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Are priorities of younger patients with knee pain addressed by PROMs? A qualitative study[★]Marielle Blackburn^{a, b, *}, Sandra L. Kaplan^b^a Burke Rehabilitation Hospital, White Plains, NY, USA^b Rutgers University, School of Health Professions, The State University of New Jersey, Newark, NJ, USA

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ABSTRACT

Objectives: To describe the impact of knee pain and dysfunction in young adults and determine whether current patient reported outcome measures (PROMs) address their recovery priorities.

Design: Qualitative.

Setting: Outpatient rehabilitation center.

Participants: Young adults, 23–30 years.

Main outcome measures: 1:1 semi-structured interviews were held and analyzed with NVivo version 11. The Lower Extremity Functional Scale (LEFS), Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC), Knee Injury and Osteoarthritis Outcome Score (KOOS), and International Knee Documentation Committee (IKDC) were compared to participant identified functional limitations.

Results: 9 themes were identified in 7 interviews: Incomplete Recovery as Acceptable, Motivation for Adequate Long Term Function, Guidance Needed to Facilitate Recovery, Sports: To Play or Not to Play, Pain, Therapy Participation and Interventions, Impact on Life, Decreased Knowledge and Condition Management, and A Wide Range of Functional Limitations. The LEFS captured 23/26 identified functional activities, the KOOS 22/26, the IKDC 16/26, and the WOMAC 13/26.

Conclusions: Incomplete recovery as an acceptable outcome was the most unique theme found in this study. LEFS captured the most relevant functional activities reported by this group. Physical Therapists should consider these findings in PROM selection to better inform meaningful outcome measurement.

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1. Introduction

Knee pain and dysfunction are common debilitating issues for millions of individuals with a wide range of ages and abilities (Cameron, Driban, & Svoboda, 2016; Hunter, 2011; MacKay, Sale, Badley, Jaglal, & Davis, 2016). Knee pain prevalence in young adults (18–40 years) has been estimated at 18–20% in the general population (Dey et al., 2016; QuickStats, 2006; Xu et al., 2018). Prior studies investigating the needs of patients with knee pain included participants >35 years even when targeting younger samples, or focused on the viewpoints of specific sub-groups of patients, such as adolescent athletes or individuals recovering from anterior cruciate ligament (ACL) reconstruction (DiSanti et al., 2018; Ezzat,

Brussoni, Whittaker, & Emery, 2018; Sonesson, Kvist, Ardern, Osterberg, & Silbernagel, 2017). It is not known if the goals or motivations of a general population of young adult patients <35 years are reflected in recommended patient reported outcome measures (PROMs).

Through shared decision making (Dogba, Menear, Stacey, Briere, & Legare, 2016) and PROM use (Rolfson et al., 2016), patients are increasingly considered major stakeholders in determining their treatment course (Hossain, Konan, Patel, Rodriguez-Merchan, & Haddad, 2015). Healthcare is moving towards more patient centered care, but there are still significant gaps in understanding the range of patients' needs (Wang, Jones, Khair, & Miniaci, 2010).

Prior studies explored the daily life experiences (Hall et al., 2008; Harding, Holland, Hinman, & Delany, 2015; Kao & Tsai, 2014; Nyvang, Hedstrom, & Gleissman, 2016), condition consequences, and insight into patients' understandings, responses, and condition related expectations. They included patients with knee pain (Jinks, Ong, & Richardson, 2007; MacKay et al., 2014a, 2014b), osteoarthritis (OA) (Hall et al., 2008; Kao & Tsai, 2014; Nyvang et al.,

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2016), and elective surgery (Lindberg et al., 2013), including ACL reconstruction (Bennell et al., 2016; Lindberg et al., 2013). Past themes included self-management, reluctance to use medications, and the recognition that pain/dysfunction was part of aging (Jinks et al., 2007). Patients reported limited coping skills, knowledge about their conditions (Bennell et al., 2016; Hall et al., 2008; Kao & Tsai, 2014), and medical resources, leading to searches for new treatments between care episodes (Jinks et al., 2007; MacKay et al., 2014c, 2016). Daily life disruptions, especially when performing higher-level or athletic activities, and recovery expectations were varied, supporting the need for individualized assessment (Nyvang et al., 2016; Witjes et al., 2017); however, no studies have been found that address the recovery priorities of a general population of adults with knee pain younger than 35 years old.

Clinical practice guidelines (CPG's) are statements based on systematic reviews of current evidence, intended to guide clinical decisions for specific health conditions (Logerstedt et al., 2017, 2018). The two most recent CPGs on knee ligament sprain (Logerstedt et al., 2017) and knee meniscal and articular cartilage lesions (Logerstedt et al., 2018) recommend using the Knee Injury and Osteoarthritis Outcome Score (KOOS) (Roos, Roos, Lohmander, Ekdahl, & Beynon, 1998), and International Knee Documentation Committee outcome tool (IKDC) (Irrgang et al., 2001) for assessing specific knee specific outcomes. Although not mentioned in the two knee-specific CPGs (Logerstedt et al., 2017, 2018), the Lower Extremity Functional Scale (LEFS) (Binkley, Stratford, Lott, & Riddle, 1999) and the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) (Bellamy, Buchanan, Goldsmith, Campbell, & Stitt, 1988) are also valid for measuring functional change in patients with knee conditions (Mahler et al., 2016; Mehta et al., 2016); they are used for both clinical and research measurement (Pua, Cowan, Wrigley, & Bennell, 2009). The WOMAC is a condition specific tool (Bellamy et al., 1988; Roos & Lohmander, 2003), originally created for older adults with hip and knee osteoarthritis (OA), but also validated for use with adolescents and young adults with knee pain and ligament injuries (Cameron et al., 2013; Heintjes, Bierma-Zeinstra, Berger, & Koes, 2008). The LEFS is a general lower extremity scale and the, IKDC, and KOOS are knee specific. Although the PROMs have all been validated specifically for use with younger adults (Binkley et al., 1999; Irrgang et al., 2001, 2006), younger patients' recovery priorities are not well documented, so it is not known if their priorities align with the content of these tools.

Along with the challenges of selecting and using PROMs, including lack of knowledge, and time (McAuley et al., 2014), insufficient guidance exists for selecting relevant PROMs or documenting the status of younger adults. By identifying younger patients' beliefs regarding their knee conditions' impact on recovery, improved decision-making tools, PROMs, and interventions may be developed. More relevant tools may focus meaningful goal-oriented interventions, which may in turn improve patient outcome measurement. The purposes of this study are to (1) describe motivations, goals, and priorities for recovery of patients with knee conditions between the ages of 18–30 years and (2) to determine whether available PROMs align with the identified priorities.

2. Methods

A qualitative phenomenological study, using 1:1 semi-structured interviews, was conducted with patients with knee conditions living in the northeast United States, ages 23–30, to identify themes regarding their priorities and their condition's life impact. The Institutional Review Boards of Burke Rehabilitation Hospital, Albert Einstein School of Medicine (Members of the

Montefiore Health System) and Rutgers University approved the study.

2.1. Recruitment

Potential participants were identified through institutional chart screenings of outpatient physical therapy referrals or by direct recommendation of evaluating physical therapists (PTs). Inclusion criteria were: newly referred patients for physical therapy, ages 18–30, a primary diagnosis affecting one or both knees, with or without recent surgery, and English language fluency. Patients were excluded with significant co-morbidities affecting function, such as dementia, stroke, brain injury, amputation, Parkinson's disease, multiple sclerosis, fibromyalgia, or other neurological or chronic pain diagnoses affecting overall body function, and systemic diseases such as diabetes mellitus or cancer. Returning patients who had demonstrated >3 consecutive "no shows" or cancellations on previous admissions and patients treated by the first author were also excluded.

Potential participants who expressed interest were provided with study information and contact instructions after their initial evaluation and/or near the beginning of their care episode. The first author met with each subject to provide additional information if requested and, for those who agreed to participate, obtained written informed consent. Purposeful criterion sampling was performed until thematic saturation occurred, and good information power was obtained (Malterud, Siersma, & Guassora, 2015; Vasileiou, Barnett, Thorpe, & Young, 2018). Sample size was based on similar research using phenomenological designs, considering the nature of the study aims, sample specificity, prior established theory, quality of the dialogue, and the analysis strategy (Malterud et al., 2015). In these studies, 5–25 individuals were included (Creswell, 2013; Polkinghorne et al., 1989). This study sought a minimum of 5 participants.

2.2. Chart reviews

Data from consented participants' charts included diagnosis, comorbidities, PROM type and scores, and patient age. The LEFS, KOOS, IKDC, and WOMAC are available at the study institution as hard copies and/or in the electronic medical record for clinical and research applications. Standard practice includes using PROMs, typically administered at a patient's initial and/or subsequent visits with the tool choice at the treating PT's discretion. Participants were assigned ID numbers and information was entered into a password secured spreadsheet.

2.3. Structured interviews

Interviews were performed early in the patient's physical therapy episode of care, lasting 15–60 min ($\bar{x} = 36 \pm 16$) as determined by the patient, and calculated from the recordings. An interview guide (Appendix 1) with open-ended questions was used to facilitate participants' responses and to minimize interviewer influence. Interviews took place in private clinic rooms and were digitally audio recorded. The first author performed all interviews. She is a PT at the facility with over 10 years experience treating patients with orthopedic conditions, fluency with PROM use, a bias toward use of standardized measures, and prior clinical research experience with patients having knee related conditions. Field notes were taken following each interview to record observations, reflections, environmental factors, and emerging themes. Saturation was determined when good information power was obtained based on the quality of dialogue, limited variability in emerging themes, and the diversity and specificity of the sample (Malterud et al., 2015).

2.4. PROM analysis

The domains and specific functional activities of the LEFS, KOOS, IKDC, and WOMAC were extracted from each tool for comparison to the topics and/or functional activity themes identified during the interviews (Table 1). Individual patient's LEFS responses were later compared to interview content for comparison and to evaluate for priming effects.

2.5. Data analysis

Recorded interviews, notes, and demographic data from the chart reviews were transcribed with Microsoft® Word®. Frequency analysis of demographic data was completed in Microsoft® Excel® (version 14.6.7). Interview transcriptions were read several times and analyzed for recurrent themes with NVivo (version 11).

2.6. Interview coding

Patient priorities, and other unique themes about recovery were inductively coded in the transcripts. Investigator triangulation occurred. Both authors separately coded prevalent themes. The first author coded 12 and the co-investigator coded 21 themes, after which the authors met to reconcile the study themes. Themes that overlapped were condensed into 12 unique themes, then further condensed into the 9 final themes. Themes were then compared to the PROM tool content.

3. Results

3.1. Sample

Nine study eligible patients were identified through chart reviews: 8 agreed to participate and 7 were interviewed, exceeding the minimum target of 5. One patient failed to participate in an interview despite several scheduled attempts. All interviews were conducted 6 or more days after the initial physical therapy evaluation, including completion of a PROM. The 7 participants contributed rich data during the interviews and were diverse in terms of knee related diagnoses, age, sex, and occupation (Table 2). They were employed in health care, law enforcement, engineering, education, as students, and in part-time retail, representing different lifestyle and occupational demands. Diagnoses included general knee pain, patellofemoral pain, ligamentous injury, osteoarthritis, and fat pad syndrome. Two patients were post-surgical. All participants completed the LEFS at initial evaluation or prior to the interview; their evaluating PTs coincidentally chose this PROM. Baseline LEFS scores averaged $42/80 \pm 16.8$ (Table 3) suggesting a wide range of functional involvement (MCID = 9 scale points) (Binkley et al., 1999). Participants identified 26 activity limitations, of which 18 were mentioned more than once (Table 4).

3.2. Interview themes

The nine final content themes included *Incomplete Recovery as Acceptable, Motivation for Adequate Long Term Function, Guidance*

Table 1
Functional activities addressed in patient reported outcome measures.

Functional Activity	LEFS	WOMAC	KOOS	IKDC
Playing impact sports (kickboxing, basketball)	(Non-specific sporting activities)	No mention	(Non-specific sporting activities)	Addressed (As highest level of activity)
Low impact sports (tennis, swimming, yoga)	(Non-specific sporting activities)		(Non-specific sporting activities)	Addressed (As higher level of activity)
Negotiating stairs	Addressed	Addressed	Addressed	Addressed
Light duty/light work activities	Included	(Light domestic duties)	(Light domestic duties)	Addressed (As lower level of activity)
Sitting	Addressed	Addressed	Addressed	Addressed
Driving (Short distances)	No mention	No mention	No mention	No mention
Driving long distances or prolonged sitting	Addressed (Sitting)	No mention	No mention	No mention
Getting up from a chair or from a prolonged seated position	Addressed (Getting out of a car)	Addressed	Addressed (Getting up from car/toilet)	Addressed (Getting up from a chair)
Bending/moving knee	No mention	No mention	Addressed	No mention
Squatting	Addressed	No mention	Addressed	Addressed
Exercise/working out	(Non-specific sporting activities)	No mention	(Non-specific sporting activities)	No mention
Caring for children/helping family members	No mention	No mention	No mention	No mention
Walking	Addressed	Addressed	Addressed	Addressed (As lower level of activity)
Heavy/Full duty work activities	Addressed	Addressed (Heavy domestic duties)	Addressed (Heavy domestic duties)	Addressed (As higher level of activity)
Jumping	Addressed	No mention	Addressed	Addressed (As highest level of activity)
Dressing	Putting on shoes and socks	Taking socks on/off	Putting on socks and stockings	No mention
Prolonged Standing	Addressed	Standing unspecified time	Standing-unspecified amount of time	No mention
Running	Addressed	No mention	Addressed	Addressed (As moderate level of activity)
Negotiating Hills and Uneven surfaces	Addressed	No mention	Addressed	No mention
Sleeping	Rolling over in bed	Addressed	At night while in bed	No mention
Dancing	No mention	No mention	No mention	No mention
Twisting	No mention	No mention	Addressed	Addressed (As highest level of activity)

Abbreviations: LEFS, Lower Extremity Functional Scale; WOMAC, Western Ontario and McMaster Universities Osteoarthritis Index; KOOS, Knee Injury and Osteoarthritis Outcome Score; IKDC, International Documentation Committee Subjective Knee Form.

Table 2
Subject characteristics summary.

Subject Characteristic	N = 7
Age, y (Range)	X = 26.9 ± 3.1 23–30
Sex	
Male	3
Female	4
Insurance	
Private	6
Other	1
Referral Diagnoses ^a	
Patellofemoral pain	1
Patella alta	1
Chronic lateral knee pain/ITB syndrome	1
Chronic ACL tear	1
s/p ACL reconstruction	1
Chronic knee Osteoarthritis	1
s/p Microfracture surgery	1
Anteromedial fat pad syndrome	1
Knee pain (unilateral or bilateral)	2
Occupation	
Healthcare	2
Social Work	1
Law Enforcement	1
Student	1
Engineering	1
Education	1
Days in Therapy (Mean ± SD)	17.7 ± 13.6
LEFS Score (Mean±SD)	42/80 ± 16.8

^a Some patients had more than one knee related diagnosis.

Needed to Facilitate Recovery, Sports: To Play or Not to Play, Pain, Therapy Participation and Interventions, Impact on Life, Patient Knowledge and Condition Management, and A Wide Range of Functional Activities.

Table 3
Frequency of functional activities.

26 Functional Activities Affected by Knee Conditions (In descending frequency of mention)
Walking 6/7
Light duty work activities 6/7
Heavy work activities 6/7
Sitting 6/7
Getting up from a chair or from prolonged Sitting 6/7
Exercising/working out 6/7
Jumping 4/7
Running 4/7
Basketball 3/7
Negotiating stairs 3/7
Driving short distances 3/7
Prolonged sitting/driving 3/7
Caring for children/helping family 3/7
Squatting 3/7
Cross Fit 3/7
Bending/moving knee 2/7
Prolonged standing 2/7
Negotiating hills/uneven surfaces 2/7
Kickboxing 1/7
Tennis 1/7
Swimming 1/7
Yoga 1/7
Dressing 1/7
Sleeping 1/7
Dancing 1/7
Twisting 1/7

3.2.1. Incomplete recovery as acceptable

All 7 patients described the notion of “incomplete recovery being acceptable”. Although patients were willing to consider a wide range of interventions to seek full recovery, they also felt they would be satisfied if their recoveries were less than complete. Patients expressed the need to achieve a minimum level of function; however, they also expressed that “walking with a limp” or “80% recovery would be “good enough”.

“I don't think I'll be like that person that is so upset about it, but I will just always be mindful ... to know my limits. If I can still remain active, but have a limit to all of that within reason, I will be absolutely fine”. *Participant 2*

Patients reported that any therapy benefits were acceptable improvements since they had already been “living with” the symptoms. “Tolerable” pain during functional tasks was described as “acceptable” when describing adequate recovery.

“I hope if I don't fully recover that I do get better though than what I am now.” *Participant 7*

3.3. Motivation for Adequate Long Term Function

Patients were motivated by desires to “live life to the fullest” but also had specific motivations as caregivers for young children, family members, or pets. They wanted to maintain adequate function to fulfill these caregiver roles and were frustrated with their activity limitations.

“I want to be able to keep up with the baby and ... be involved ... when she grows up and things that she wants to do.” *Participant 2*

Patients were just beginning their careers and/or looking ahead to decades of work or activities, such as long distance driving, prolonged standing, and long work shifts, that would demand higher levels of physical function.

“I am ten years in now but I have another 20 years to go working like this and I can't have this impact.” *Participant 2*

Leisure and social activities were also motivations for recovery. Some were most motivated by the actions of others in their lives.

“Just seeing my brothers in college playing sports ... they don't have pain or any injuries.” *Participant 7*

3.4. Guidance Needed to Facilitate Recovery

Patients needed guidance or assistance with their recovery; all patients stated that physical therapy played an important role, despite apparent knowledge limitations about their injury, treatment, and course of recovery. They expressed a willingness to do “almost anything that makes sense” to achieve their functional goals.

“... just being able to come in and get basically guidance to better recover is definitely very useful. Imagine if I had gone for another week or so without putting weight on my leg ... properly ... It would be a little worse now”. *Participant 5*

Patients felt that “reminders” were important for keeping them

Table 4
Theme comparisons.

Themes from this Study	Themes in Prior Research of Patients with Knee Conditions
Incomplete Recovery as Acceptable <i>If I can still remain active, but have a limit to all of that within reason, I will be absolutely fine ... Participant 2</i>	Unique to this study
Motivation for Adequate Long Term Recovery <i>I am ten years in now but I have another 20 years to go working like this and I can't have this impact ... Participant 2</i>	Unique Motivations in this study
Guidance Needed to Facilitate Recovery <i>When I don't have her [the PT] as a reminder twice a week ... am I going to let work and after work events side track me? Participant 6</i>	Unique Facilitators in this study
Decreased Condition Knowledge and Self Management* <i>I was in school at the time so I went back to school; not a big deal, and then it went on for about a year and a half ... Participant 5</i>	Similar to <i>Seeking Solutions</i> (Nyang et al., 2016) and <i>Taking Action</i> (Harding et al., 2015; Wang et al., 2010)
Pain† <i>I'm limping by the end of the day because it hurts ... Participant 3</i>	Similar to prior pain themes (Dogba et al., 2016; Hossain et al., 2015)
Sports: To Play or Not to Play <i>I haven't been able to ... play basketball as much as I wanted to ... Participant 7</i>	Reinforced concept of younger patients expecting to perform work and leisure activities at demanding levels (DiSanti et al., 2018; Ezzat et al., 2018; MacKay et al., 2014a, 2014b; Sonesson et al., 2017)
Therapy Participation and Outside Interventions <i>I am not big on the whole drug thing ... Participant 4</i>	Similar to <i>Taking medication causes side effects and dependency</i> (Dogba et al., 2016)
Impact on life <i>I am always worrying about taking care of my knee, not doing anything that will push too far, avoiding things ... Participant 6</i>	Similar to <i>Struggling through everyday life</i> (Rolfson et al., 2016)
A Wide Range of Functional Activities <i>I can't work as much as I want to ... Participant 4</i>	Function was discussed in other studies including <i>Physical activity is for enjoying living</i> (Kao & Tsai, 2014)

*Patient knowledge/self management was unique in that patients ignored symptoms.

†Pain tolerance was mentioned by patients as a unique aspect of this theme and is not measured in current PROMs.

focused on their recovery plan; PTs and family members assisted in this role. Patients also described the need for guidance to prevent them from “cheating” with potentially damaging activities or letting their “busy lives” get in the way of optimal recovery.

“... when I don't have her [the PT] as a reminder twice a week ... am I going to let work and after work events side track me? ...”
Participant 6

3.5. Decreased condition knowledge and management

There were notable limitations in the patients' knowledge regarding their conditions and the need to seek medical care. They described symptoms as “coming and going”; some ignored symptoms for extended periods of time before seeking intervention.

“I was in school at the time so I went back to school; not a big deal, and then it went on for about a year and a half.” Participant 5

Some patients masked symptoms with medications, including NSAIDs or prescription opiates, or passive modalities like heat, ice, and compression sleeves. Patients went on to “overdo it”, “deal with it”, or “allow life to get in the way,” delaying access to skilled care. Patients delayed treatment despite universally stating their willingness to be active participants in their recovery. Even after receiving care, patients seemed to lack general knowledge regarding their recovery and went on to self manage without consulting their primary PTs about outside activities.

3.6. Pain

Pain was a functional recovery theme for 6/7 patients. Many limited the quantity and quality of their daily activities secondary to pain or made an effort to “work through the pain”.

“Stupidly, I still sucked it up and walked up the stairs but one step at a time holding on the railing. With every step, it hurt.”- Participant 2

Patients were conflicted when choosing treatments for pain. They spoke about pain tolerance being “high” or “low”. Some described the pain as being difficult to deal with while others “worked through it”, “limping by the end of the day because it hurts”. Without regard to pain levels or tolerance, patients expressed reluctance to medicate with “pills” or seek additional surgery, preferring a “more natural approach” to recovery. They conveyed preferences for pain management methods such as therapy, taping, hot and cold packs, and if more invasive interventions were required, injections.

3.7. Sports: to play or not to play

Sports were important to 6/7 of these young adults. Some patients had goals to return to low impact athletic activities (e.g. swimming, and yoga); others wished to return to high impact sports (e.g. basketball, kickboxing, cross-fit, and dancing). Patients described the desire to “play through the pain” during activities.

“I haven't been able to ... play basketball as much as I wanted to”
Participant 7

“I enjoy going for a run, or playing basketball, or just working out and doing squats and I know, it may not be the smartest decision having knee pain but prior to the pain, like I enjoyed it.”
Participant 2

Patients expressed their intention to return to the game regardless of therapy outcome, stating they would “be a little upset” without a full recovery but would “still continue to play”. Some patients described needing to “hold back” or “step back” in sports. Patients noted a tendency to “overdo it”, and “keep doing whatever activities for the day,” potentially impeding their healing and

recovery.

3.8. Therapy Participation and outside interventions

Patients expressed strong desires to “try anything and everything” or “anything short of another [surgical] procedure” to achieve satisfactory recoveries. They expressed commitment to performing exercises during therapy and compliance with home exercise programs. Although some strictly followed their physical therapy regimens, others mentioned using “outside” interventions and activities, (e.g. going to gyms, using hot “saunas,” “sleeves” and cold modalities of their own design, or orthoses of their own choosing).

“Soon as I leave here, I’ll go [to the gym] ... I’ll do some of the stretches ... sit in the sauna. I’ll do the [stair climber], jump rope; and probably get into the pool. Maybe that will help.” *Participant 7*

These outside interventions took place concomitant with their physical therapy but were admittedly performed without the knowledge, guidance, or direction of their PTs.

3.9. Impact on Life

Patients described normal daily functional activities as more difficult, time consuming, and strenuous to perform.

“When I sit down at the computer and then have to get up to run somewhere after, it can take a minute”. *Participant 1*

Some patients were reluctant to perform functional activities, whereas others frequently would “overdo it” or would require extra effort to stop from “pushing too far”.

“I want to be able to sit comfortably, walk and not have to worry. I am always worrying about taking care of my knee, not doing anything that will push too far, avoiding things ... so I just want to be able to not worry about it”. *Participant 6*

“Can I go exercise? ... I need to exercise. I am not one of those people who sit down and do nothing.” *Participant 3*

Being “young active adults” was important to most patients. Patients “avoiding activities” or “overdoing it” felt their conditions interfered with daily life and performing desired tasks.

3.10. A Wide Range of Functional Activities

Patients described 26 functional activities affected by their knee conditions, 18 of which were mentioned more than once (Table 4). Most emphasized difficulty with completing activities of daily living, including walking, work activities, sitting, exercising, running, and jumping. Less frequently, driving short distances, caregiver duties, squatting down, negotiating stairs, uneven surfaces, changing position/bending, and specific sports, were mentioned. Prolonged activities including sitting, standing, and driving long distances were particularly described as challenging.

“Walking is difficult” *Participant 6* and “I can’t work as much as I want to” *Participant 4*.

Patients were “frustrated” with basic or mundane activity limitations and refraining from more physically demanding workplace tasks during their rehabilitation. They reported concerns with

returning to work. Most had goals to return to activities without pain or increased effort and/or time.

3.11. Analysis of existing PROMs and prior studies

PROM content was compared to the functions mentioned in interviews. The LEFS captured the most (3 missing functions), followed by the KOOS (4 missing), IKDC (10 missing), and WOMAC (13 missing) (Table 3). Caring for children or family members and driving were not included in any of the reviewed PROMs. Comparisons between patients’ LEFS and interview responses were inconsistent. Patients reported functional limitations in interviews that were not reported on the LEFS and the LEFS asked about items that were not mentioned in the interviews. Comparisons of the interview themes with prior studies (See Table 4) revealed both themes unique to this younger group, and themes similar to prior research with older patients.

4. Discussion

4.1. Patient reported outcome measures

The results of this study suggest that younger patients with knee conditions have unique priorities for recovery not fully addressed by PROMs. Knee specific PROMs did not capture all 26 functional activities identified as priorities for these younger patients. Although the broader LEFS encompassed the most activities, many LEFS categories are vague, and only abstractly related to some activities mentioned. No tools capture a range of recovery levels and although pain is a component in the WOMAC, KOOS, and IKDC, it is not put into the personal context of perceived “tolerance” or coping ability, leaving out a relevant component of pain measurement (Thomee, Thomee, & Karlsson, 2002).

Although 3 condition specific CPGs recommend using the IKDC (Logerstedt et al., 2017, 2018), the KOOS (Logerstedt et al., 2017, 2018; Peter et al., 2011), or the WOMAC (Peter et al., 2011), and additional tools to measure activity level, quality of life, and psychological readiness to return to sports as supplements (Logerstedt et al., 2017, 2018), the LEFS is not mentioned for patients of any age. The “fast paced” nature of this patient group and out-patient clinic settings may not support having patients complete 3–4 PROMs at the start and end of physical therapy, nor allow ample time to interpret those tools. Alternative strategies are needed to augment PROMs for establishing patient recovery goals.

4.2. Themes

Incomplete recovery as an acceptable outcome is unique and not previously found in the literature; patients were willing to try interventions including “anything and everything”, yet were universally satisfied with a recovery that was less than 100%. Despite incomplete recovery, patients were motivated to “live life to the fullest” and fulfill roles in new careers and/or as caregivers. Older patients in previous studies had activity limitations while fulfilling similar roles (Anderson et al., 2006; Harding et al., 2015; Witjes et al., 2017), but this younger sample was challenged by being at the beginning of their lives and careers, and needing to sustain high functional demands for decades into the future.

Unlike older patients in prior studies, symptoms, even when chronic, were not related to aging. This sample ignored symptoms, allowing “life to get in the way”. Unlike past themes pertaining to patient knowledge and self management (MacKay et al., 2014a, 2014b), these patients delayed care, prioritizing other aspects of life ahead of their conditions.

Pain was relevant to both this younger sample and participants

in previous studies (Jinks et al., 2007; Lindberg et al., 2013). Like older patients (Nyvang et al., 2016), this sample struggled through daily life. Motivation was an important driver of recovery. Return to sport was a major motivator for young adolescents and adult patients recovering from ACL repair surgery (Sonesson et al., 2017) while pain was the primary motivating factor for this sample. Pain motivated patients in this study to eventually seek treatment and facilitated therapy adherence, though goals were sometimes conflicting. The same patients expressing the need to be “pain free” also were willing to “play through the pain” and/or be satisfied if some pain remained or recovery was incomplete. While pain presence influenced all aspects of daily function, pain tolerance was a consideration for returning to expected levels, with or without full recovery. Pain response may have been influenced by psychosocial factors, affecting patients’ perceived therapy outcomes; patients experiencing more pain may have greater functional limitations and require more time to achieve a satisfactory recovery (Brander et al., 2003; Creamer & Hochberg, 1998; de Raaij, Ostelo, Maissan, Mollema, & Wittink, 2018).

4.3. Strategies to bridge the gaps

Developing treatment goals cognizant of the contradictory concept of incomplete recovery may enhance meaningful achievement in this younger age range. Outcome measurement may be enhanced by combining goal attainment scaling (GAS) with PROMs, using open dialogue to augment current PROMs, or adjusting care delivery. These strategies may address the diverse functional goals and tolerance of incomplete recovery as an acceptable outcome for this group.

The use of GAS to individualize outcome measurement may be helpful for establishing criteria that are relevant and that minimize risk (Kiresuk & Sherman, 1968; Witjes et al., 2016, 2017). If patients are satisfied with an incomplete recovery, patients may be at increased risk for re-injury. Discharge criteria may need to be adapted to reflect a recovery level that is both relevant and meaningful. Using GAS can be a fast and efficient way to monitor progress throughout the plan of care to ensure a patient’s expected level of achievement continues to agree with their actual functional progress. The expected achievement level can be set at <100%, and higher levels can be set at and/or beyond 100% to exceed expectations. Combining 1–2 individualized GAS goals with a broader PROM, such as the LEFS, may help to tailor treatment expectations and goals for younger patients.

Open dialogue with younger patients may help identify “overdoers” and patients seeking outside interventions. Seeking details about patients’ outside activities including the types and intensity of sport involvement (Witjes et al., 2017), and use of home remedies, may provide more accurate information about potential influences on progress. Personal goals should be discussed with patients, so that specific and appropriate interventions are chosen and education is tailored for re-injury prevention to minimize risk. Physical requirements for safe and gradual participation in sports and anticipating pain signals should be discussed to better align *incomplete recovery* with the achievement of high impact athletic goals (Von Rosen, Kottorp, Friden, Frohm, & Heijne, 2018). Clinicians should emphasize reasonable home programs with emphasis on lifelong re-injury prophylaxis.

Adjusted care delivery with fewer clinic visits per week may help reduce time commitments and add flexibility within the busy schedules of younger patients. Facilitators for recovery that support reduced clinic treatment time may include e-mail or text reminders, or exercise tracking applications. These may assist younger patients, who admit to preferring reminders, to be proactive and stay on track for recovery.

4.4. Recommendations and clinical impact

Patients expressed unique priorities that are not all addressed by current recommended tools. Clinicians should consider individualizing PROMs with GAS to establish individualized goals with younger patients. Generic tools including the LEFS, although less condition specific, may be better at covering the wider range of functional activities important to younger patients. GAS, LEFS and adjusted delivery of care with fewer in-person visits, may be more time efficient and motivating for full recovery in this age group.

Further exploration of the priorities of younger patients with knee or other orthopedic conditions is recommended as a basis for measuring meaningful outcomes. Additionally, PTs’ use of PROMs should be explored for patients with knee pain to determine how guideline recommendations are implemented or supplemented with younger patients.

4.5. Limitations

Although meaningful dialogue was obtained and thematic saturation occurred, rendering adequate information power (Malterud et al., 2015), the sample size was small and patient time commitments and scheduling constraints may have limited the level of detail and depth that patients shared during interviews, because of “rushing” or being distracted by future obligations. All subjects were attending physical therapy at the same hospital system, 6/7 at the same outpatient clinic. This homogeneity may introduce biases due to the characteristics of patients who self selected the facility, methods of evaluation and/or therapy treatment, or geographic or cultural norms of the area. Although patients completed PROMs a minimum of 6 days prior to the interview and interview responses differed from initial PROM responses, it is possible that priming effects may have influenced activity limitations mentioned during the interviews.

In conclusion, young adults described 9 themes related to recovery from their knee conditions, with *incomplete recovery as acceptable* being the most clinically meaningful and unique. Individuals described a wide range of activities important for recovery; not all included in current knee or lower extremity PROMs. A broader outcome tool for this population, the LEFS, and the GAS, which could help individualize PROMs are not discussed in current knee related CPGs (Logerstedt et al., 2017, 2018). More research is warranted to evaluate clinical preferences in this age group and current patterns of PROM use to identify appropriate functional outcome tools and inform meaningful outcome measurement.

Declarations of interest

None.

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Appendix 1. Interview Guide

Interview Question 1. What has been the impact on your life due to your knee condition?

Additional prompts:

What functional activities are important for your recovery?

Are there any limitations in your daily life?

Interview Question 2. What are your ultimate goals for recovery?

Additional prompts:

Specific to their goals “what does that entail?”

What needs to change?

Interview Question 3. What helps or hinders your recovery?

Additional prompts:

What motivates your recovery?

What are you willing to do in order to recover?

Do you perceive any barriers to recovery?

Interview Question 4. What would you consider a full recovery?

How would you feel if you don't fully return to the way you functioned before or do not achieve your goals?

Additional prompts:

Are there specific activities or goals that are more meaningful to you than others?

Interview Question 5. How important is PT for your recovery?

Additional prompts:

Is physical therapy addressing your goals for recovery?

Interview Question 6. Are you doing anything else to help you recover or achieve your goals?

Interview Question 7. Is there anything else about your knee condition and how it impacts your life that you think I should know about?

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ptsp.2019.09.005>.

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