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Health Literacy Challenges Among Older Adult Orthopaedic Rehabilitation Patients

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ABSTRACT

The aim of this study was to discover the health literacy based gaps, barriers, and challenges associated with recovery from knee replacements in middle to older adults. Qualitative case studies of three patients who underwent total knee replacement were carried out to document the health-related decisions associated with this procedure and subsequent rehabilitation. Semi-structured interviews were recorded, transcribed and coded for analysis. The participants were interviewed about their TKR experiences and responses fell into three main categories: (1) Adaptations & Limitations, (2) Advocacy & Attitude and (3) Fears & Burdens. The health literacy related challenges we identified focused on awareness of the TKR procedure, and expectations for the rehabilitation phase of treatment. Participants came to terms with changed bodies through new 'rules' for approaching meaningful activity and new responsibilities concerning self-advocacy. These case studies highlighted the limitations of viewing health literacy from a 'patient deficits' perspective and emphasized the importance of literate health systems through institutional health literacy and clear health-related communication.

Keywords: Meaningful activity, TKR rehabilitation, case study design

INTRODUCTION

Health literacy is and the negative effects that inadequate health literacy has on patients, such as inability to interpret medical information, increased costs of health care due to higher frequency in emergency room visits, and failure to follow instructions that are given by a healthcare professional. [1-2] Possible barriers to health literacy including age, socioeconomic status, cognitive level, and chronic disease, as well as a strong correlation between older age and lower health literacy have been previously documented. [3-5]

Previous studies have examined the effects of musculoskeletal conditions and/or

hip fractures had on patients' life satisfaction scores. [6-8] These studies also investigated the impact that musculoskeletal conditions and hip fractures had on self-ratings of successful aging. Additional research has been conducted regarding strategies and models that would help to improve health literacy and overall compliance of patients. [9]

Limited health literacy in conjunction with age related changes, including chronic disease and cognition changes in older adults is a significant issue that requires a patient-centered approach. [5]

Prior research found that cognitive decline in older adults negatively impacts

upon health literacy, resulting in barriers for the following: processing information, managing multiple messages, and comprehending abstract ideas. Along with cognitive aging, older adults are more likely to experience adverse musculoskeletal conditions, such as osteoarthritis, which in turn, affect life satisfaction. [8]

In a qualitative longitudinal study on chronic knee pain, it was revealed that many individuals with osteoarthritis engaged in self-management to cope with pain, fatigue, stiffness, and discomfort; because they believed that few medical treatment options are available to them. [10]

Brach and colleagues [11] describe ten attributes of a health literate organization, which act as guidelines for healthcare organizations to provide consumers with appropriate healthcare services and resources to allow them to make informed health care decisions (see table below). Schillinger and Keller [12] suggest that by implementing these attributes, organizations will be more responsive to the needs of populations with limited health literacy and enhance health care for all Americans. Existing models such as the Health Literate Care Model, focused on improving health literacy by implementing health literacy strategies into organizations, utilizing the teach-back method, altering the way medical information is presented, and including patients in shared decision-making. [9]

Research based on this model also found that a patient's health literacy could be negatively affected following the stress of a new illness or condition. However, evidence addressing the specific conditions and causes of diminished health literacy in patients are scarce. Although there is a considerable amount of research regarding health literacy, causes of low health literacy, and the effects that certain diseases and conditions have on overall life satisfaction and successful aging, there is limited

research on the associations between these factors.

Unlike the concept of self-management, which focuses on a single person working hard to manage his or her condition independently, the Person-Environment-Occupational Performance model (PEOP) encompasses various dimensions that affect healthcare interactions and behavior. [13] It includes a person's individual factors, the complexity of the environment, and the skills required to take care of one's health. Explained in this model is the importance of health literacy as it includes psychological, social, and environmental components that impact occupational engagement in the management of health.

This study's aims were to explore the relationship between health literacy and outcomes after patients have experienced total knee replacement, TKR, identify the health literacy-based gaps, barriers, and challenges associated with recovery from knee replacement and to address the existing gaps in knowledge regarding patient rehabilitation education in middle to older adult orthopaedic patients, specifically those who have undergone knee replacement. Increased awareness of these gaps, barriers, and challenges will be beneficial specifically for future and current healthcare professionals, and will assist in providing optimal care to patients.

Current literature indicates the essential need for health literate organizations and patient-centered care. Many of the above studies separately mention health literacy issues, physical conditions, and overall well-being in this target population; however the direct correlation between health literacy and physical well-being in middle to older adults should be explicitly emphasized. In this study, we were seeking to discover the health literacy based gaps, barriers, and

challenges associated with recovery from knee replacements in middle to older adults.

The guiding conceptual model for our study was the Person-Environment Occupational Performance (PEOP) conceptual model. [14] The PEOP describes the interaction of intrinsic (person) factors such as physiological, cognitive, spiritual, neurobehavioral and psychological, with extrinsic (environmental) factors such as social support, social and economic systems, culture and values, built environment in relation to technology and natural environment, along with the tasks needed to perform the occupation (in this case, managing the health care requirements of post-TKR or THR) and the ability to perform these tasks to achieve optimal occupational performance. Any disruption in any of these components (i.e. if a patient has cognitive impairments or if the environment is too complex) will affect occupational performance. In this study, we examined the relationship of older adults (person), the complex health care environment in relation to cultural values and the tasks required to perform the occupation of post- TKR care.

METHODS

Research Design

These qualitative case studies (n=3) allowed for analysis on patient-identified barriers and challenges in health-related decisions post total knee replacement (TKR). Cognitively intact, English speaking patients between the ages of 45 and 99 were recruited through posted flyers at a local Orthopaedic facility, as well as postings on campus message boards, and through the researchers' personal network of colleagues. Approval from the local IRB Human Subject Committee was obtained before the start of data collection and all ethical guidelines were followed. One white man, one white woman, and one African-American woman ranging in age from early 50s to early 60s

participated in this project. Participants were consented and informed of all project details before data collection, in accordance with university IRB regulations. Interviews were conducted privately, at times and locations convenient to each participant.

Instruments

Semi-structured, face-to-face interviews were used for data collection. This style of interview guided the interview process, for example, follow-up and probing questions were used as necessary to further explore the participants' experiences. Questions focused on participants' experiences with knee replacements, quality of rehabilitative care, communication with follow-up care, participant expectations and miscommunications regarding received health care. The Principal Investigator conducted all interviews. Interviews were recorded and transcribed verbatim for analysis.

These data were analyzed using the constant comparative method, or Grounded Theory. [15] Transcripts were independently coded by the research team, contrasted, refined and re-coded for consensus. Themes were identified and defined as they emerged from the transcripts. These themes were developed into conceptual constructs that shed light on the process and knowledge and health care environment informing our participants' health-related decisions post TKR.

RESULTS

The sample for this study consisted of three (n=3) mid-to-older adults, two women and one man, who had each experienced at least one TKR. The total number of TKR procedures was 7. The participants were interviewed about their TKR experiences and their responses fell into three main categories: (1) Adaptations & Limitations, (2) Advocacy & Attitude and (3) Fears & Burdens (see table 1). These

terms, along with examples from the patient narratives will be discussed next.

Adaptations and Limitations

Participants shared that knee pain [and subsequent knee replacement] resulted in changes to the ways in which they approached meaningful activities. Some of our participants had new limits placed on their activities post TKR, for example, anything that required bending down or kneeling on the ground became difficult or impossible. There were new rules for their new bodies to follow, and some activities had to be relearned. One woman explained why she no longer wears shorts or skirts that expose her legs, due to self-consciousness post-surgery: “I don't know if it's just me, I don't consider myself vain, but the scars...they bother me. I don't wear shorts. I only wear capris now. I don't like people seeing my knees.”

Other adjustments participants had to make post-surgery included instillation of raised beds for gardening, shower grab bars, use of a walker and strategic pillow placement under the new knee in order to drive. Some changes are perceived to be permanent, like riding a bicycle: “I still cannot ride a bike. This left knee just will not go around”, while other changes were discussed as temporary, like walking sideways down steps. To illustrate further, one woman looked forward to being more active in the future, but at the time of data collection did not yet consider herself fully recovered: “I can't walk across campus to go to lunch with coworkers yet.” And, “Going places or doing things, long walks or going to Wal-Mart, using box stores, a big box store is a challenge.” One man shared that he and his family have had to accept a new reality where his ‘zippered’ knees are concerned:

Well, getting down on the floor, getting on my knees is impossible. My grandkids would like for me to be able to run after them and get down—I can get

down on the floor but getting up is a little bit of a challenge. But you know, being able to go out and actually run and chase after my grandkids. I can't do that, but they understand. My oldest grandkids, they were used to seeing my knees with the staples in them. They call them zippers. So they know that as much as they'd like to be around me and sit on my knee and whatever else they know that they have to be careful.

Advocacy and Attitude

The participants' ability to seek out information, to make sense of the TKR and rehabilitation, and to challenge how TKR affected his/her life, along with the participants' attitudes toward treatment each played a role in shaping the experience for these participants. One man explained how the decision was made to replace his knees separately, rather than both at once, or bilateral knee replacement. His surgeon's negative outcome with a past patient influenced how future TKRs, including his own 3rd and 4th were scheduled:

I went in for the third knee [replacement] on my left side, I asked my doctor if he could go ahead and do the right knee, he said absolutely not. He said he'd only done that one time with one other person and he almost lost that person. I don't know if it was the age or what it was but he didn't feel that it was a good progress or a good policy for any doctor to do both of them at the same time.

In contrast to the previous example, this next participant was not satisfied with her own involvement in the decision-making process: “...one thing in hindsight I wish I had done more research is the kind of knee replacement of what they use. I didn't get good instructions of what to expect at home.” This participant experienced an unfortunate complication when cancer was detected during her TKR:

...therapy was discontinued due to doctor's orders. “you know if there had been some collaboration between the two groups

[cancer doctor and Orthopaedic doctor], the doctor's office, you know, maybe something could have been done differently" and " if I have another one done, if and when, I will ask a lot more questions. And maybe not necessarily change doctors, but I would challenge the mythology of discontinuing my therapy and also what's new, what'd being done different within your group that-are they comparing their success rates with different patients.

Our third participant explained why she sought-out information about the surgery initially, and then reconsidered once she began to realize the seriousness of the procedure:

They met with me at first and they explained what they were going to do. And they gave me a Web site which they told me I could go on and you could see the surgery. But I didn't look at it. It was a good thing [to avoid looking at the website].

I was under the impression they were just going to go in, you know, put this little piece in and everything. But it's totally different. They chop out your whole knee, it's gone. [laughs] And they have to drill a hole in your bottom bone and then in the top bone. And they literally take a hammer and nail the pieces in!

Fears and Burdens

The fear and avoidance related behavior surrounding activity, the treatment-related expenses, and financial burdens of treatment each became obstacles of one kind or another for our participants. Their processes for navigating these obstacles shed light on the health literacy concept and its challenges, especially regarding the challenge of creating literate health systems. The very legitimate fears of falling post

TKR impacted upon our participants in their personal as well as professional lives, as exemplified by the following statement from a single female participant: "You could shower [post-surgery] but about the first three weeks, since I was by myself and I didn't have anyone there, I just washed up. I was not going to take a chance of getting in the shower and falling." Taking chances with daily activities and leisure pursuits was also mentioned by this male participant when asked about concerns for wintering in the cold and icy Midwest:

Very worried. Because I don't have full extension on my left knee. You know as you walk you're supposed to get full extension. That kind of locks your leg in place. I don't have full extension on my left side so therefore I'm very, very leery of falling. If I know that I'm going to be out, whether I'm going to a park or whatever, with wife and grandkids, you know, I'll take the cane with me just for a little bit more stability. I have fallen. It's not fun.

All three of our participants had insurance coverage for the TKR and rehabilitation, however, that did not prevent these procedures from resulting in financial consequences, as one participant explained: "Yes, I did have concerns because insurance only pays—you have to pay \$25 and then the insurance will kick in the rest, and when you're going three times a week that's a lot of money". The burden of insurance co-payments caused this participant to shorten the duration of her rehabilitation. It was not known at the time of data collection whether or not limiting her scheduled rehabilitation sessions resulted in any negative recovery outcomes.

Table 1: Health literacy based gaps, barriers, and challenges associated with recovery from knee replacements in middle to older adults.

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|----------------------------|---|---|
| Adaptations & Limitations, | Limitations & activity adaptations | Changing/relearning how to approach meaningful activities after undergoing TKR. Coping with new limits on activities, new rules for the new bodies to follow. |
| Advocacy & attitude | Personal growth, advocacy, education & patient role | Seeking out, understanding, & challenging how TKR affected his/her life. Initiation/verification of TKR rehabilitation, and attitude toward treatment. |
| Fears & burdens | Fear, avoidance, expense and financial burdens of treatment | Participant processes for navigating obstacles related to treatment and rehab (fear, avoidance of activity, financial issues). |

DISCUSSION

Health literacy related challenges were identified in all three of our participants, and our participants represented a broad spectrum of awareness regarding TKR procedure and rehabilitation expectations. Participants and their families came to terms with changed bodies through new 'rules' for approaching meaningful activity, new responsibilities and expectations for themselves concerning self-advocacy, new fears to overcome and new challenges to address. These case studies highlighted the limitations of viewing health literacy from a 'patient deficits' perspective and emphasized the importance of literate health systems through institutional health literacy and clear health-related communication, beyond the use of plain language. ^[9]

All three participants in our study faced limitations to activities that were previously an integral part of daily life. Such activities include showering, driving, shopping, playing with grandkids, gardening, riding a bike, and overall functional mobility. According to the participants, some activities can be relearned as they progress through recovery but some they will never be able to do again. The results of our research support the PEOP model, which states that individual factors, environmental demands, and activity components all interact in order to carry out meaningful occupations. ^[13] Our findings of the activity challenges associated with TKR support previous research on self-management and adaptive strategies of individuals living with chronic knee pain. ^[10] Along with the physical pain, swelling, and movement limitations that occur in musculoskeletal conditions is a psychosocial component that affects the patient's outlook on life. ^[8]

Various forms of advocacy and attitude were experienced by all three of the participants in our study, including our

participants' abilities to seek out, understand, and apply TKR care, along with their attitude toward treatment and how it impacted upon their daily experiences. Our participants reported advocacy through prior experiences of TKR and being able to contribute to the decision making process of future procedures and follow-up care. Attitude toward treatment, rehabilitation and recovery was expressed through personal beliefs about the relationship between pre-procedure knowledge and quality of recovery. Our research findings support evidence in the existing literature that people who undergo surgery need to be informed about their care, in order to increase functional ability, decrease pain, fatigue, stiffness, and discomfort. ^[10]

Fear, avoidance and financial burden associated with TKR were common themes among all three of our participants. In this study, fears and burdens were reflected in the process participants used to navigate obstacles related to treatment and rehabilitation. Fears and burdens reported by our three participants included financial burdens associated with treatment, fear of falling, and the fears and conflicting emotions associated with pre and post TKR education. Possible indications for fear-related behavior with our participants included inadequate patient education, limited system-wide collaboration between disciplines, health literacy gaps among professionals as well as patients, and fear related to high costs associated with treatment. Examples of inconsistent patient education with our participants included not knowing what follow-up care would entail, lack of instructions and explanation about what to expect at home and little information about the procedure and what to expect in the case of a complication. Our findings reflect existing research in support of the notion that satisfactory health and wellbeing for patients requires health literate health systems which empower patients to

navigate health literacy barriers, low reading levels, poor cognition and poor provider-patient Communication [1,5,11]

CONCLUSION

Coping with new limits on activities, attitudes and approached toward the TKR process have been identified as challenging areas of TKR recovery in middle to older adults. Limitations of this study include small sample size and similar ages of the participants. In addition, we did not have objective measures for our participants, such as FIM scores, literacy assessments and home evaluations. Participants were only interviewed once. Therefore, a larger sample size, increased diversity of participants, and follow-up interviews would have potentially yielded further insights about overcoming health literacy challenges.

Communicating with patients, addressing patient expectations and shared decision-making is essential when trying to make the most of scarce health resources. In addition, health professionals should be aware of the importance of achieving and maintaining health literate systems, especially for patients who have undergone major surgical procedures, such as TKR. An important aspect of health literate systems is patient education and advocacy so that optimal results can be achieved. Patient education prior to and following TKR will allow patients to achieve better understanding of the process, recovery, and precautions associated with TKR, which will enhance participation in activities of daily living.

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