Published in final edited form as:

J Clin Nurs. 2018 August ; 27(15-16): 2953–2962. doi:10.1111/jocn.14377.

A QUALITATIVE STUDY OF OLDER ADULTS' AND FAMILY CAREGIVERS' PERSPECTIVES REGARDING THEIR PREOPERATIVE CARE TRANSITIONS

Ann M. Malley, PhD, APRN-BC,

NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing, Philadelphia, PA; and, Massachusetts General Hospital, Boston, MA

Mary Bourbonniere, PhD, RN, and

Massachusetts General Hospital, Boston, MA

Mary Naylor, PhD, RN, FAAN

NewCourtland Center for Transitions and Health, University of Pennsylvania School of Nursing, Philadelphia, PA

Abstract

Aims and objectives—To explore how older patients with multiple chronic conditions and their family caregivers perceive their engagement and overall care experience throughout the preoperative phase of elective orthopedic hip or knee joint replacement.

Background—Patient engagement is a critical component of care necessary for improving patient outcomes. Little is known about how older adults with multiple chronic conditions and their family caregivers engage in preoperative care transitions and the subsequent impact of this experience on postoperative health outcomes.

Design—Prospective qualitative descriptive design was used.

Methods—Semi-structured telephone interviews with a convenience sample of older adults coping with multiple chronic conditions and their family caregivers. Interviews were conducted prior to surgery and again 21 days post-surgery, were audio recorded and transcribed for qualitative content analysis. The Quality Health Outcomes Model was used to categorize study findings.

Results—Eleven patients and 5 family caregivers participated. Guided by the Quality Health Outcomes Model, four major themes were identified. (1) Older adults perceive that joint replacement is about quality of life. (2) Standardized interventions often fail to address the unique needs of complex older adults. (3) Family caregivers perceive they are the primary care coordinators. (4) Post-operative outcomes and resource utilization vary widely in complex older adults.

Conclusion—Findings suggest that current preoperative care interventions are often not designed to effectively engage complex older patients and their family caregivers. Coordinated patient centered preoperative care that reflects the needs and goals of complex older patients and their family caregivers may positively influence perioperative care transitions and outcomes beyond this episode of care.

Relevance to clinical practice—The current research documents the need for more in-depth knowledge about the relationship between older adults' and their family caregivers' engagement preoperatively and post-operative outcomes and resource utilization.

Keywords

Older Patients; Orthopedics; Patients' Experience; Caregivers

INTRODUCTION

Older adults living with multiple chronic conditions, coupled with advances in surgical technology are challenging our health care system to provide value based care. Joint replacement represents the single largest cost center for the Centers for Medicare & Medicaid Services (CMS) and there can be extreme variability in cost and outcome (CMS, 2015). The Centers for Medicare & Medicaid Services (CMS), is a federal agency within the United States Department of Health and Human Services (HHS) that administers the Medicare program and works in partnership with state governments to administer Medicaid. Patient engagement (Institute of Medicine, 2011) is a critical component of care necessary for improving patient outcomes. Older adults with multiple chronic conditions are less able to engage and participate effectively in their own care and frequently family caregivers are often left to navigate care systems on behalf of the care recipient.

Research on older adults' care transitions has predominantly focused on the process of discharge from acute care environments with minimal attention given to the transition of care upon admission for elective surgery. Additionally, the experiences of family caregivers of older adults with multiple chronic conditions presenting for surgical procedures has not been explored.

Currently little is known about how older adults with multiple chronic conditions and their family caregivers engage in preoperative care transitions and the subsequent impact of this experience on postoperative health outcomes and resource utilization. The purpose of our qualitative study was to explore how older adults with multiple chronic conditions and their family caregivers perceive their engagement and overall care experience throughout the preoperative phase of elective orthopedic hip or knee joint replacement.

BACKGROUND

Increased age and higher rates of obesity contribute to an increased prevalence of osteoarthritis and a greater need for joint replacements, particularly knee replacement (Ruiz et al., 2013). Between 2005 and 2010, the number of Americans receiving artificial knees increased from 471,000 to 650,000 and the number receiving artificial hips grew from

232,000 to 293,000 (Robinson, 2015). As the United States population ages, these numbers are expected to grow to over 500,000 and 1.4 million respectively by 2020 (Robinson, 2015). Furthermore, nearly fifty percent of adults over 65 years have three or more chronic illness and more than 20 % live with more than five chronic conditions (Bradway & Trotta, 2012). Older adults with one or more chronic conditions tend to have a greater likelihood of disability and can visit up to eight different health care providers over the course of one year (Coleman, 2003). Moreover, persons with multiple chronic conditions who have multiple providers tend to use a greater number of healthcare services which makes coordination of care more difficult for these individuals which in turn, can lead to suboptimal care (Vogeli et al., 2007). Compounding the difficulties of reconciling instructions of multiple providers, patients with multiple chronic conditions are often less able to participate effectively in their own care (Townsend et al., 2003).

Growing evidence reveals that patient engagement (Institute of Medicine, 2011) is a critical component of care necessary for improving patient outcomes. Naylor and colleagues (2013, p.1) define patient engagement as “deliberate and consistent efforts by healthcare professionals and organizations to advance the central role of this patient group in defining what matters to them, promote informed and shared decision-making regarding their plans of care, foster shared accountability for actions related to these care plans, and assure reciprocal and respectful relationships”. As patient variability influences patient outcomes, (Charlson, 2015) it is critical that we recognize individual patient needs, preferences and capacities in the preoperative environment through effective patient engagement. The degree of patient engagement for older complex adults with multiple chronic conditions in the preoperative environment may have implications for their care trajectory and outcomes *well beyond the perioperative episode of care*.

Family caregivers have been defined as unpaid individuals (spouse, partners, family members, friends, or neighbors) involved in assisting others with activities of daily living and or medical tasks. It is estimated that 65.7 million caregivers (29 % of the US adult population) provide care to someone who is ill, disabled, or aged (National Alliance for Caregiving and American Association of Retired Persons, 2009). Despite the magnitude of their role in facilitating healthcare, family caregivers often are left to navigate complex care systems on behalf of the care recipient without support from health team members, frequently at the expense of the caregiver’s own health and well-being (National Academy of Sciences, 2016). As family caregivers are largely responsible for ensuring that plans are followed, it is critical that family caregiver engagement occurs as older patients experience transitions in care.

Transitions in care have been defined by the American Geriatrics Society (2003) as a set of actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care within the same location. Representative locations include (but are not limited to) hospitals, sub-acute and post-acute nursing facilities, the patient’s home, primary and specialty care offices, and long-term care facilities. In the transition to the perioperative environment many care processes including the preoperative assessment often are clinician driven protocols that are standardized to maximize efficiency (Fleisher, 2007; Klein, 2008; Vetter et al., 2013). Standardization

facilitates efficiency, but arguably every patient has different needs, preferences and capacities throughout the transition of care from the primary care clinicians to their perioperative care team. When transitions in care is viewed as a process, anticipating and understanding the multiple dimensions of patient and family caregiver needs is more likely to result in enhanced patient centered outcomes (Meleis,1986).

The first transition in care for patients undergoing elective joint replacement occurs when the patient confers with an orthopedic surgeon and the decision is made to have surgery. This initial or *preoperative phase of care* becomes the genesis of the care trajectory for the joint replacement patient (Malley & Young, 2016). The preoperative transition in care for older adults with multiple chronic conditions involves multiple specialists. However, care is often narrowly focused in scope related to provider specialty and is attentive toward mitigating perioperative comorbid disease specific risk (Polderman & Hoeks, 2008). The relative lack of holistic care focused on multimorbidity and even less on older adults' preoperative care goals and caregivers' needs may cause both older adults and caregivers to experience more challenges navigating this phase of care where standardized care interventions abound. In turn, the challenges confronting complex older adults can influence their engagement and negatively affect their surgical outcomes. Patient engagement can lead to better health outcomes (Epstein & Street, 2008). Furthermore, patients who are able to engage in adaptive health behaviors prior to joint replacement report better relief of pain and symptoms and overall greater satisfaction after surgery (Andrawis et al., 2015). In contrast, patients who are less likely to report engaging in adaptive behaviors are less likely to perform self-management behaviors and reported lower satisfaction and quality of life scores (Mosen et al, 2017).

There is a crucial gap in knowledge related to how older adults with multiple chronic conditions and their family caregivers engage in preoperative care transitions and the subsequent impact of this experience on postoperative health outcomes. Research on older adults' care transitions has predominantly focused on the process of discharge from acute care environments with minimal attention given to the transition of care upon admission for elective surgery. Additionally, the experiences of family caregivers of older adults with multiple chronic conditions presenting for surgical procedures has not been explored. The purpose of this study is to (a) describe the experience of older adults with multiple chronic conditions and their family caregivers in preoperative care transitions and (b) examine preoperative engagement perceived by older adults and their family caregivers before surgery and their reflections of preparation postoperatively.

METHODS

The Quality Health Outcomes Model (QHOM, Mitchell, 1998) provided the framework to conceptualize the study aim and methods, including the identification of key patient and family engagement variables within the context of preoperative care transitions. This Model proposes that “dynamic relationships with indicators not only act upon, but reciprocally affect the various outcomes” (Mitchell et al., 1998, p.1). In addition, the Model suggests that “the effect of an intervention is mediated by client and system characteristics” (Mitchell et

al., 1998, p.2). The QHOM guides us to consider the relationship between characteristics of preoperative ‘systems’ in relation to those of patients and their family caregivers.

Study Design

A prospective qualitative descriptive design (Sandelowski, 2000) was chosen to obtain candid descriptions of older adults’ and family caregivers’ perspectives regarding their engagement and overall experiences throughout the preoperative phase of care. Currently, little is known about the dimensions of patient engagement in the preoperative phase and the nature and impact of care transitions that begin in the preoperative environment on patients’ and family caregivers’ care experience. Qualitative inquiry is extremely valuable when trying to gain a relational understanding of a multifaceted phenomenon in a particular environment when such knowledge is limited (Patton, 1990).

The study sample was recruited from a group of older adults hospitalized for an elective hip or knee joint replacement at a 975 bed medical center in the Northeast United States during the period April 2016 through June 2016. Purposive sampling was used to select patients and their caregivers who could provide insight in to the phenomenon of interest. Criteria for inclusion in this study were participants who were age 75 years or older, had 2 or more documented chronic co-morbid conditions, were English speaking, cognitively intact and had completed the preoperative phase for orthopedic hip or knee joint replacement but had not yet had surgery. Family caregivers were identified by participants. Patients and their family caregivers (if applicable as not all patients reported caregivers) were identified and recruited via informational fliers that were made available to them by the orthopedic surgical schedulers at the time the patient scheduled surgery. If they agreed to participate, their contact information was sent to the research team. Participant enrollment continued until data saturation was achieved (Polit & Beck, 2012). Data saturation was reached after interviewing 11 patients and 5 family caregivers.

Data Collection

At the time of the interview, an informational script was read outlining the purpose and procedures of the study and noted that participation was voluntary. Participants were informed of the study goals, risks, benefits and confidentiality (with disclosure that the interviews would be audio recorded) and verbal consent was obtained. The only Protected Health Information (PHI) collected were phone numbers to re-contact participants for follow up interviews. Additionally, a Health Insurance Portability and Accountability Act (HIPPA) authorization handout was provided to participants (Appendix C).

The first author (AM) conducted all of the interviews. Eleven older adults and five family caregivers (identified by the patient) participated in semi- structured telephone interviews at two points in time; preoperatively (T1) and again postoperatively (T2). Interview guides comprised of open and closed ended questions regarding older adults’ and family caregivers’ preoperative experiences were developed based on available research and clinical experiences with this patient population (T1) (Appendix A), (T2) (Appendix B). The preoperative interview questions sought to ascertain descriptions of preoperative experiences, expectations, goals in relation to visits and value of preoperative visits. The

postoperative interview questions and prompts were constructed to capture the patients' and family caregivers' sense of preparation for and engagement during this specific transition and their overall reflections on this care experience. Questions were developed by the first author, reviewed by the project team, pre-tested with a small sample of older adults and refined. The preoperative interviews were conducted soon after the preoperative phase of care was completed, on average 5 days before surgery. Previous studies related to patients' ability to recall preoperative experiences such as pain and functional status three months after total knee arthroplasty demonstrated only moderate agreement with what the patients had reported prospectively (Linegard, 2010). In attempts to leverage patients' capacity to recall their preoperative experience and recognizing that patients undergoing knee or hip replacement have varied post-operative care trajectories (Roos, 2003), the study team determined that follow up interviews conducted 21 days post procedure would be most appropriate. The mean length of each interview was 25 minutes. The voice recorded data were transcribed and uploaded as text documents to Atlas software and stored in an encrypted secure electronic database. Field notes were recorded after each initial interview to document reflections and initial thoughts.

Data Analysis

Qualitative content analysis (Sandelowski, 2000) was performed to systematically analyze the data. The first author (AM) reviewed the transcripts multiple times to identify patterns within the transcripts. In vivo codes were constructed to identify meanings or themes pertaining to the way patients and family caregivers describe their experiences and engagement in preoperative care transitions. Credibility, transferability, dependability and confirmability as described by Lincoln and Guba (1985) were addressed in multiple ways. Initial data analysis was performed by the lead researcher, and preliminary codes and emerging themes were reviewed with other members of the research team. To address internal consistency or dependability (Lincoln and Guba, 1985) another experienced researcher (MB) independently coded the transcripts. The result was a high degree of agreement in the coding of statements thus supporting the reliability of the coding process. Internal validity was attended to by linking data to emerging themes (Lincoln and Guba, 1985). Codes were then grouped into over-arching themes and reviewed with the research team. The key themes were further conceptualized within the framework of the Quality Health Outcomes Model (Mitchell, 2004) elements consisting of Client, System, Intervention and Outcome. The four key themes described below reflect patterns in the text that were consistent across the patient and family caregiver interviews.

Client	Joint Replacement is Often Not Elective; it is Quality of Life
System	Standardized Preoperative Interventions
Intervention	Family Caregivers as the Care Coordinators and Mediators of the Environment
Outcome	Extreme Variability in Outcomes and Resource Utilization

ETHICAL CONSIDERATIONS

The study was approved by the hospital's Institutional Review Board. All data were de-identified and secured on an encrypted password-protected hard drive to protect participant information. Each participant was assigned a numerical code to track transcripts.

RESULTS

Eleven patients (nine females and 2 males), with a median age of 81 years and five family caregivers consisting of adult children or elderly spouses were recruited. Nine of the patients were Caucasian and two were African American.

Client: Joint Replacement is Often Not Elective; its Quality of Life.

In our study, older adults overwhelmingly conveyed that their orthopedic joint replacement procedure was not elective. *“These knees are really bad- they need to be done- if I went down to the floor - I would not be able to get myself up... they hurt so much, I have to have the surgery... I don't plan on dying tomorrow”* (Patient 1). Patients' declining functional status was entwined with their emotional status and ultimately perceived quality of life. *“It's hard for another person to understand how your pain affects your daily life; this has changed my life a great deal”* (Patient 5). *“I really am suffering in the sense that those quality of life issues are going downhill...and I am seriously unhappy about it”* (Patient 9). *“I have so much pain I cannot walk- I have no life”* (Patient 4). Family caregivers concurred; *“She has not been walking well...we are worried she could fall...she cannot get up- she gets help”* (Caregiver 3). *“It really was not much of a choice”* (Caregiver 5). *“I asked her, do you want your independence or do you want to sit in a wheelchair”* (Caregiver 2).

In addition to decreasing functional capacity due to joint disease, older adults often have many other disease burdens, some age related, that influence their decision-making and preparation for surgery. *“I still don't want to do it- but it comes to the point where you just have to bite the bullet. I have other issues...its tiresome to have it {pain} all the time- I have no choice”* (Patient 8). Subsequently, many noted their varying degrees of capacity to participate in preoperative interventions. *“My memory box is bad... you have to have a lot of patience and if you don't- you are going to be in trouble- you really have to focus on the moment and do your reading – its homework”* (Patient 5). Despite these age related challenges, and challenges related to having multiple chronic conditions, older adults' comments reflected merits of being highly engaged in their care. *“You just have to take the initiative yourself, you have to help yourself and you have got to ask questions...it is not going to be a miracle just having it done- you have to get yourself ready”* (Patient 3). *“Everybody is different; it depends upon your stamina and your outlook”* (Patient 2). *“It is not an easy thing to go through and is a lot of work afterwards- you have to do the work or you're not going to recover well”* (Patient 5). Patients defined the preoperative care transition as one of preparation and a time when they sought interventions, instructions and education to prepare them to meet their individualized needs. *“The most important thing right now is to get myself ready for surgery”* (Patient 2). *“I made the effort and once a week worked with the trainer to build [my strength]”* (Patient 3).

The System: Standardized Preoperative Interventions

Preoperative interventions and education was seen as valuable, but for some older adults the standardized mode of delivery was beyond their capacity to effectively participate. *"We had to download the {pre op} booklet from the website"* (Caregiver 2). *"The computer stuff drives me crazy I am no good with the computer anyway and I kept getting these things ...I got an email-and I don't even know who sent it to tell you the truth. What do people my age do...if they don't even have a computer, I am not a big fan of technology and I don't like to ask for help"* (Patient 8). Some patients in our study described challenges with standardized interventions that were not easy to reconcile; *"The video of it is horrible from what people said... I did not watch it and I am not going to"* (Patient 6).

Thus this population managed to find other ways to engage and obtain the knowledge that they felt was needed to prepare them for their surgery. Patients in our study frequently relied on information from conversation with those who have had the experience. *"I am an activist if anybody has information for me- I will go after it... I have a neighbor who had the surgery in Florida ...if I know anybody- I ask them"* (Patient 5). *"I have been asking a lot of people who have had this surgery done... it is helpful to me, I met someone when I went to get my nails done and she is worse than me with her hips"* (Patient 10). *"My landscaping man- he is in his mid 70's- ...we would share a lot about this...he was just overwhelmed to see the books that came- I got 2 different ones prepping me as to what to expect"* (Patient 3). *"I pretty much knew what to expect talking to other people who have done it"* (Patient 11).

Patients often described the preoperative environment as fast paced. *"Everybody is so busy- they are just overly busy...it does not make for a comfortable situation when you know somebody's rushed"* (Patient 8). Family caregivers reinforced this concern, *"I think they tend to talk too fast to elderly patients...I am like- slow down, too much to absorb. It is hard enough for me to take it all in and I'm 30 plus years younger than my mother. They need to slow down and explain a bit more with the elderly"* (Caregiver 5). *"I just saw the surgeon for 5 minutes...then I went to the primary care then the anesthesiologist"* (Patient 10).

Intervention: Family Caregivers as the care coordinators and mediators of the environment

Older adults and family caregivers described the involvement of multiple providers who focused on different aspects of their clinical conditions in the preoperative environment *"I have a lot of doctors here- my Coumadin doctor, the PCP- is going to get in touch with the heart doctor"* (Patient 11). Moreover, participants described a lack of care coordination amongst disciplines within the preoperative environment *"we did a lot of foot work ourselves"* (Patient 3). *"I am very lucky that I have my daughter, she is a godsend...she is my mind right now...my mind is not doing too well from the medication I am on"* (Patient 7). Family caregivers expressed, *"you need to have your advocate to help you go thru the process"* (Caregiver 2). *"I can't imagine somebody not helping or not having an advocate for getting things more straightened up for an elderly person...some of the instructions aren't really clear...like stop the medication three days before surgery or the day before surgery"* (Caregiver 2). *"We saw the doctor...he did a blood test while we were at the hospital the first time...but then we had to see her primary because he need to sign off, then a week later we saw the cardiologist, then a few days after- the anesthesiologist for the pre op, is that a*

lot or not?” (Caregiver 3). “There was a little confusion on where the responsibility lay... we found it confusing – I can’t imagine an elderly person maneuvering all of that by themselves” (Caregiver 5).

The burden of care coordination for older complex adults varied but predominantly was assumed by caregivers. *“My Dad has been doing most of the work...he is exhausted. I have been doing this since March- I have used up so much earned time {from work} and it is really a lot for the family to try to juggle this...I do not know how people do it when they do not have family around...I just do not even know” (Caregiver 3). “There is coordination of care in the hospital with the case managers, nurses and doctors- but I am not really sure they understood all the challenges that we were going to have in the 3 weeks that we waited for surgery. People do not realize just how hard it was to just do the moving and getting her out... I kept asking why are we going out again - this women has not walked in a year” (Caregiver 3).*

Outcome: Extreme Variability in Outcomes and Resource Utilization

Older adults in our study described a wide variety of care experiences and post-operative outcomes. *“My total time in rehab was 45 days” (Patient 1). “I was in three days and 2 nights” (Patient 2). “I went home from the hospital after 5 days” (Patient 5). Additionally three were readmitted to the acute care environment after discharged. “She went to rehab for almost 2 weeks and then she came home and three days later she fell...she had a developed a UTI (urinary tract infection) and urinary frequency necessitating up and down to use the commode- it fell over and she broke her wrist- she had to have cast on it and went back to rehab for almost 3 weeks” (Patient 7). Some noted a sense of lack of preparation regarding the perioperative care trajectory. “There is no way I could be prepared for this” (Patient 5). “I am very nervous because of what is going on- they found something in my bone {during hip replacement} they need to inform people if they’re elderly this could happen” (Patient 10). “That {medication} made her a little crazy...she was hearing people- thought the housekeepers were dealing drugs...if they would just educate- you know tell family members about and prepare them for post-op delirium” (Caregiver 1). “She left {the hospital} with a UTI we did not know- – it is hindering her rehab with the hip... she is really depressed” (Caregiver 3). ...if I knew what I was getting myself into I never would have done it...everything thing that happened I was surprised by...I felt when I came home I was bewildered and lost” (Patient 1). For those whose care trajectory was apparently straight forward, there seemed to be a degree of unpreparedness. “She did not know that she would be given a walker when she left...it was a little bit of a surprise” (Caregiver 4).*

Caregivers were forth right in their recommendations. *“Patients want to know the actual things that are going to happen in relative sequence...you should have knowledge like this... it is comforting to know what is going to happen...that is where the ball gets dropped” (Caregiver 4). “Big picture no- I would say {we} were not prepared...if my mom knew what this was really going to be like she probably would not have done it” (Caregiver 2).*

DISCUSSION

A predominant characteristic of the complex older adult and their family caregiver (clients) in our study was the desire to maintain what was most important to them. Their functional status was entwined with their perception of quality of life. Therefore having a joint replacement was considered by this sample to be essential. This is consistent with the literature that suggests that older adults especially those with chronic comorbid conditions, value physical functioning as one of the most important contributors to quality of life (Goins et al., 2014; Spiers et al., 1996). Successful joint replacement offers the opportunity to enhance quality of life by reducing pain and improving functional status (Jones et al, 2007).

Older adults in our study frequently described being challenged in both understanding preoperative information and obtaining information given to them thus affecting their ability to participate effectively during the transition of care into the preoperative environment. This is consistent with the literature and may be due to several reasons. The physiological changes associated with aging such as the decline in brain size and cerebral perfusion (Rabbitt et al., 2007) can contribute to short term memory loss, reduced reaction time and difficulty consolidating information (Mamaril, 2006). Secondly, the literature suggests that there is a *combined deleterious effect* of having certain chronic co-morbid conditions that can negatively impact activities of daily living as well as instrumental activities of daily living (Tinetti et al., 2011).

Participants described preoperative processes (characteristics of the system) that relied on technology in the form of emails or websites in relation to preoperative instructions. Some participants cited the lack of access to or the inability to use a computer to retrieve their preoperative instructions. Often this mode of care delivery was not within their ability. This is consistent with the literature that informs older adults are often challenged with low health literacy when trying to engage in their care (Carman et al., 2013). In addition to experiencing standardized electronic preoperative care processes, patients in our study expressed little opportunity to have ‘one on one’ with providers. Prior research informs us that patients who perceive their care is based on their needs and preferences are more likely to adhere to therapies and have better post hospital outcomes (Kangovi, 2014). Moreover, patient centered interventions have been shown to improve transitions across sites of care (Naylor et al., 1994; Naylor et al., 1999; Parry et al., 2003; Naylor et al., 2004).

Levinson et al., (2005) found that older people tend to prefer a physician-directed style of care, independent of health status, and they are more reliant on providers to guide them directly. The current mode of electronic and web based preparation and education may be undermining the ability of some older patients to fully prepare themselves during this transition of care. Information was shared-yet often not in a manner that was conducive to learning in this generation of patients who engage differently (MacCracken, 2015).

Older adults and their family caregivers in our study described a multitude of providers involved in the preoperative care environment and numerous dimensions of care coordination that was imposed on caregivers due to a lack of coordination in their preoperative processes. In a recent study (Malley & Young, 2017), preoperative patients

presenting for elective surgery described preoperative care in terms of learning what to expect with the surgical procedure and the entire perioperative care trajectory. Both patients and providers described the need for care coordination, access to resources, and the capacity of providers to partner and communicate effectively with their multidisciplinary care team members as well as with patients.

In our study, some family caregivers and their unique needs were often overlooked. This is consistent with the literature (National Academies of Sciences, 2016) that examined family caregivers' experiences in healthcare and found that family caregivers of older adults are often disregarded in health care transactions by both providers and systems of care. In many instances our family caregivers became care coordinators of the older adult with multiple chronic conditions. Furthermore, depending on caregiver characteristics, an adult child or elderly spouse who potentially is limited functionally; the capacity to engage and coordinate needs can be much different. Generational diversity within family caregivers must be recognized and reconciled to fully engage family caregivers who often become the mediators of patient care in today's complex care environment. Family caregiver's capacity to engage and thus mediate effectively perhaps is influencing patient outcomes.

In our study, older adults describe various postoperative care trajectories. Patients described being discharged to home anywhere from 3–5 days after surgery to inpatient rehabilitation stays ranging from 14–45 days. The literature suggests that the post-operative care trajectory for older patients undergoing joint replacement does indeed vary. Medicare spends an average of \$16,500 (knee) to \$33,000 (hip) per patient for the perioperative care and recovery from hip and knee joint replacements (CMS, 2015). Depending on the provider and where the treatment takes place, the quality and cost of these types of joint replacements can vary. The complication rate can be more than three times higher at some facilities which in turn often results in re-hospitalizations (CMS, 2015). Unlike other surgeries; when it is over there is an initial period when quality of life (QOL) is not immediately improved (Jones et al, 2007) and patients are still quite functionally limited particularly if underlying comorbidities have become exacerbated and entwined in the context of perioperative care.

The Quality Health Outcomes Model informs us that dynamic relationships can exist between characteristics of clients and systems; and an intervention can be mediated by both clients' and systems' characteristics which in-turn impacts outcomes (Mitchell, 2004). The QHOM suggests that preoperative interventions are mediated by the capacity of patients and their family caregivers to engage in their care. Interventions that *affect* and are *affected by both* may ultimately impact patients' overall care trajectory and outcomes. If patients and their family caregivers (clients) have the capacity to mediate preoperative institutional systems and reconcile the gap between organizational interventions and patient specific goals through effective engagement; preoperative transitions in care appear to be satisfying to patients and their and caregivers. However, when the needs of patients and their family care giver exceed their capacity to mediate and navigate organizational processes; the burden of care become unmanageable and perhaps the care trajectory less certain and accordingly more varied.

CONCLUSION

The value of older adults' and family caregivers' perceptions of the transition in care experience cannot be underestimated as they are the only common thread traversing the perioperative span of care. Joint replacement outcomes, though influenced by patient characteristics (Boraiah et al., 2015) perhaps are also reflective of a system where embedded standardized preoperative care interventions are received with uncertainty and mediated by the older adult and their family caregiver with variability. Subsequently, this variability influences the level of older adult preparedness and engagement and may be influencing the overall care trajectories for those most vulnerable. Total joint replacement in Medicare patients represents the single largest cost center for the Centers for Medicare & Medicaid Services (CMS). Given the exponential growth in need for these types of elective procedures and the potential extreme variability in cost and outcome it is important to discern the salient variables that may be impacting the entire perioperative care trajectory.

RELEVANCE TO CLINICAL PRACTICE

Our findings suggest that the value of preoperative care is embedded in the degree to which care is centered on the unique needs and goals of the patient and their family caregiver. The value of preoperative care is potentially amplified clinically through the prevention of postoperative complications and economically through a decrease in utilization of resources. The knowledge gained in our study suggests that nursing care for older adults preparing for joint replacement has the potential to be enriched through the message about how older adults and family caregiver engagement preoperatively may impact post-operative outcome and resource utilization. Accordingly, preoperative nursing care may benefit from the incorporation of an assessment of both patients and family caregivers that includes an elicitation of their goals of care during the preoperative care transition.

LIMITATIONS

A key limitation of the study is that all data were from a single academic center in the Northeast. Accordingly, transferability of findings needs to be established. Additionally, there was little cultural diversity among our sample and a disproportionate number of females to males which may impact the generalizability of the findings.

Appendix A Interview Schedule

(T- 1) Patient and Family Caregiver Interview Guide :

1. Can you describe your experience since you learned that you were going to have surgery/ joint replacement (from the time you saw your PCP (if you did), the visit with the surgeon, through today's visit) - in the pre-admitting area visit? (Probes: What was good about this experience? Why?)
2. Did anyone ask about what is most important to you or matters most to you (and caregiver) as you are preparing for this procedure? (Probe- what does matter most to you now?)

3. Did the health care team members during this time of preoperative care seem to know you, to have all the information about you? (Probe: If yes – how does that make you feel? (Probe: If no, can you tell me what was missing?))
4. What were your expectations for this time before surgery? Were your expectations or needs for information met? (Probe : Did you have to look for information on your own? from whom?).
5. Were the visits you had leading up to surgery important to you ...(Probe if yes- in what way? If no why not- what could have been done differently?
6. Do you and your family/caregiver feel ready for surgery? (Probe: why? why not?)
7. Is there anything else I should know about your experience that I did not ask?

Appendix B

(T-2) Patient and Family caregiver Interview Guide for 21 day phone call follow up

1. Did the preparation/ experience before surgery get you ready for your surgery and for going home? (Probe if yes- how so- in what way, if no what information or instruction or equipment was missing...did anything surprised you?)
2. Did the team who cared for you in the hospital seem to know you and what you needed...Probe: what mattered most to you and your family caregiver?)
3. Now that you are home- how do you feel about the experience in the hospital.. Did you know what to do when you got home? (Probe: with your incision? With your medicines? What activity was ok? When or who to call for a problem?
4. Are you and your family comfortable with your current status? Was there anything in particular you wish you were prepared for?
5. Is there anything I should know but did not ask? Would you recommend this procedure to anyone you know?

Appendix C

HIPPA Authorization Handout

We are required by the Health Insurance Portability and Accountability Act (HIPAA) to protect the privacy of health information obtained for research. This is an abbreviated notice, and does not describe all details of this requirement. During this study, identifiable information about you or your health will be collected and shared with the researchers conducting the research. In general, under federal law, identifiable health information is private. However, there are exceptions to this rule. In some cases, others may see your identifiable health information for purposes of research oversight, quality control, public health and safety, or law enforcement. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy

REFERENCES

- Andrawis J, Akhavan S, Chan V, Lehil M, Pong D, & Bozic KJ (2015). Higher preoperative patient activation associated with better patient-reported outcomes after total joint arthroplasty. *Clinical Orthopedics and Related Research*, 473(8), 2688–2697. 10.1007/s11999-015-4247-4
- Boraiah S, Joo L, Inneh IA, Rathod P, Meftah M, Band P, & Iorio R (2015). Management of modifiable risk factors prior to primary hip and knee arthroplasty. *Journal of Bone and Joint Surgery. American Volume*, 97(23), 1921–1928. 10.2106/JBJS.N.01196
- Bradway C, Trotta R, Bixby MB, McPartland E, Wollman MC, Kapustka H, ... Naylor MD (2012). A qualitative analysis of an advanced practice nurse-directed transitional care model intervention. *The Gerontologist*, 52(3), 394–407. 10.1093/geront/gnr078 [PubMed: 21908805]
- Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, & Sweeney J (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223–231. 10.1377/hlthaff.2012.1133 [PubMed: 23381514]
- Charlson M, Ash A, & Elixhauser A (2015). How to measure multimorbidity? HCSRN-OAIC aging initiative dissemination workgroup webinar series. Retrieved from <http://mpci.webex.com/mpci>
- CMS (2015). Mandatory Medicare bundled payments: Comprehensive care for joint replacements, bridging business & healthcare. Retrieved from <http://healthcareblog.pyapc.com2015/07/articles/healthcare-reform/mandatory>
- Coleman EA (2003). Falling through the cracks: Challenges and opportunities for improving transitional care for persons with continuous complex care needs. *Journal of the American Geriatrics Society*, 51(4), 549–555. 10.1046/j.1532-5415.2003.51185.x [PubMed: 12657078]
- Coleman EA, Boulton C, & The American Geriatrics Society Health Care Systems Committee (2003). Improving the quality of transitional care for persons with complex care needs. *Journal of the American Geriatrics Society*, 51(4), 556–557. 10.1046/j.1532-5415.2003.51186.x
- Epstein R, & Street R (2008). Patient-centered care for the 21st century: Physicians' roles and patients' preferences. Philadelphia, PA: ABIM Foundation.
- Fleisher LA, Beckman JA, Brown KA, Calkins H, Chaikof EL, Fleischmann KE, ... Riegel B (2007). ACC/AHA 2007 guidelines on perioperative cardiovascular evaluation for noncardiac surgery. *Circulation*, 116(17), e418–e500. 10.1161/CIRCULATIONAHA.107.185699 [PubMed: 17901357]
- Goins RT, Jones J, Schure M, Rosenberg DE, Phelan EA, Dodson S, & Jones DL (2014). Older adults' perceptions of mobility: A metasynthesis of qualitative studies. *The Gerontologist*, 55(6), 929–942. [PubMed: 24637252]
- Institute of Medicine (2011). Engaging patients to improve a science and value in a learning health system (pp. 103–110). Washington, DC: National Academies Press.
- Jones CA, Beaupre LA, Johnston DWC, & Suarez-Almazor ME (2007). Total joint arthroplasties: Current concepts of patient outcomes after surgery. *Rheumatic Disease Clinics of North America*, 33 (1), 71–86. 10.1016/j.rdc.2006.12.008 [PubMed: 17367693]
- Kangovi S, Mitra N, Grande D, White ML, McCollum S, Sellman J, ... Long JA (2014). Patient-centered community health worker intervention to improve posthospital outcomes: A randomized clinical trial. *JAMA Internal Medicine*, 174(4), 535–543. 10.1001/jamainternmed.2013.14327 [PubMed: 24515422]
- Klein J (2008). Multimodal multidisciplinary standardization of perioperative care: Still a long way to go. *Current Opinion in Anaesthesiology*, 21(2), 187–190. 10.1097/ACO.0b013e3282f70042 [PubMed: 18443486]
- Levinson W, Kao A, Kuby A, & Thisted RA (2005). Not all patients want to participate in decision making. *Journal of General Internal Medicine*, 20(6), 531–535. 10.1111/j.1525-1497.2005.04101.x [PubMed: 15987329]
- Lincoln YS, & Guba EG (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Lingard EA, Wright EA, Sledge CB, & Kinemax Outcomes Group (2001). Pitfalls of using patient recall to derive preoperative status in outcome studies of total knee arthroplasty. *Journal of Bone and Joint Surgery. American Volume*, 83(8), 1149–1156. 10.2106/00004623-200108000-00003

- MacCracken L (2015). Engaging physicians and patients across generations. Retrieved from www.hhnmag.com/articles/3413
- Malley A, & Young GJ (2016). A qualitative study of patient and provider experiences during preoperative care transitions. *Journal of Clinical Nursing*, 26(13–14), 2016–2024.
- Mamari ME (2006). Nursing considerations in the geriatric surgical patient: The perioperative continuum of care. *Nursing Clinics of North America*, 41(2), 313–328. 10.1016/j.cnur.2006.01.001 [PubMed: 16698344]
- Meleis AI (1985). *Theoretical nursing: Development and progress*. Philadelphia, PA: Lippincott.
- Mitchell PH, Ferketich S, & Jennings BM (1998). Quality health outcomes model. *Image: The Journal of Nursing Scholarship*, 30(1), 43–46. [PubMed: 9549940]
- Mitchell PH, & Lang NM (2004). Framing the problem of measuring and improving healthcare quality: Has the Quality Health Outcomes Model been useful? *Medical Care*, 42(2), II–4.
- Mosen DM, Schmittiel J, Hibbard J, Sobel D, Remmers C, & Bel-lows J (2007). Is patient activation associated with outcomes of care for adults with chronic conditions? *The Journal of Ambulatory Care Management*, 30(1), 21–29. 10.1097/00004479-200701000-00005 [PubMed: 17170635]
- National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. Washington, DC: National Academies Press.
- National Alliance for Caregiving and AARP (2009). *Caregiving in the U.S.* National Alliance for Caregiving, Washington, DC Retrieved from <https://www.caregiver.org>
- Naylor MD, Broton D, Campbell R, Jacobsen BS, Mezey MD, Pauly MV, & Schwartz JS (1999). Comprehensive discharge planning and home follow-up of hospitalized elders: A randomized clinical trial. *JAMA*, 281(7), 613–620. 10.1001/jama.281.7.613 [PubMed: 10029122]
- Naylor MD, Broton DA, Campbell RL, Maislin G, McCauley KM, & Schwartz JS (2004). Transitional care of older adults hospitalized with heart failure: A randomized, controlled trial. *Journal of the American Geriatrics Society*, 52(5), 675–684. 10.1111/(ISSN)1532-5415 [PubMed: 15086645]
- Naylor M, Broton D, Jones R, Lavizzo-Mourey R, Mezey M, & Pauly M (1994). Comprehensive discharge planning for the hospitalized elderly: A randomized clinical trial. *Annals of Internal Medicine*, 120(12), 999–1006. 10.7326/0003-4819-120-12-199406150-00005 [PubMed: 8185149]
- Naylor MD, Hirschman KB, O'Connor M, Barg R, & Pauly MV (2013). Engaging older adults in their transitional care: What more needs to be done? *Journal of Comparative Effectiveness Research*, 2(5), 457–468. 10.2217/ce.13.58 [PubMed: 24236743]
- Parry C, Coleman EA, Smith JD, Frank J, & Kramer AM (2003). The care transitions intervention: A patient-centered approach to ensuring effective transfers between sites of geriatric care. *Home Health Care Services Quarterly*, 22(3), 1–17. 10.1300/J027v22n03_01
- Patton MQ (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.
- Poldermans D, Hoeks SE, & Feringa HH (2008). Pre-operative risk assessment and risk reduction before surgery. *Journal of the American College of Cardiology*, 51(20), 1913–1924. 10.1016/j.jacc.2008.03.005 [PubMed: 18482658]
- Polit DF, & Beck CT (2012). *Resource manual for nursing research*. Wolters Kluwer, Philadelphia PA.
- Rabbitt P, Scott M, Lunn M, Thacker N, Lowe C, Pendleton N, & Jackson A (2007). White matter lesions account for all age-related declines in speed but not in intelligence. *Neuropsychology*, 21(3), 363 10.1037/0894-4105.21.3.363 [PubMed: 17484599]
- Robinson JC (2015). *Purchasing medical innovation: The right technology, for the right patient, at the right price*. Oakland, CA: University of California Press.
- Roos EM (2003). Effectiveness and practice variation of rehabilitation after joint replacement. *Current Opinion in Rheumatology*, 15(2), 160–162. 10.1097/00002281-200303000-00014 [PubMed: 12598806]
- Ruiz D, Koenig L, Dall TM, Gallo P, Narzikul A, Parvizi J, & Tongue J (2013). The direct and indirect costs to society of treatment for end-stage knee osteoarthritis. *Journal of Bone and Joint Surgery. American Volume*, 95(16), 1473–1480. 10.2106/JBJS.L.01488
- Sandelowski M (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334–340. 10.1002/(ISSN)1098-240X [PubMed: 10940958]

- Author Manuscript
- Author Manuscript
- Author Manuscript
- Author Manuscript
- Spiers N, Jagger C, & Clarke M (1996). Physical function and perceived health: Cohort differences and interrelationships in older people. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 51(5), S226–S233. 10.1093/geronb/51B.5.S226
- Tinetti ME, McAvay GJ, Chang SS, Newman AB, Fitzpatrick AL, Fried TR, & Peduzzi PN (2011). Contribution of multiple chronic conditions to universal health outcomes. *Journal of the American Geriatrics Society*, 59(9), 1686–1691. 10.1111/j.1532-5415.2011.03573.x [PubMed: 21883118]
- Townsend A, Hunt K, & Wyke S (2003). Managing multiple morbidity in mid-life: A qualitative study of attitudes to drug use. *BMJ*, 327 (7419), 837 10.1136/bmj.327.7419.837 [PubMed: 14551097]
- Vetter TR, Goeddel LA, Boudreaux AM, Hunt TR, Jones KA, & Pittet JF (2013). The perioperative surgical home: How can it make the case so everyone wins? *BMC Anesthesiology*, 13, 6 10.1186/1471-2253-13-6 [PubMed: 23497277]
- Vogeli C, Shields AE, Lee TA, Gibson TB, Marder WD, Weiss KB, & Blumenthal D (2007). Multiple chronic conditions: Prevalence, health consequences, and implications for quality, care management, and costs. *Journal of General Internal Medicine*, 22(3), 391–395. 10.1007/s11606-007-0322-1 [PubMed: 18026807]

Impact Statement

What does this paper contribute to the wider global clinical community?

- The knowledge gained in our study suggests that nursing care for older adults preparing for joint replacement has the potential to be enriched through the message about how older adults and family caregiver engagement preoperatively may impact post- operative outcome and resource utilization.
- Preoperative nursing care may benefit from the incorporation of an assessment of both patients and family caregivers that includes an elicitation of their goals of care during the preoperative care transition.
- These findings may encourage the development of larger studies that examine the need for educational initiatives to address issues around preoperative care and patient and family caregiver engagement.