required to determine what facets of SDM and patient-centred communication training lead to tangible improvements in SDM experiences.

Most non-modifiable patient characteristics (including age) were not significantly associated with the quality of SDM or goal-setting. Only total family income was associated with SDM experience. These findings corroborate the literature that SDM is a skill that can be taught and not an innate trait of an individual [58]. Total family income is a marker of socioeconomic status and relative vulnerability; it is not about capacity or education because education level was not associated with SDM experience. Further strategies and training are likely required to support providers and organizations in identifying, then approaching and empowering, more economically-vulnerable patients in SDM.

The literature describes SDM, while highly relational (conceptually and practically), is influenced by contextual factors such as time and setting [18, 59, 60]. Our findings do not quantify further details on the contextual factors. Our regression results suggested that geographical settings do vary on quality of SDM. Non-metropolitan areas, which often have more resources but busier clinics, had lower likelihoods of high-quality SDM experiences compared to rural and regional settings. Geographical areas did vary statistically on types of rehabilitation providers, monthes patient and provider knew each other, and, provider training in patient-centred principles. Finally, as different disciplines seem to have varying success with SDM, there may be an opportunity to promote greater transdisciplinary learning, practice and sharing in community-rehabilitation sites. This would support the development of a community of practice, which would also sustain learnings from person-centred training (e.g. HealthChange®) through ongoing discussion.

Based on participant demographics, these findings confidently apply to diverse community rehabilitation settings across Alberta. The patient population was fairly distributed amongst different family incomes, insurance access, and employment. These findings were not as highly represented from patients originating from rural communities, ethnocultural communities, and less-educated populations (i.e. less than high school).

Participating providers were mostly fairly experienced. The findings apply to hospital-based and community-based settings. These findings may not apply to new-graduates or providers trained outside of Canada. Most providers represented two rehabilitation disciplines: occupational therapy and physiotherapy. While several other disciplines were present to a lesser degree, it may be useful to examine these research questions where these other disciplines are more populous.

Limitations

We recognize several study limitations. First, we tried to minimize recall (memory) bias by placing a 24-hour limit on participants to complete surveys, so the appointment is fresh in their minds. We recognize that patients may not have completed the survey on-time with take-home packages since it was outside the supervision of researchers and recruiters.

Second, we tried to lessen the risk of loss at 3-month follow-up using several tactics from Dillman et al. [61]. These tactics included allowing participant preference to dictate the form of follow-up (email or paper); using a mix of email and phone reminders both pre- and post- T1. We lost about 40% of patients at T1. Demographically, the patient-participants at recruitment and follow-up did not differ significantly on any patient characteristics.

Third, Phase-1 learnings suggested that there may be a selection bias and non-response bias. Patients with extreme experiences (either good or bad) could have been more interested in participation, which could differ significantly from the general patient-population experience. It was unlikely, given the difficulty in patient recruitment generally, to recruit non-responders to participate in a non-responder survey. This study prioritized significant recruitment using convenience sampling to lessen the influence of these biases.

Fourth, there may have been a Hawthorne effect on providers wherein their knowledge of a study assessing their communication altered their communicative behaviours. A previous feasibility study demonstrated that rehabilitation professionals were accustomed to being observed during practice given their own training, the multidisciplinary players, and trainee presence at many sites. For patients, they would generally not know of the study until after their appointment, so their actions likely would not be influenced by reactive effects.

Fifth, there may have been acquiescence and social desirability bias whereby participants frequently endorsed positive statements and where participants wished to present themselves at their best, including being fully engaged in SDM. Historically, this has been shown to have a small but pervasive effect. To minimize this, we aimed to recruit until a high survey sample size and diversity of population were recruited.

Sixth, for feasibility, survey tools were used differently from their original validation process. The WatLX^{TM} was completed 3-months after recruitment which corresponded differently across patients' rehabilitation journey; not all patients completed the WatLX^{TM} within the two weeks after care ended. Most patients stated at recruitment that they were neither at the first nor last appointment. Only 4.4% of patients were on their last appointment at recruitment. The most egregious difference in WatLX^{TM} completion (i.e. 3 months after last appointment) was only possible for a rarity of participants. The gains made in data collection compared to the feasibility study suggest that this compromise in data collection was worthwhile. The resonance and corroboration of findings across methods and studies confirms that the tools remained valid.

Seventh, we cannot guarantee that ASK-MI survey completion was based on assessments of the recruitment-date appointment only rather than on the totality of experience with that patient, provider or clinic. Many participating patient comments in the ASK-MI referred to the entirety of their rehabilitation care. Patients may have felt that there was commonality or consistency in interactions across appointments, so it was then appropriate to assess SDM across the rehabilitation journey. Further research is required to understand when and how patients judge SDM in rehabilitation along the different points in the rehabilitation journey.

Conclusions

While we recognize several study limitations, we believe our forethought and planning to consider and address these limits ensures the methodological rigour of this study. This study complements our qualitative findings,[62], that SDM is complex not monolithic in community rehabilitation. There is room to improve upon patient and provider practices of SDM and collaborative goal-setting in these settings, and we offer strategies such as further person-centred training, enhancing privacy during appointments, and building transdisciplinary communities of practice around how rehabilitation providers can approach SDM with patients. Further research is required to determine whether novel scoring of the ASK-MI influences SDM prevalence, which tactics to identify and redress the vulnerability of low-family-income patients are useful to advance SDM for this vulnerable group. This study suggests that SDM experience and goal-setting are not associated with longitudinal perceptions of rehabilitation experience and treatment goals being met, using a tool with high ceiling effects. We recommend more research into strategies that advance highly-functional goal-setting with patients, and to re-examine these relationships with tools without (or with less prominent) ceiling effects.

Acknowledgements

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Author Contributions:

KPM helped contribute to the study's conceptualization and design. KPM implemented the study methodology, managed resources, and developed all manuscript drafts.

KO helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (SV, TW) regarding its methods, conduct, analysis, and manuscript development.

KC helped contribute to the study's operationalization; provided ongoing support on conduct, analysis, and manuscript development; and, reviewed and edited this manuscript.

PF helped contribute to data analysis during study implementation, final write-up of the organizational report, and this manuscript's analyses and results and discussion write-up; and, reviewed and edited this manuscript.

SV helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (KO, TW) regarding its methods, conduct, analysis, and manuscript development.

TW helped contribute to the study's conceptualization and provided ongoing supervision in close collaboration with the other senior authors (KO, SV) regarding its methods, conduct, analysis, and manuscript development.

Competing Interests: none

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Ethics Approval: Research ethics board approval was secured for this study from the Conjoint Health Research Ethics Board, University of Calgary.

Provenance, Peer Review: Not commissioned; externally peer reviewed.

Data Sharing Statement: Availability of data and materials. For the data wherein patients consented to future data sharing, the de-identified data is currently being prepared for deposit in a secure data repository for data sharing upon application.

Patient Consent: Patient-participants provided consent to share aggregated data in peer-reviewed publications.

Patient and Public Involvement: Two Patient and Community Engagement Researchers (PaCERs) were involved in informing and vetting the research proposal including research questions, methods, data collection and plans for data analysis. Patients were not involved in study recruitment. Provider participants were invited to webinars describing the study findings. The PaCERs are acknowledged in the acknowledgement section, as was their preference.

Figure 1. The Alberta Shared Decision-Making Measurement Instrument (ASK-MI)

Figure 2. Patient Responses on the Six ASK-MI Items on SDM Experience

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Figure 4. Patient Perceptions of Goal Setting Occurrence

Figure 5. Level of Functionality of Patient-Stated Goals

Figure 6. Patient Ratings of Experience on Individual WatLX^{TM} Items

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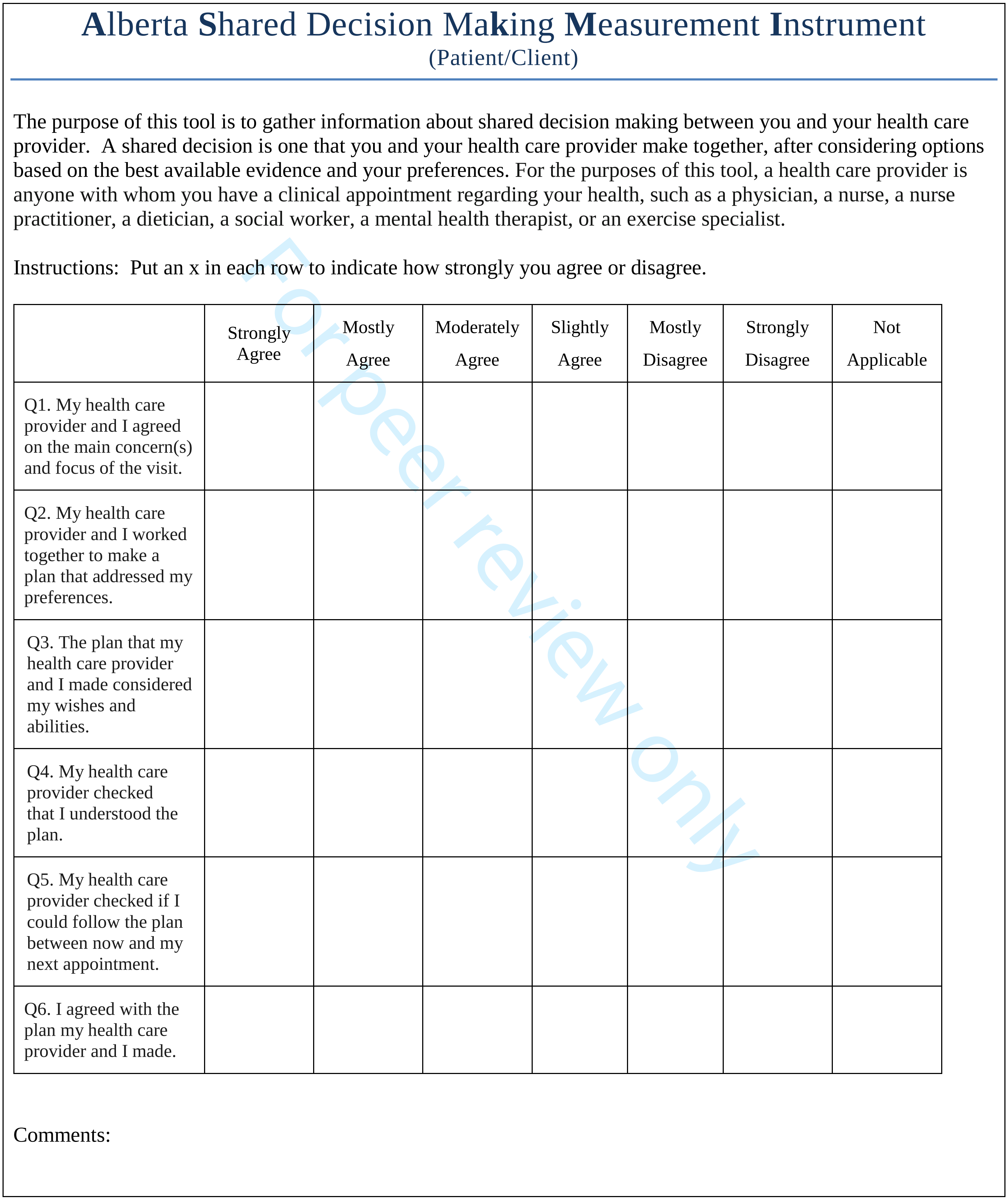
Figure 1. The Alberta Shared Decision-Making Measurement Instrument (ASK-MI)



Alberta Shared Decision Making Measurement Instrument
(Patient/Client)

The purpose of this tool is to gather information about shared decision making between you and your health care provider. A shared decision is one that you and your health care provider make together, after considering options based on the best available evidence and your preferences. For the purposes of this tool, a health care provider is anyone with whom you have a clinical appointment regarding your health, such as a physician, a nurse, a nurse practitioner, a dietician, a social worker, a mental health therapist, or an exercise specialist.

Instructions: Put an x in each row to indicate how strongly you agree or disagree.

	Strongly Agree	Mostly Agree	Moderately Agree	Slightly Agree	Mostly Disagree	Strongly Disagree	Not Applicable
Q1. My health care provider and I agreed on the main concern(s) and focus of the visit.							
Q2. My health care provider and I worked together to make a plan that addressed my preferences.							
Q3. The plan that my health care provider and I made considered my wishes and abilities.							
Q4. My health care provider checked that I understood the plan.							
Q5. My health care provider checked if I could follow the plan between now and my next appointment.							
Q6. I agreed with the plan my health care provider and I made.							

Comments:

Figure 2. Patient Responses on the Six ASK-MI Items on SDM Experience

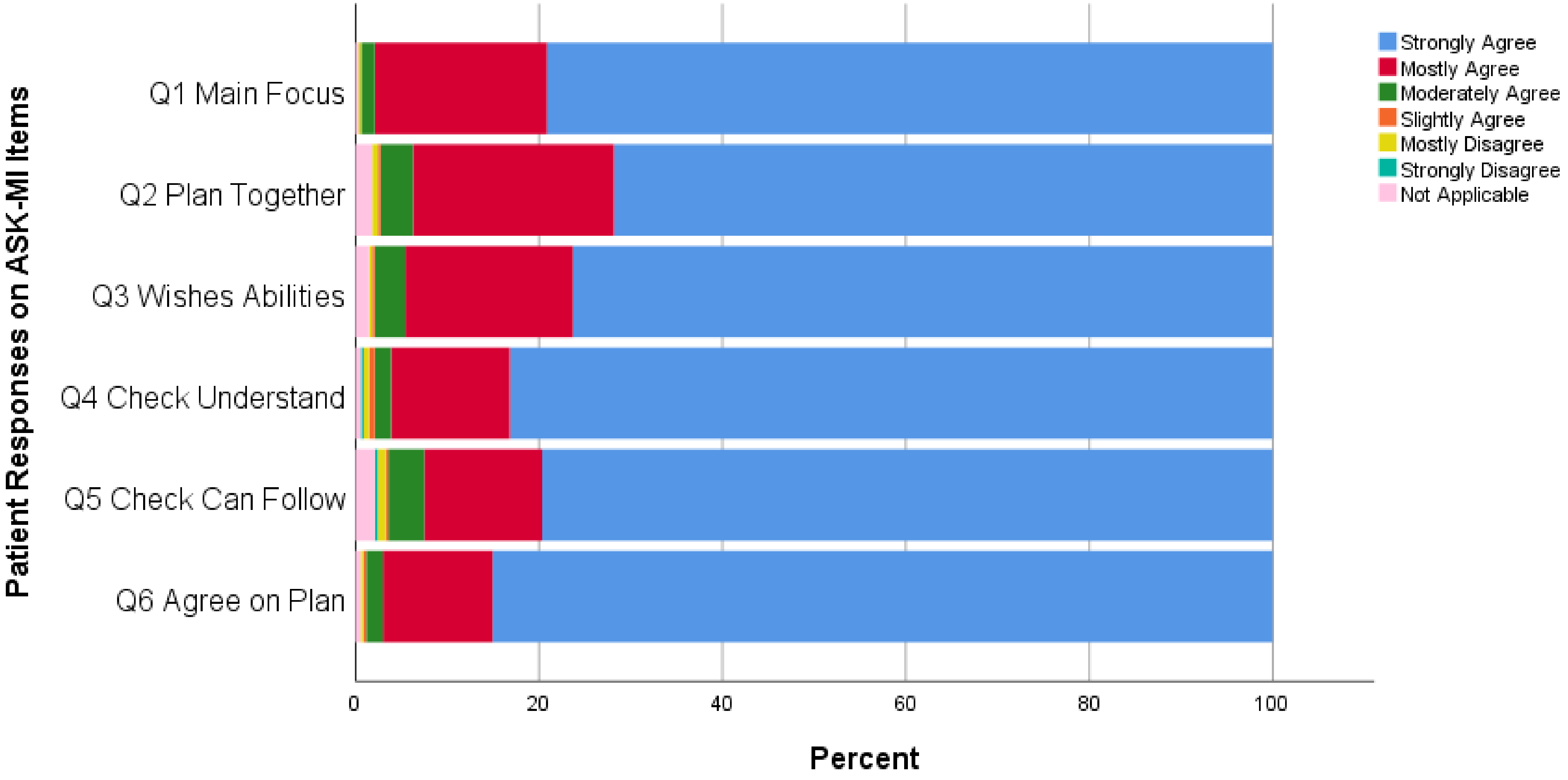


Figure 3. Provider Responses on the Six ASK-MI Items on SDM Experience

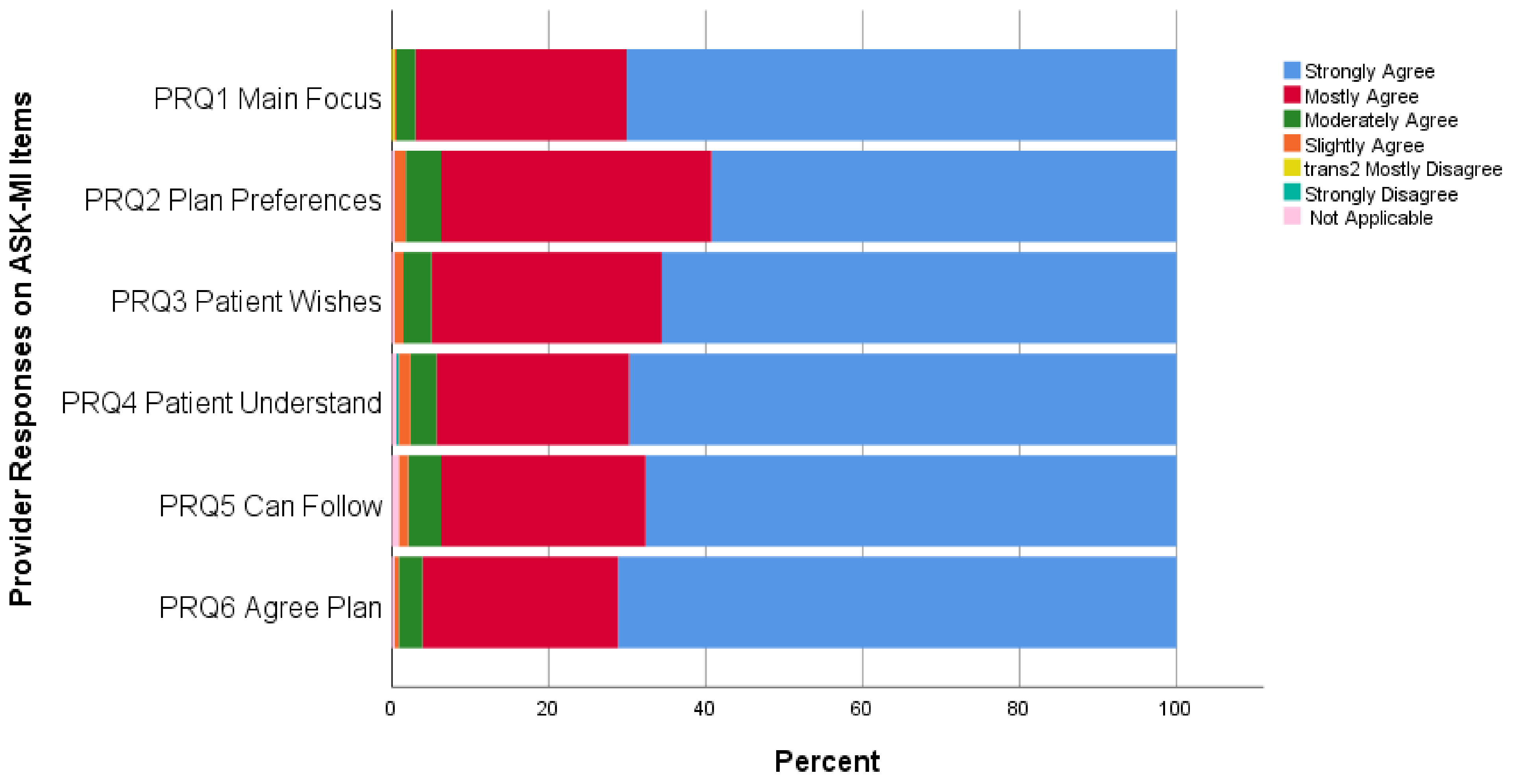


Figure 4. Patient Perceptions of Goal Setting Occurrence

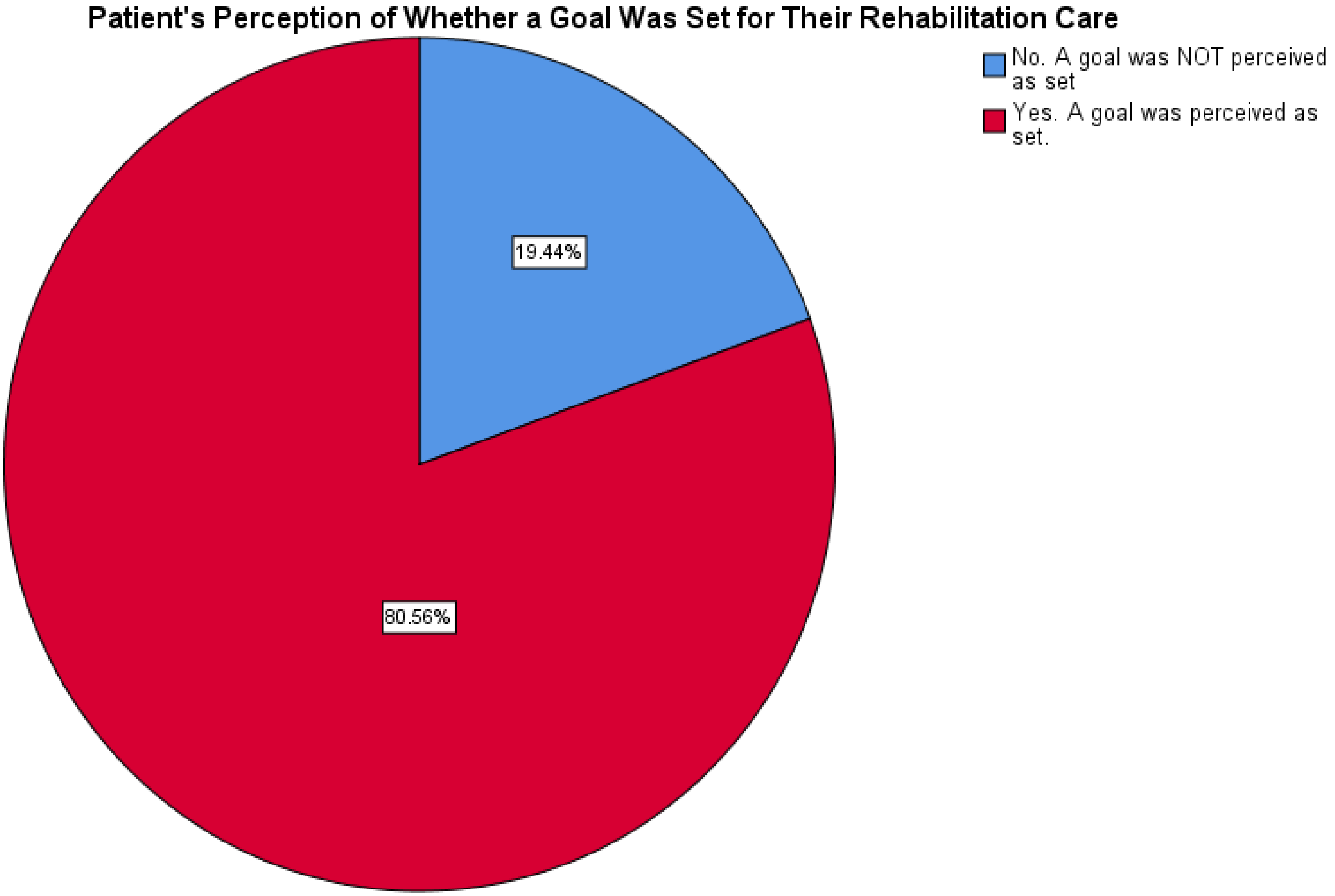


Figure 5. Level of Functionality of Patient-Stated Goals

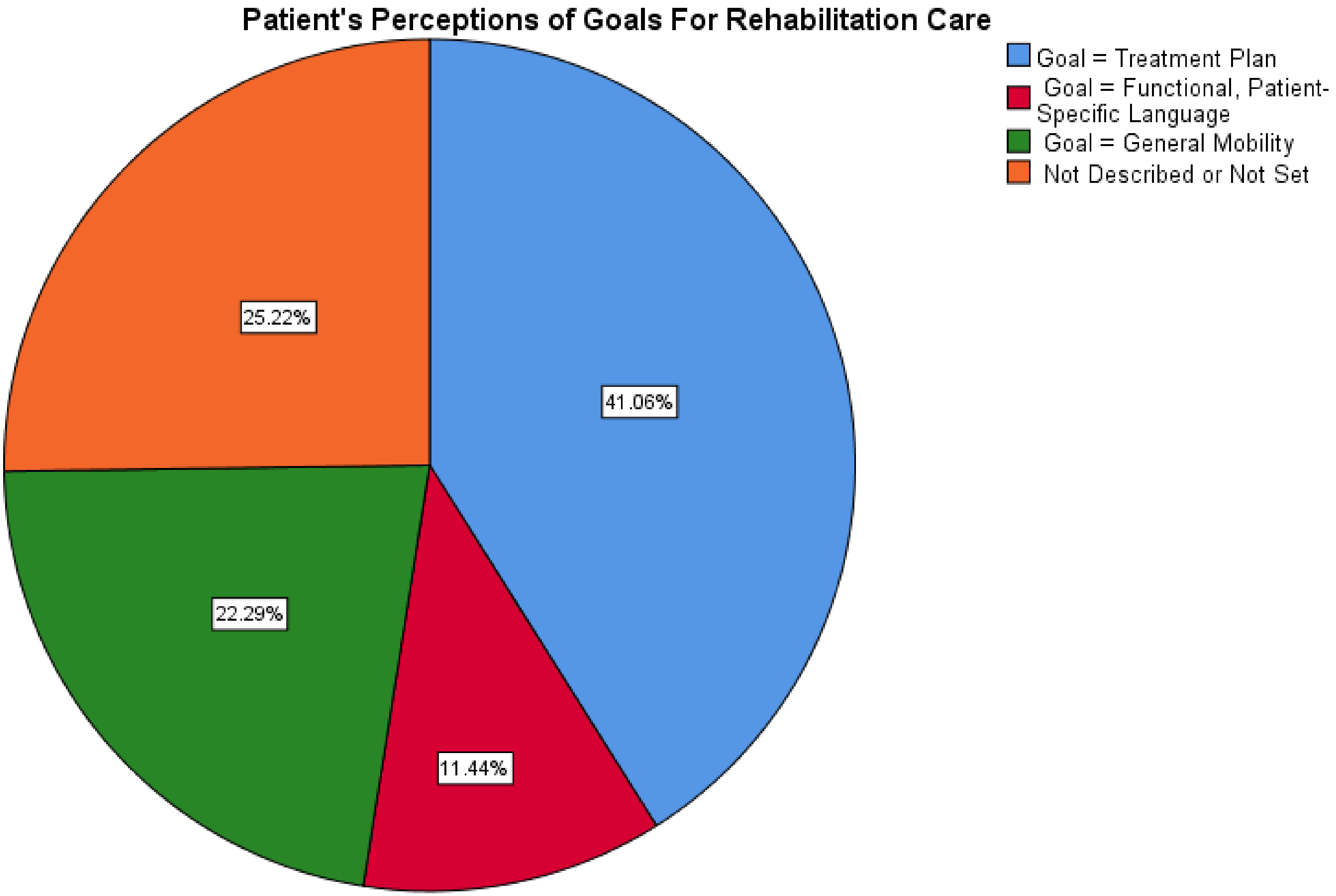
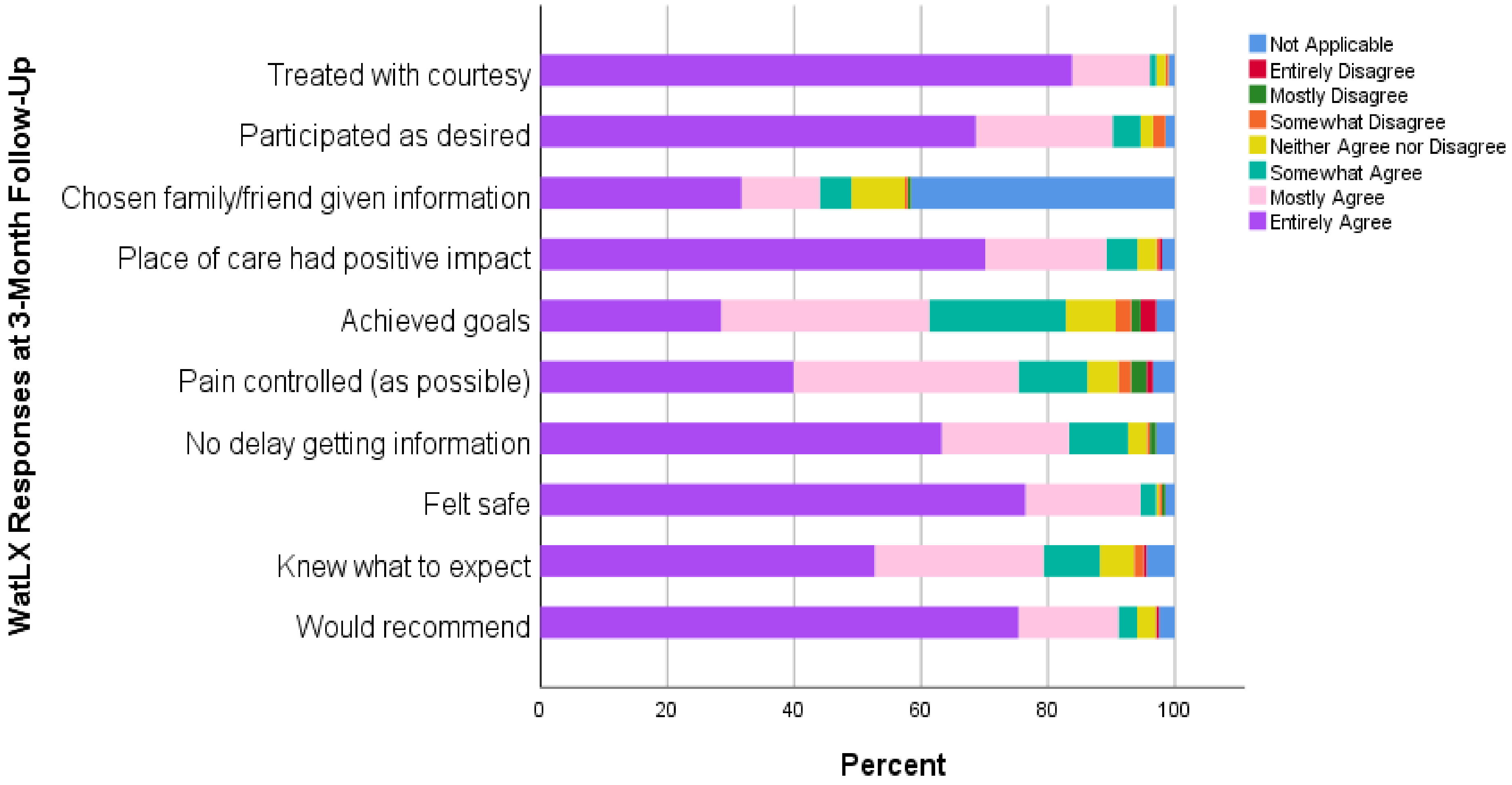


Figure 6. Patient Ratings of Experience on Individual WatLX™ Items



Reporting checklist for cohort study.

Based on the STROBE cohort guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cohortreporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gotzsche PC, Vandenbroucke JP. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

		Reporting Item	Page Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1
Abstract	#1b	Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background / rationale	#2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	#3	State specific objectives, including any prespecified hypotheses	4
Methods			

Study design	#4	Present key elements of study design early in the paper	4
Setting	#5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up.	5
Eligibility criteria	#6b	For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	#7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources / measurement	#8	For each variable of interest give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group. Give information separately for for exposed and unexposed groups if applicable.	5
Bias	#9	Describe any efforts to address potential sources of bias	13
Study size	#10	Explain how the study size was arrived at	5
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	7
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	7
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	7
Statistical methods	#12c	Explain how missing data were addressed	7
Statistical methods	#12d	If applicable, explain how loss to follow-up was addressed	7
Statistical methods	#12e	Describe any sensitivity analyses	n/a

Results

Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	7
Participants	#13b	Give reasons for non-participation at each stage	7
Participants	#13c	Consider use of a flow diagram	n/a
Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	8
Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	8-11, Tables
Descriptive data	#14c	Summarise follow-up time (eg, average and total amount)	6
Outcome data	#15	Report numbers of outcome events or summary measures over time. Give information separately for exposed and unexposed groups if applicable.	8-11, Tables
Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8-11, Tables
Main results	#16b	Report category boundaries when continuous variables were categorized	8-11, Tables
Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a
Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	7

Discussion

Key results	#18	Summarise key results with reference to study objectives	11-12

Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	13-14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	12-13
Generalisability	#21	Discuss the generalisability (external validity) of the study results	13
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

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