PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Measuring Shared Decision-Making and Collaborative Goal Setting in Community Rehabilitation: A Focused Ethnography Using Cross-Sectional Surveys in Canada
AUTHORS	Manhas, Kiran; Olson, Karin; Churchill, Katie; Faris, Peter; Vohra, Sunita; Wasylak, Tracy

VERSION 1 – REVIEW

REVIEWER	Sheeba Rosewilliam University of Birmingham, UK
REVIEW RETURNED	04-Nov-2019

GENERAL COMMENTS	There is very limited literature on shared decision making in rehabilitation and this work could add to the evidence base. The title states that this study looks at measuring SDM and goal setting in the community. However, the abstract does not mention gaol setting in the aim or methods. Not clear why there is a discussion of lack of outcome measures. A large part of the background focusses on the development of the ASK-MI tool. For the above reasons the background reads like the background for evaluating the new tool rather than an exploratory or descriptive study of the practice of SDM and goal setting in the community. There is an assumption that there was a prevalence of high quality SDM in the aims stated. Was there a reason for this? Were the clinicians trained to do SDM in the study settings? There is no justification of why the study was carried out i.e. what was the need to study the stated aims which are to measure prevalence of SDM or goal setting perceptions. In fact, there is no mention of why study goal setting prior to the statement of aims. This further raises questions in the results section about why the variable 'whether goals were set' is compared against other variables? I am not sure this mixed methods study with predominantly surveys can be described as ethnography as it does not provide holistic in-depth data on people's interactions, perceptions and behaviours. The data collection describes the survey method in detail. Even based on the definition of ethnography that the authors have provided, there is no cultural inferences derived in this study because of what has been studied. Surveys are not the best ways to study what people said or how they behaved, nature of setting or the artefacts they use. The methods section does not specify the

	statistical tests done other than Chi square. Were any statistical tests done for checking errors or false positives due to multiple comparisons? Who is the provider? Is it therapists, doctors, nurses, social services workers or administrators? Moreover, it is not clear why a second time point T1 was used for assessment with patients. Just asking whether goal setting was done and stating that goal setting in this setting was measured is misleading. There is a lot of unexpected information in the results section which needs to be introduced in the methods section. For example, what is the need to study waiting list status or attendance at the health change course? The new information just throws the reader off track as the importance of this information has not been explained previously. The first part of the page 18 presents the evaluation of the ASK-MI tool. Authors need to be clear whether this article is about evaluation of the tool or exploration/description of practice. The level of functionality of the goal has been presented in the results. How did this data come about? Who did the classification of the goals? The ASK-MI descriptive results provided on pg 18 and 19 should be presented in a table format for easy comparison of patient and provider data. The text is vague without the numbers. The results section on goal classification reads like the methods section. The RMoC classification and how it was done should be presented in the methods section. While there are some interesting points raised in the discussion section, only the significant results are discussed, but not the non-significant variables. Moreover, the discussion is not embedded in wider literature and reads like opinions of the authors. It is not clear why do an assessment at T1 and what were the findings?

REVIEWER	Jeanette Melin RISE, Sweden
REVIEW RETURNED	24-Nov-2019

GENERAL COMMENTS	Many thanks for inviting me to review the article, Measuring Shared Decision-Making and Collaborative Goal-Setting in Community Rehabilitation: A Focused Ethnography Using a Prospective Cohort. You address an important topic and stress the importance of accurate measurements of SDM - that is really good. However, I have two major concerns with your chosen methods to accomplish your purpose. i) You have not chosen a measurement that can answer you research questions; you know from previous studies that there are major problems with floor effects. Consequently, the reliability in your measure is low and in turn measurement accuracy is limited. If your are using the choosen questionniares, this needs to be justified. ii) Questionnaire self-reports are always giving ordinal data, but measurements are always interval data. Calculating sum-scores from ordinal data is not suitable, and there are several methods to

	overcome this. However, the next problem is that you have not considered a separation between person characteristics and item attributes. This is necessary to talk about a measurement, and the only available method that both separate person and item factors as well as transform the ordinal data into a linear invariant measure is the Rasch Model. Thus, this is a prerequisite before any statistical analyses. With regard to those shorages, I think there is a need for revision before any other comments. The results are probably too biased, and consequently needs to be addressed in the discussion.

REVIEWER	Marie-France Coutu Universite de Sherbrooke
REVIEW RETURNED	10-Jan-2020

GENERAL COMMENTS	The objective of this study is to measure shared-decision-making experience from the perspective of patients and providers in rehabilitation. There are several aspects of this study that are of great concern to me. The scientific background focuses on measures of shared decision-making (SDM). However, it misses the most commonly used measure the OPTION GRID. This is a third-party observer measure, which known to be superior to self-rated measures. Therefore, authors should argue their choice to use a self-report measure and one that is newly developed. Especially since it ended up having a ceiling effect. Previous studies have also assessed SDM in a rehabilitation context with occupational therapists and physiotherapists. Therefore, the added value of the current study needs to be highlighted. As the aim of the paper is to measure SDM, it needs to be specific on which component is measured. SDM process has been lengthy discussed in the literature and a program (MAGIC program) and an operationalized model for rehabilitation have also been published. It is essential to define what, in the SDM, was specifically being measured. For example, in this document, the central element of the SDM, the deliberation phase, is not mentioned. In shared decision-making, deliberation must take place on the various options for achieving the goal. The main outcome in this study, the ASK-MI, has no published psychometric properties. Having a new measure does not allow comparisons with other studies. Furthermore, by looking at Figure 1, this measure appears to be more closely related to the concept of working alliances (Horvath et al. 1994). In fact, the manuscript appears to refer more closely to the working alliance, and not SDM. A longitudinal design was reported, but there is no justification on its theoretical contribution to the objective. Moreover, in the data analysis section and results section, no analysis is presented for the time effect. Univariate analyses were conducted, but since sociodemographic factors are highly correlated, why not perform a multivariate analysis? In addition, the time of entry in the study could highly influence the alliance in the dyad. This factor should have been included as a confounding factor. Another confounding factor is the fact that some professionals followed a registered training (HEALTHCHANGE). Based on available information, this training is not dedicated to SDM, but appear to include some element of SDM. In fact, this again points out to training on the working alliance and some behaviour modification techniques. Most of the result section presents differences between two groups

	of SDM levels on several sociodemographic factors. It is not clear why these analyses were conducted. It seems that a secondary objective, not formally stated, was to explore factors associated with the SDM levels of implementation. Again, this type of study has been conducted in SDM and the added value of the study needs to be clarified. Exploring sociodemographic variables also appears to have been the reason for the term “ethnographic” in the title. The term “ethnographic” in the title should be removed, as it is misleading for those who know ethnographic studies. In the discussion section, page 25 mainly discussed points not related to the results. In addition, a significance level of 0.086 cannot support the idea that HEALTCHANGE is associated with better SDM encounter. Also very limited references support statements.

VERSION 1 – AUTHOR RESPONSE

REVIEWER 1 (Sheeba Rosewilliam)
There is very limited literature on shared decision making in rehabilitation and this work could add to the evidence base. Not clear why there is a discussion of lack of outcome measures. A large part of the background focusses on the development of the ASK-MI tool. For the above reasons the background reads like the background for evaluating the new tool rather than an exploratory or descriptive study of the practice of SDM and goal setting in the community. -The introduction was completely re-written to better represent the focus of this paper, which is as an exploratory study of the practice of SDM and goal-setting in community rehabilitation.
“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 [45]. 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;

(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." Introduction (p. 3-4, all paras)

The title states that this study looks at measuring SDM and goal setting in the community. However, the abstract does not mention gaol setting in the aim or methods. -Abstract objective changed to: "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."

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

Abstract (p. 2)

There is an assumption that there was a prevalence of high quality SDM in the aims stated. Was there a reason for this? Were the clinicians trained to do SDM in the study settings? -The aim is stated as such to reflect the outcomes available using the ASK-MI (SDM measurement instrument), which leads to binary outcomes (high quality (full agreement on SDM excellence) or less than high quality SDM (not full agreement on SDM excellence).

-For clarify, objective aim is re-written as "measure the prevalence of high-quality SDM experiences (compared to less than high quality SDM experiences)" Introduction, p 5, para 4, ln 3.

There is no justification of why the study was carried out i.e. what was the need to study the stated aims which are to measure prevalence of SDM or goal setting perceptions. In fact, there is no mention of why study goal setting prior to the statement of aims. This further raises questions in the results section about why the variable 'whether goals were set' is compared against other variables? -Changes to the introduction section should better justify the need for this study:

-a paragraph was added detailing the health-system context and need for this study: "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."

-The connections between shared decision-making and collaborative goal setting in rehabilitation are elaborated: "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]."

-The objectives (alongside the above changes) should better reflect the need to consider both shared decision-making and collaborative goal-setting perceptions as markers of whether patient-centred care occurred or not: "In this study, for patients and providers of diverse community-rehabilitation sites across a single province in an industrialized country, we aimed to:

(d) measure the prevalence of high-quality SDM experiences (compared to less than high quality SDM experiences);

(e) measure goal-setting perceptions by patients;

(f) determine any associations between SDM experience or goal-setting perceptions and demographic and contextual factors (e.g. geography, patient and provider age, gender, discipline).

Introduction, p 5, para 3

Introduction, p 4, para 3

I am not sure this mixed methods study with predominantly surveys can be described as ethnography as it does not provide holistic in-depth data on people's interactions, perceptions and behaviours. The data collection describes the survey method in detail. Even based on the definition of ethnography that the authors have provided, there is no cultural inferences derived in this study because of what has been studied. Surveys are not the best ways to study what people said or how they behaved, nature of setting or the artefacts they use. The methods section does not specify the statistical tests done other than Chi square. Were any statistical tests done for checking errors or false positives due to multiple comparisons? -Added the following information to Methods section: "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)." Methods section, p. 8, para 1.

Who is the provider? Is it therapists, doctors, nurses, social services workers or administrators? -Added clarifying sentence: "Providers included allied-health professionals who were members of the rehabilitation team (e.g. physical therapists, occupational therapists, speech-language pathologists)."

Methods,
Moreover, it is not clear why a second time point T1 was used for assessment with patients. Just asking whether goal setting was done and stating that goal setting in this setting was measured is misleading. -We clarified what data was captured at T0 and T1 to demonstrate utility: "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 (WatLXTM survey). Survey completion took 5-7 minutes per time-point.
Methods, Data Collection (p9), para. 2
There is a lot of unexpected information in the results section which needs to be introduced in the methods section. For example, what is the need to study waiting list status or attendance at the health change course? The new information just throws the reader off track as the importance of this information has not been explained previously. -Added information to methods (particularly data collection) to clarify what data collected and what is Healthchange.

"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 [47]."
Methods, Data Collection (pg 9), para. 2
The first part of the page 18 presents the evaluation of the ASK-MI tool. Authors need to be clear whether this article is about evaluation of the tool or exploration/description of practice. -See above changes to Introduction and methods to emphasize that this study is exploring shared decision-making and collaborative goal-setting in community rehabilitation, not evaluating a new tool.
-We also added our pilot feasibility results to the results section to further clarify our understanding of the tool reliability before start of the study.
"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 WatLXTM, we can only assessed the reliability of the EQ-5D-5L and ASK-MI surveys in this population. Table 1 depicts 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. 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
-See above introduction and methods

-Results, pg. 13, para 3 and pg 14, para 1 and table 1.
The level of functionality of the goal has been presented in the results. How did this data come about? Who did the classification of the goals? -We elaborated the development and implementation of the coding rubric for goal functionality in the methods section.

"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" [49]. 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.
Methods, Data Collection (pg. 11), para. 4
The ASK-MI descriptive results provided on pg 18 and 19 should be presented in a table format for easy comparison of patient and provider data. The text is vague without the numbers. We have made the substantial changes to the manuscript for clarity on methods and results. We feel this lessens the vagueness of this section. With 8 tables in this manuscript, we feel that it may be too many tables to report. As such, we will maintain the presentation of these results in the text alone.

Changes to results include:
"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?
Yes

No

76.9%
23.1%

74.4%
25.6%
0.313 (df 2)
0.855
Appointment Timing at Recruitment
First Appointment
Near Start of Care
Near End of Care
Last Appointment

27.9%
37.2%
30.2%
4.7%

22.6%
35.4%
38.7%
3.3%

13.57 (df 6)

0.035
Appointment Type
Group
Individual
6.6%
93.4%
9.5%
90.5%
0.734 (df 2)
0.693
Where in Facility
Open Area
Private Area or Other
39.8%
60.2%
49.3%
50.7%
7.05 (df 3)
0.070
Patient Perceived Goals Set?
Yes
No

80.2%
19.8%

81.7%
18.3%

2.567 (df 2)

0.277
Perceived Goals were Functional?
Yes
No

14.3%
85.7%

10.9%
89.1%

0.793 (df 2)

0.673
Female Gender 58.2% 58.6% 0.015 (df 2) 0.993
Marital Status
Married (incl common law)
Not, or No Longer, Married
72.5%
27.5%
69.9%
30.1%
3.08 (df 3)
0.379
Education
High school diploma or less
Any post-secondary education
30.8%
69.2%
26.5%
73.5%
2.68 (df 3)
0.443
Employment
Employed
Unemployed
Retired
41.8%
16.5%
41.8%
42.9%
17.8%
39.3%
3.50 (df 6)
0.743
Insurance

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

73.9%
26.1%

41.2%
58.8%
11.11 (df 6)
0.085
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 %

WatLXTM 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% χ2=0.666 (df 1) 0.414

% Providers took HealthChange® 39.2% 42.6% χ2=0.474 (df 2) 0.789
Where in Facility
Open Area
Private Area or Other
49.1%
50.9%
37.5%
62.5% χ2= 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%) χ2=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%) χ2=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%) χ2=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%) χ2=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%) χ^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 WatLXTM 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)."

Results, pg 18-24

The results section on goal classification reads like the methods section. The RMoC classification and how it was done should be presented in the methods section. This information was removed from the results section and presented in the methods section. (see above changes to methods) Results, pg 19, para 1.

And Methods, Data Collection (pg. 11), para. 4

While there are some interesting points raised in the discussion section, only the significant results are discussed, but not the non-significant variables. Moreover, the discussion is not embedded in wider literature and reads like opinions of the authors. -We modified the discussion section to discuss non-significant findings, the wider literature and tempered language that may appear to be opinion:

Discussion

These findings correspond with current literature but also provide a foundation for expansion [23–25, 54, 55]. Previous literature reviews suggested very negative and limited SDM experiences in rehabilitation [54]. 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 [54]. 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 [54, 56], 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 [57]. 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, 58, 59]. 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.

Discussion, pg 24 to 27
It is not clear why do an assessment at T1 and what were the findings? -See above: We clarified what data was captured at T0 and T1 to demonstrate utility: "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 (WatLXTM survey). Survey completion took 5-7 minutes per time-point.
-See above updates of the feasibility study in the results section. Methods, Data Collection (p9), para. 2
REVIEWER 2 (Jeanette Melin)
You have not chosen a measurement that can answer you research questions; you know from previous studies
that there are major problems with floor effects. Consequently, the reliability in your measure is low and in turn measurement accuracy is limited. If your are using the choosen questionniares, this needs to be justified. -We did not know of the floor effects in this tool the ASK-MI until we completed our study.
-For clarity, we added information from our pilot feasibility study to the methods and results of this paper to demonstrate that we had some data to justify the reliability of the instrument to move forward with it and we also discuss in the introduction and methods how other tools were infeasible or found unsuitable to the unique Canadian context in which we work.:

"METHODS:
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 (WatLXTM 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 [47]. 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 WatLXTM is a 2-page outpatient rehabilitation care patient experience survey meant for post-completion of rehabilitation care. The WatLXTM consists of 10 questions, where respondents can respond either not applicable or on a 7-point Likert scale. Psychometric testing of the WatLXTM 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 [48]. Reliability analyses compared the use of a 7-point to 5-point Likert scale in the WatLXTM. 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 [48]. Generally, the higher the score, the more positive the patient experience. There is evidence of ceiling effects with the WatLXTM.

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 WatLXTM). 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" [49]. 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 (WatLXTM). 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 [50]. 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 WatLXTM, we can 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. 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 "

…
-Methods, pg 9, para 3. To pg 12
-Results, pg. 13, para 3 and pg 14, para 1 and table 1.

Questionnaire self-reports are always giving ordinal data, but measurements are always interval data. Calculating sum-scores from ordinal data is not suitable, and there are several methods to overcome this. However, the next problem is that you have not considered a separation between person characteristics and item attributes. This is necessary to talk about a measurement, and the only available method that both separate person and item
factors as well as transform the ordinal data into a linear invariant measure is the Rasch Model. Thus, this is a prerequisite before any statistical analyses. -As described in the methods section, the use of the full agreement on the SDM excellence metric is not a sum score calculation. Rather it looks for full agreement. Our bio-statistician indicated that because we are not inappropriately summing the ordinal scores, the Rasch model (while reasonable in other contexts) is not applicable.
-We clarified our introduction and methods to confirm that we aimed to describe the experience of shared decision-making in community rehabilitation. We completed a small pilot to ascertain internal consistency. Our co-authors will present data in a manuscript under submission elsewhere that describes the full psychometric validity of the ASK-MI (something that is beyond the aims and word count of this paper):

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 [45]. 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:

(g) measure the prevalence of high-quality SDM experiences;
(h) measure goal-setting perceptions by patients;
(i) 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:

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 (WatLXTM 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 [47]. Survey completion took 5-7 minutes per time-point.

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months). The data collected was used to determine study logistics feasibility and the reliability of the ASK-MI results (via Cronbach's alpha determination).

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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.

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Data Analysis

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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 [50]. 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 WatLXTM, we can 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. 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

See Methods (pg 9-12) and

Introduction (p. 3-4, all paras) and Results (12-13)

I think there is a need for revision before any other comments. The results are probably too biased, and consequently needs to be addressed in the discussion. We have clarified the intent of this manuscript on description, not tool validation, which is being presented in a separate manuscript under review. See above described introduction and objectives. Introduction pg4-5 (esp para 2, pg 5)

REVIEWER 3 (Marie-France Coutu)

The scientific background focuses on measures of shared decision-making (SDM). However, it misses the most commonly used measure the OPTION GRID. This is a third-party observer measure, which known to be superior to self-rated measures. Therefore, authors should argue their choice to use a self-report measure and one that is newly developed. Especially since it ended up having a ceiling effect. See above substantial changes to introduction (discussing the infeasibility of the OPTION GRID) and the inclusion of our feasibility pilot data.

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 [45]. 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:

(j) measure the prevalence of high-quality SDM experiences;
(k) measure goal-setting perceptions by patients;
(l) 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: …

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 (WatLXTM 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 [47]. 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 WatLXTM is a 2-page outpatient rehabilitation care patient experience survey meant for post-completion of rehabilitation care. The WatLXTM consists of 10 questions, where respondents can respond either not applicable or on a 7-point Likert scale. Psychometric testing of the WatLXTM 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 [48]. Reliability analyses compared the use of a 7-point to 5-point Likert scale in the WatLXTM. 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 [48]. Generally, the higher the score, the more positive the patient experience. There is evidence of ceiling effects with the WatLXTM.

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 WatLXTM). 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” [49]. 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 (WatLXTM). 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 [50]. 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

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Because only four patients completed follow-up surveys that included the WatLXTM, we can 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. 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)
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Table 1. Internal Consistency of Surveys in Pilot Feasibility Study

…

Introduction pg4-5 (esp para 2, pg 5)
Methods: pg 9 (para 2) to pg 12
Results: pg 12-13

Previous studies have also assessed SDM in a rehabilitation context with occupational therapists and physiotherapists. Therefore, the added value of the current study needs to be highlighted. See above additions in the introduction that touched upon the organizational context and specific need in this health system to study the experience of shared decision-making and collaborative goal-setting. In particular, we added the following:

- “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.” Introduction, pg 5, para. 3.

As the aim of the paper is to measure SDM, it needs to be specific on which component is measured. SDM process has been lengthy discussed in the literature and a program (MAGIC program) and an operationalized model for rehabilitation have also been published. It is essential to define what, in the SDM, was specifically being measured. For example, in this document, the central element of the SDM, the deliberation phase, is not mentioned. In shared decision-making, deliberation must take place on the various options for achieving the goal. -See changes to the introduction to better contextualize our understanding of SDM, the literature and the framework (Makoul & Clayman). Introduction, pg 4

The main outcome in this study, the ASK-MI, has no published psychometric properties. Having a new measure does not allow comparisons with other studies.
-See above changes to introduction, methods and results especially the pilot feasibility study.
-The psychometric properties of the ASK-MI are in a manuscript under review, and is led by some of the co-authors. Introduction (p 4), Methods (p. 8), Results (12)

Furthermore, by looking at Figure 1, this measure appears to be more closely related to the concept of working alliances (Horvath et al. 1994). In fact, the manuscript appears to refer

more closely to the working alliance, and not SDM. -See changes to the introduction to better contextualize our understanding of SDM, the literature and the grounding in the SDM framework by Makoul & Clayman. This framework informed the framing of our work, not that of working alliances (Horvath et al 1994). Introduction, pg 4
A longitudinal design was reported, but there is no justification on its theoretical contribution to the objective. -We clarified in the methods sections what different data was captured at T0 vs. T1:
“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 (WatLXTM 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 [47]. Survey completion took 5-7 minutes per time-point.” Methods, Data Collection (p9), para. 2
Moreover, in the data analysis section and results section, no analysis is presented for the time effect. -We clarified the methods that different data captured at T0 vs. T1. There was no second measurement on the ASK-MI or demographic data. Methods, Data Collection (p9), para. 2
Univariate analyses were conducted, but since sociodemographic factors are highly correlated, why not perform a multivariate analysis?
In addition, the time of entry in the study could highly influence the alliance in the dyad. This factor should have been included as a confounding factor. -Based on this reviewer feedback, we completed an additional backwards, step-wise binary logistic regression model to determine the effect on quality of SDM (as reflected in the binary comparative variable of full agreement in SDM excellence) by four key variables: 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).
-Changes to Methods section included addition of this sentence to Data analysis:
“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.”

-Changes to Results section:
“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?
Yes
No

76.9%
23.1%

74.4%
25.6%
0.313 (df 2)
0.855
Appointment Timing at Recruitment
First Appointment
Near Start of Care
Near End of Care
Last Appointment

27.9%
37.2%
30.2%
4.7%

22.6%
35.4%
38.7%
3.3%

13.57 (df 6)

0.035
Appointment Type
Group
Individual
6.6%
93.4%
9.5%
90.5%
0.734 (df 2)
0.693
Where in Facility
Open Area
Private Area or Other
39.8%
60.2%
49.3%
50.7%
7.05 (df 3)
0.070
Patient Perceived Goals Set?

Yes
No

80.2%
19.8%

81.7%
18.3%

2.567 (df 2)

0.277
Perceived Goals were Functional?
Yes
No

14.3%
85.7%

10.9%
89.1%

0.793 (df 2)

0.673
Female Gender 58.2% 58.6% 0.015 (df 2) 0.993
Marital Status
Married (incl common law)
Not, or No Longer, Married
72.5%
27.5%
69.9%
30.1%
3.08 (df 3)
0.379
Education
High school diploma or less
Any post-secondary education
30.8%
69.2%
26.5%
73.5%
2.68 (df 3)
0.443
Employment
Employed
Unemployed
Retired
41.8%
16.5%
41.8%
42.9%

17.8%
39.3%
3.50 (df 6)
0.743
Insurance
Yes
No
Prefer not to answer
45.1%
41.8%
13.2%
43.8%
48.4%
7.8%
7.515 (df 6)
0.276
Income
Less than $59999
$60000 to 99999
$100000 or More
Prefer not to answer
34.3%
27.4%
13.9%
24.3%
50.0%
23.5%
11.8%
14.7%
5.91 (df 6)
0.43
Provider Discipline
Physiotherapy
Occupational Therapy
Other
74.4%
25.6%
0%
81.3%
15.5%
3.1%
12.69 (df 6)
0.048
Provider Took HealthChange?
Yes
No

73.9%
26.1%

41.2%
58.8%

11.11 (df 6)
0.085
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 %
WatLXTM 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% χ2=0.666 (df 1) 0.414
% Providers took HealthChange® 39.2% 42.6% χ2=0.474 (df 2) 0.789
Where in Facility
Open Area
Private Area or Other
49.1%
50.9%
37.5%
62.5% χ2= 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%) χ2=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%) χ2=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%) χ2=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%) χ2=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%) χ2=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 WatLXTM 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).

-Changes to Discussion section:
"These findings correspond with current literature but also provide a foundation for expansion [23–25, 54, 55]. Previous literature reviews suggested very negative and limited SDM experiences in rehabilitation [54]. 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 [54]. 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 [54, 56], 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 [57]. 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, 58, 59]. 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.”

Methods, Data Collection (p12), para. 2

Results, pg19 (para. 2) to pg24

Discussion pg. 24 (para. 3) to 27
Another confounding factor is the fact that some professionals followed a registered training (HEALTHCHANGE). Based on available information, this training is not dedicated to SDM, but appear to include some element of SDM. In fact, this again points out to training on the working alliance and some behaviour modification techniques. In methods, we detail what data was collected including defining what is HealthChange:
"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 (WatLXTM 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 [47]. Survey completion took 5-7 minutes per time-point."
Methods, pg 9, para 2
Most of the result section presents differences between two groups of SDM levels on several sociodemographic
factors. It is not clear why these analyses were conducted. It seems that a secondary objective, not formally stated,
was to explore factors associated with the SDM levels of implementation. Again, this type of study has been
conducted in SDM and the added value of the study needs to be clarified. We clarified the objectives to the following:
"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)."
Introduction, pg 5 para. 4
Exploring sociodemographic variables
also appears to have been the reason for the term "ethnographic" in the title. The term "ethnographic" in the title
should be removed, as it is misleading for those who know ethnographic studies. We explain in the methods section that this study is part of a larger study, and ethnography is the overarching methodology guiding our approach and data collection. As in many ethnographic studies, we use multiple data collection techniques. This paper reflects but one: survey data collection.
"We used focused ethnography in this research program [43]. Ethnography involves making cultural inferences "(1) from what people say; (2) from the way people act; and (3) from the artifacts people use" [44]. 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 [45, 46].

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)."
Methods, pg 7, para. 1
In the discussion section, page 25 mainly discussed points not related to the results. In addition, a significance level
of 0.086 cannot support the idea that HEALTCHANGE is associated with better SDM encounter. Also very limited
references support statements. We updated the discussion to discuss a few more references, to be less opinionated", and to clarify the healthchange difference is clinically significant but more research is required.
Discussion:
"These findings correspond with current literature but also provide a foundation for expansion [23–25, 54, 55]. Previous literature reviews suggested very negative and limited SDM experiences in rehabilitation [54]. 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 [54]. 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 [54, 56], 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].
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Discussion, pg 23, paras 2 onwards.

VERSION 2 – REVIEW

REVIEWER	Marie-France Coutu Universite de Sherbrooke
REVIEW RETURNED	07-May-2020

GENERAL COMMENTS	The authors have done an excellent job of clarifying the points raised in the first revision. The article is clear and contributes significantly to knowledge. I am not sure how the references currently under review should be cited in the text. I suggest on page 12, Lines 49-53 to replace the sentence with "For details, please refer to …"

VERSION 2 – AUTHOR RESPONSE

I am not sure how the references currently under review should be cited in the text.

I suggest on page 12, Lines 49-53 to replace the sentence with “For details, please refer to …”
There were six instances where we refer to other manuscripts under review. One manuscript has been accepted since we submitted this manuscript to BMJ Open, while the other has not. As such, we made the following changes.
- We removed “(manuscript under review)” and added citation [42] (recently published qualitative work). [in Introduction, page 5, 2nd para.]
- We removed, “(Olson K, et al. as the manuscript “Development of the Alberta Shared Decision-Making Measurement Instrument, Under Review), and added “For details, please refer to Olson K, et al. as the manuscript “Development of the Alberta Shared Decision-Making Measurement Instrument” is under review.” (this manuscript on psychometric details is not yet published). [in Introduction, page 5, 2nd para.]
- We removed “(manuscript under review)” and added citation [42] (recently published qualitative work). [in Introduction, page 6, 1st para.]
- We removed “(manuscript under review)” and added citation [42] (recently published qualitative work). [in Methods, page 6, 2nd para.]
- We removed “(manuscript under review)” (this manuscript on psychometric details is not yet published). We replaced with “(for details, please contact co-authors as the manuscript is under review).” [in Methods, page 8, 2nd para]
- We removed “(manuscript under review)” (this manuscript on psychometric details is not yet published). We replaced with “(for details, please contact co-authors as the manuscript is under review).” [in Results, page 11, last para]