Barriers and Facilitators of Patient's Engagement in Musculoskeletal Research

Kizito I. Enonbun, The University of Western Ontario

Supervisor: Joy C. MacDermid, The University of Western Ontario
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Abstract

In recent years there has been a growing interest by stakeholders in engaging patients in research where the preferences/expectations and input of patients are important in the conceptualization and execution of the research projects/medical procedures. Patients are becoming more informed, empowered and active partners in their healthcare, and are seeking to be more engaged in the research engagement continuum. The purpose of this thesis was to 1) assess and identify the facilitators and significant barriers of patients' engagement in musculoskeletal research; and document factors that facilitate patient engagement in musculoskeletal research. 2) identify and synthesize evidence that determines the extent to which expectations are predictive of postoperative outcomes in patients undergoing total shoulder, elbow, or radial head replacement and metacarpophalangeal joint arthroplasty. We conducted a literature review on patient engagement in research and a systematic review on patient expectations in musculoskeletal arthroplasty. Although there was a limited but significant association between patients’ preoperative expectations and postoperative outcomes for total shoulder arthroplasty yet we found in both studies that patients’ beliefs/self-efficacy expectations, barriers and potential benefits according to Health Belief Model influenced patients’ engagement in health research and the outcomes on total joint arthroplasty. We also found that lack of awareness of research was a major barrier to patient engagement in research Only a few (10.8%) have ever been involved in the research engagement continuum as team members. This finding was very important because it highlights a major gap in the implementation of patient engagement in the research. Several other barriers were identified in the study such as the cost of transportation to the research site, work commitment, and patients’ concerns about the potential effect of research on their health. The participants also expressed their preferences and some factors that could facilitate
their engagement in research. One key message from this thesis was that given the fact that patients' knowledge and participation are important for participation in research, future research initiatives should be flexible enough to accommodate patients’ preferences and expectations.

**Keywords.** Patients’ Expectations, Patients’ Engagement, Patients’ Preferences, Barriers, Facilitators, Systematic Review.
Lay Summary

Patient engagement in health research is the process of involving people who have personal experiences of a health issue and their family, friends, and caregivers in the research process - not just as study subjects but as partners, helpers in planning, doing and spreading the result of the research. There is a growing interest in patient engagement in research because it ensures relevant topics and outcomes to patients are selected for study, which has increased the number of patients enrolling in research and also helps the researchers in getting funding. Increased interest in patient engagement comes at a time when healthcare spending is steadily rising in Canada. Our aim in this research is to assess the barriers (hindrance) and facilitators (enablers) of patients in taking part in upper limb musculoskeletal research (research relating to muscles and bones) and find out the extent to which expectations influence postoperative outcomes in patients undergoing total shoulder, elbow, joint arthroplasty. We found here was a limited but significant association between patients’ preoperative expectations and postoperative outcomes for total shoulder arthroplasty. We also found that lack of awareness of research was a major barrier to patient engagement in research. Only a few (10.8%) have ever been involved in the research process as team members. This finding was very important because it highlights a major gap in the implementation of patient engagement in the research. One important message from this thesis was that given the fact that patients' knowledge and participation are important for participation in research, future research initiatives should be flexible enough to accommodate patients’ preferences and expectations.
Co-Authorship Statement

The thesis question and the design of the studies were formulated by Kizito Enonbun and by his supervisor, Joy C MacDermid. Co-investigators were recruited when additional expertise was required. The specific roles of each of the authors are listed below:

Chapter 1: Introduction

Kizito Enonbun – sole author

Chapter 2: Patients’ expectations of upper extremity total joint arthroplasty

Kizito Enonbun – primary author, study design, data collection, data analysis and manuscript interpretation

Rochelle Furtado – co-author, was involved in literature search, and interpretation of data and drafting

Thomas Overend – co-author, involved in the review of the manuscript

Joy C MacDermid – co-author, involved in the conception and design of the study, drafting and revising the manuscript for important intellectual content

Chapter 3: Patients’ engagement in musculoskeletal research

Kizito Enonbun – primary author, study design, data collection, data analysis and data interpretation

Trevor Birmingham – co-author, involved in the study design, review of the manuscript

David Walton – co-author, involved in the review of the manuscript

Joy C. MacDermid – co-author, study design, manuscript reviewer
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CHAPTER 1

INTRODUCTION

What is Patient Engagement?

Patient engagement in health research is the involvement of people who have personal experiences of a health issue and their family, friends, and caregivers in the research process, not just as study subjects but as partners, collaborators in planning, executing and translating research outcomes (Bethell et al., 2018). In Canada, patient engagement in health research has been defined by the Canadian Institute for Health Research’s Strategy for Patient Outcome Research (SPOR) as “occur[ing] when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge” (Canadian Institutes of Health Research, 2014). Patient engagement in research is considered an important part of high-quality healthcare service and has contributed greatly to the existing literature, as patients are considered experts of a particular condition/illness from their experience of living with the condition (Mazzoni, Cornet, van Leeuw, Myllys, & Cicognani, 2018).

Different countries tend to use different definitions for ‘engagement’ but there is consistency in the involvement of people with personal experience of a health challenge, friends family and caregivers. Some other definitions include patient organizations, potential patients, knowledge users (INVOLVE National Institutes for Health Research, 2018), or even clinicians or other health providers (PCORI, 2015). In Canada, Patient engagement is used (Canadian Institutes of Health Research, 2014), Patient involvement is used in the United Kingdom (INVOLVE, 2018) and Patient-Centered Outcomes Research Institute [PCORI] in the U.S. (PCORI, 2015).
Interest in Patient Engagement

There is a growing interest in patient engagement in research because it ensures relevant topics and outcomes to patients are selected for research, which has increased study enrollment and aids the researcher in securing funding, and its feasibility is often during the planning and protocol development stage of the research (Domecq et al., 2014). Patient engagement in research contributes to patient empowerment and facilitates the development of partnership with patients (Amirav et al., 2017), (Phoenix et al., 2018).

There has been an increased interest in promoting patient engagement by funding agencies who also have provided some recommendations on how to best-engaged patients in research. (INVOLVE, 2018). These recommendations are however not sufficient in informing best practices in research (Domecq et al. 2014), (Camden et al. 2015), (Manaflo et al. 2018)

Patient Engagement Framework

Evaluative efforts on patient engagement has expanded recently, with the development of evaluation principles and frameworks (Boivin et al., 2018). Through the Canadian Institutes for Health Research (CIHR) Supporting Patient-Oriented Research Visual Value Model for Patient Engagement and Patient Engagement Framework, there is national guidance to ensure research and innovation is focused on the priorities that are important to patients’ engaging in the research process in a meaningful way and produces information that is genuinely taken up and used to improve health care practice, therapies, and policies. (Canadian Institutes of Health Research, 2014), (Ruco & Nichol., 2016).

Patient engagement presents a positive opportunity for patients, researchers and healthcare systems across the research continuum in improving patients and healthcare
outcomes altogether (Manafo et al., 2018). Current efforts in patient engagement have been limited to preliminary activities that do not cut across the research entire research process and this is mostly caused by some barriers in the research process such as awareness and understanding of patient engagement guiding framework and validated methods, constraint in resources like time and money for adequate planning for patient engagement. (Manafo et al. 2018).

**Current Efforts to Engage Patients in Health Research**

Irrespective of the overarching values of patient engagement in the research process, there has been limited consensus on how to engage patients due to limited understanding of the concept and framework of patient engagement. (Manafo et al., 2018).

Patient engagement has been mostly focused on decisions at the point of care but there is emerging a growing agreement that patient engagement needs to occur earlier in the research process and encompassing all stakeholders which will foster collaborative attitudes that would ultimately lead to identifying the best solutions for the patients (Boutin et al., 2017.). Regulators which include the US Food and drug administration, European Medicines Agency have made patient engagement a priority in their research activities, and patients' perspectives are increasingly being considered in decisions for reimbursement (Arnstein et al., 2020), (Sheridan et al., 2017). Pharmaceutical industries are currently empowering patients' voices in medicine development and are also partnering with healthcare professionals and international patient advocacy organizations to create and establish principles and ethical frameworks to facilitate patient engagement (Consensus Framework for Ethical Collaboration between Patients’ Organisations, Healthcare Professionals and the Pharmaceutical Industry., 2014), (Hamoir et al., 2019). In this era of knowledge users,
patients are increasingly seeking information from peer-reviewed publications and this trend may likely increase (Pushparajah, 2018). In recent times, due to the increasing interest of patients and their advocates. Some medical journals are beginning to facilitate greater patient engagement in the research process as co-authors, editors, readers and peer reviewers in the research publications by requiring researchers to include a Patient and Public Involvement (PPI) statement in all research articles (New requirements for patient and public involvement statements in BMJ Open, 2011). Furthermore, in recent times, more attention is given to engaging patients in writing plain language summaries of clinical trials due to the requirement of the European Medicine Agency for lay summaries in clinical trial results (European Commission. Regulation (EU) No 536, 2014).

**Cost-Effectiveness of Patient Engagement in Research**

In these tight economic times, funders of basic biomedical research, including federal and provincial governments and health charities, are anxious to see and to explain to taxpayers and donors the public benefit of the billions of dollars invested in scientific research CIHR.,(2016). Increased interest in patient engagement comes at a time when healthcare spending is steadily increasing in Canada – In 2018, total health expenditure in Canada was expected to reach $253.5 billion, or $ 6,839 per person. It is anticipated that, overall, health spending will represent 11.3% of Canada’s gross domestic product (Health spending | CIHI). Having people with lived experience participate in research, makes room for improved knowledge translation, and promotes a better understanding of the treatments researchers study (Belton, Hoens, Scott, & Ardern, 2019). Funding bodies such as the National Institute for Health Research (NIHR), require public and patient involvement (PPI) at all stages of research (Stocks, Giles, Cheraghi-Sohi, & Campbell, 2015). However, patient
involvement and engagement have been evident to reduce healthcare and research waste, by increasing the possibility of treatments to align with the population of interests (patients) needs, therefore, leading to better research designs and outcomes (de Wit, et al., 2019).

Investment in health research is also more accountable and transparent by engaging patients, which has, in turn, provided new insights with the potential of leading to innovative discoveries by ensuring patients’ concerns are addressed in the research (Canadian Institutes of Health Research, 2014). Increasing resources and attention are devoted to patient engagement in the research process because of the understanding that patient engagement in designing, execution, dissemination of research will improve the translation into clinical practice to improve the value of research to patients (Domecq et al. 2014), (Finney Rutten et al. 2015), (Sullivan and Goldmann, 2011).

Phases of Patient Engagement

In a systematic review by Bethell et al., (2018) and Domecq et al., (2014), patient engagement in research has been categorized into three different research phases: 1) Preparatory phase; 2) Execution phase; 3) Translation phase (Domecq et al. 2014), (Shippee et al. 2015).

The first preparatory phase involves agenda setting and funding. Patients get engaged in the agenda stage by helping to shape the priority of researchers, by specifically identifying important topics or questions that should be addressed based on their observation and dissatisfaction with the existing care as consumers of the service (Shippee, et al., 2015). According to Saunders et al., (2007), patients can sometimes get engaged in the funding stage of this phase by joining a review panel that reviews eligible research proposals and research grant applications and based on consumer review criteria, assigns a public view
weighting to each. In addition, patients also review eligible topics by bringing the public's views on what is valued as important in deciding what research should be funded (Saunders et al., 2007).

The second phase of patient engagement is the execution phase and it involves stages such as study design and procedure, participants recruitment and participation, data collection, and data analysis (Shippee, et al., 2015). In the study design and procedure stage, the patient gets involved by highlighting and emphasizing ethical concerns to assist in ensuring the successful implementation of the research (Morin, et al., 2008). The next stage is the recruiting of participants, and patient engagement in this stage is to ensure that a clearer communication of the structure and aim of the research is in place, to give prospective participants a better understanding of the study (Shippee, et al., 2015). Patients can also get involved in this stage as the subject of the study. Patient engagement in the data collection stage involves patients giving their input on the mode of data collection, and self-reported questionnaires/surveys, to ensure that the minimization of bias towards the providers’ perspective (Whitley., 2005). The last stage of this phase is data analysis, and this involves presenting findings from the study to participants before publication in order to account for diverse perspectives and increase the validity of the findings (Duffett., 2017).

The final phase of patient engagement is the translational phase. This phase involves the dissemination of findings, implementation, and evaluation (Domecq, et al., 2014). In the dissemination aspect of this phase, patient engagement involves working closely with researchers to create a dissemination method where the content of the information is more appropriate and accessible by the target population (Staniszewska, Brett, Mockford, & Barber., 2011). Patients engagement at the implementation stage is not widely assessed, however, patients’ inputs are recommended in the development of high-quality patient-
oriented clinical practice guidelines (Del Campo, Gracia, Blasco, & Andradas, 2011). In this phase, patients generally serve as a consultant, and they give their input on different stages as experts.

Patients and stakeholders can be engaged across different stages of research, which includes research topic, choosing hypothesis, analyzing data and disseminating findings and the levels of engagement range from consultation to collaboration in bi-directional partnerships with researchers (Domecq et al., 2014), (Forsythe et al., 2019).

Factors Affecting Patient engagement in Research

Health care providers play an important role in facilitating patient engagement in a research study. Patients who receive a recommendation for the study from their attending physician/health care provider often have a higher possibility of engaging in the clinical trials as participants (Baquet, Commiskey, Mullins, & Mishra, 2006). Patients are more interested in engaging in research when their healthcare provider recommending the clinical trial has well-grounded information and is confident about the study (Getz, 2017). Patients’ decision to engage or not engage in research can vary from various reasons such as the structures or processes of research, and/or the individual’s relationship with the researcher (Stocks, Giles, Cheraghi-Sohi, & Campbell, 2015). Patient engagement in research can be hindered and limited due to, low patient response to research recruitment as a result of low awareness and literacy (Probstfield & Frye, 2011); low motivation to participate in research due to preconceived perception about research (Getz, 2014); and complex research design containing multiple inclusion and exclusion criteria (Getz, & Stergiopoulos, 2014). Sometimes the inability of researchers to properly plan and execute engagement initiatives could hinder patient’s participation in research (Lamberti, Mathias, Myles, Howe & Getz, 2011).
Patients can sometimes get frustrated and choose to opt out of the research when there is a lengthy process involved in training, transportation, attendance, etc. (Minogue, & Girdlestone., 2010). In a survey of over 1,600 patients with chronic illnesses conducted by DasMahapatra et al., (2017) to understand facilitators and barriers to trial participation, and to identify opportunities to improve patients’ clinical trial experiences, patients had a high level of willingness to participate in trials but had a low level of experience since they are rarely given the opportunity to participate in clinical trials. They reported that lack of awareness was the main barrier to trials’ participation, with 61% of the patients not being invited to take part by their physicians.

In this thesis, we also explored the outcomes of patient’s expectations/preferences in engaging in musculoskeletal arthroplasty. In the next few pages, we present an overview of musculoskeletal arthroplasty.

**Patient Expectations in Engagement in Musculoskeletal Arthroplasty**

In recent years, there has been a gradual paradigm shift in assessing the effectiveness and success of medical procedures from clinicians’ outcome measures towards patients’ outcome measures which includes patients’ preferences and expectations (Wong et al., 2016). In the traditional medical model, patients’ postoperative recovery has been thought to be influenced mainly by the technical knowledge and the biomedical method used by the surgeon. However, in recent times, patients’ expectations have been shown to have a major impact on the postoperative recovery of the patient. Therefore, it is important to understand other psychological factors that could impact the effectiveness of surgical procedures (Auer et al., 2016).
**Total Joint Arthroplasty**

Total joint Arthroplasty has become an effective procedure for managing arthritis and improving the functional use of the hand and leg joint by the patient and this procedure has reduced pain by over 90% in patients (Hawker et al., 1998; Mahomed et al., 2002; Wong et al., 2016). Presently, according to Badley et al., (2019), about 6 million Canadians have arthritis which is about 20% of the population 15+ years has arthritis or 1 in 5. As many as 25,000 Canadian children and adolescents seek healthcare for arthritis. Nearly 60% of people with arthritis are women, that is 1 in 4 Canadian women and 1 in 6 Canadian men have arthritis. Although arthritis affects people of all ages, age increases the likelihood of the disease. It has been projected that by 2040 about 50% more people which will be about 24th of the population will have arthritis. (Badley et al., 2019).

It has been estimated that over 35,000 total shoulder arthroplasty procedures have been performed annually in both United States and the United Kingdom (Henn et al., 2011), (Ravenscroft & Cavert., 2004). In the United States, patients who are 55 years old or younger has an increasing demand for shoulder arthroplasty at the rate of 8.2% per year and it has been projected to increase by 333.3% by 2030 among younger patients 55 years or younger and 755.4% increase among older patients 55 years or older (Padegimas et al., 2015). Despite the success and effectiveness of shoulder arthroplasty published in the literature, some patients still experience dissatisfactory results or low functional postoperative recovery which is often because there has been more focus on physician-reported outcome measures than patient report outcomes measures (Franta, et al., 2007; Neuberger, et al., 2013; Rolfson, et al., 2011).

In recent times, elbow arthroplasty has been reported in some studies to be particularly very effective for treating elderly patients diagnosed with different types of
arthritis which include; posttraumatic arthritis, rheumatoid arthritis, comminuted fracture of the distal humerus with intraarticular extension (Cobb & Morrey, 1997; Connor & Morrey, 1998; Hildebrand, Patterson, Regan, MacDermid, & King, 2000). But in general, elbow arthroplasty is not a commonly performed procedure as other types of arthroplasty such as hip and knee arthroplasty (as cited by Kumar & Mahanta, 2013).

According to the report by Berliner et al., (2016) researching the outcomes of patients undergoing knee and hip arthroplasty, the research showed that despite the effectiveness of the procedure, some patients still experience chronic pain leading to impaired function and postoperative dissatisfaction. This has resulted in high medical costs and low quality of life for these subsets of patients (Berliner et al., 2016; Fortin et al., 1999). This, therefore, means that there are other factors other than arthroplasty techniques that impact the results of the surgeries in which the physician needs to take note of which might impact their decision and recommendations to patients electing for these procedures (Haanstra et al., 2012). Therefore, understanding the impact of patients’ preoperative expectations could supply the tool clinicians need to help and guide patients in deriving realistic expectations which will result in greater satisfaction. (Chung, et al., 2015).

**Patients’ Expectations**

According to Bowling, Rowe, & McKee., (2013, p.144), “Patients’ expectations have been defined as the anticipation that given events are likely to occur during, or as an outcome of, healthcare”. It is what people anticipate receiving from their care in comparison with their observation of the care they received or experienced. It is often said that when the perceived healthcare delivery exceeds what a patient expects of the care, the patient often is satisfied
with the care. Likewise, if their expectations are not met, then they become dissatisfied (Bowling et al., 2013; Thompson & Sunoi., 1995).

According to Bandura's self-efficacy theory, there are three types of expectations which are defined as: Outcome expectations: beliefs that certain actions will achieve particular outcomes; Process expectations: beliefs about the content and process of interventions and, Self-efficacy expectations: beliefs in one’s capabilities to organize and execute the courses of action required to produce given attainments (Bandura., 1982).

Bowling et al., (2013) explained further in their studies that there are two factors to expectations. The first relates to what the expectation of the patients would be in an ideal condition in a developed country and the second relates to what the patients would realistically expect to happen in their care. These expectations are often determined by a host of other factors including patients’ characteristics such as their beliefs on the outcome of engagement in a medical procedure. Some of these beliefs have been supported by empirical evidence such as the beliefs of older people who have lived for most of their lives in austere conditions in developing countries, will tend to be more grateful for whatever the healthcare has to offer hence may have low expectations while the younger folks who have lived most of their life in developed countries tend to expect more from their healthcare system (Bowling et al., 2012).

**Patients’ Satisfaction**

In recent years in the healthcare system, patient satisfaction has been used more often to evaluate the quality of medical service (Hudak & Wright., 2000). This has resulted in the reduction of the risk of litigation and improving patients’ rating of the quality of healthcare service they have received (Williams., 1994). Some studies have explained patient
satisfaction as the direct personal observation and experiences of the patient of the care
received which is often affected by their psychological wellbeing and health status (Hardy.,
1996; Thompson & Sunoi., 1995). Some other studies have described satisfaction with
respect to outcome, as a multidimensional measure, among which are the degree of pre-
treatment symptoms, beliefs on what they expect the outcomes of treatment to achieve and
the treatment delivery which is also influenced by location, environment and the issues with
staff (Gepstein, Arinzon, Adunsky, & Folman., 2006; Mcgregor, Doré, & Morris., 2013).
Mcgregor et al., (2013) explained in their study that measures of expectation have
increasingly been associated with measures of satisfaction. In another recent study, assessing
patients' satisfaction in joint arthroplasty, the study suggested that the overall patient’s
satisfaction can be based on three factors which include met preoperative expectations,
satisfactory hospital experience and satisfactory relief from pain (Hamilton et al., 2013).
More work is undoubtedly needed to clarify these complex relationships (McGregor, Doré,
and Morris., 2013)

**Current Issues on Patient’s Expectations on Arthroplasty**

In the past two decades, quite a few research has been focused on understanding the
role of patients’ expectations for medical and surgical procedures. Lately, patients’
expectations have become an integral part, when comparing and analyzing the effectiveness
of treatment outcomes of surgical and medical procedures (Chung et al., 2015). The body of
literature suggests that patients' expectations could be measured and could also influence the
outcomes of different treatments. (Haanstra et al., 2012; Henn et al., 2007; Jawa et al.,
2016). The outcomes of patient’s treatment have been correlated more often with their
expectations. Patients’ who are positively higher in their expectations often record greater
satisfaction. (Henn et al., 2011; Mahomed et al., 2002; Mondloch et al., 2001). In a study conducted by Styron et al. (2015) on patients for total shoulder arthroplasty, the study showed there was a correlation between preoperative patient expectation and functional outcomes. (Styron et al., 2015). Henn et al; (2007) did a study on the rotator cuff which showed that the preoperative expectation of patients was correlated with the patient’s self-assessment. In another study on total shoulder arthroplasty by Henn et al, the research showed younger patients had higher expectations than older patients (Henn et al., 2011). Many other studies have also shown better outcomes are related to greater expectations. (Mahomed et al., 2002; Zywiel et al., 2013; Henn et al., 2007; Noble et al., 2006; Carol et al., 1997).

Some studies have shown that lower patients expectations were related to unmet expectations. (Henn et al., 2007; Mancuso et al., 1997; Noble et al., 2006; Tashjian et al., 2007). Some studies have also shown that high patients realistic expectations have an association with postoperative patient satisfaction and improved outcomes after total knee arthroplasty, total hip arthroplasty, (Haworth, et al., 1981; Koenen et al., 2014; Mancuso et al., 1997), lumbar laminectomy (Iversen et al., 1998), brain surgery for epilepsy (Wheelock et al., 1998), rotator cuff repair (Henn et al., 2007), cataract surgery (Chen, Bain, Horan, Hawkins, & Littleton, 2007; Pager., 2004), heart transplantation (Leedham et al., 1995) and total shoulder arthroplasty. (Henn et al., 2011).

Patients’ recovery and perception of the postoperative outcome may be impacted by high expectations or beliefs which might be reflected by a generally positive attitude to an arthroplasty. (Carver, et al., 1993; Reed, et al., 1994; Leedham, et al., 1995).

Iles et al., (2009) systematic review on the ability of recovery expectations in predicting the outcome of low back pain found a strong predictive impact of expectations on
the recovery expectations in patients who had acute low back pain. Moreover, Haanstra et al., (2012) in their systematic review on the impact of preoperative expectation on the outcomes on total knee and total hip arthroplasty showed that there was a medium-long term association between self-efficacy and outcome expectations with pain and a medium-term association between self-efficacy and outcome expectations with function. They however concluded that for patients undergoing total knee and total hip arthroplasty, there was no consistency across the studies in the association between patients’ preoperative expectation and treatment outcomes which could be impacted by the variety of definitions and measurement methods of expectations. Waljee et al., (2014), expressed the need for physicians to understand the effect of patients’ expectations on outcomes of their surgeries to better manage their patients more effectively.

There is little research on patients’ expectations of total joint arthroplasty of the upper extremity as most of the studies focused more on the lower extremities such as the hip and the knee (Gonzalez Sáenz De Tejada et al., 2010; Iversen et al., 1998; Mahomed et al., 2002; Mancuso et al., 2001). We cannot concisely infer or conclude that the outcomes of these studies can be translated to interpret the patients’ expectations on total joint arthroplasty of the upper extremities. This is due to the significant functional differences between the joints in the upper and lower extremities.

This research also identified and synthesized evidence that determines the extent to which three types of preoperative expectations (process expectations, self-efficacy expectations and outcome expectations) are predictive of postoperative outcomes (pain, function, patient satisfaction) in patients undergoing total shoulder, elbow or radial head replacement.
Patients’ Conceptual Behavioral Model

Different models have been used to explain concepts and behaviour of patients to health-related actions. This thesis also explored the conceptual framework of the Health Belief Model (HBM) to understand how patients’ perceptions of benefits, barriers, cues to action, and self-efficacy play a role in the likelihood of patients’ engagement in research and electing to undergo total joint arthroplasty. The Health belief model also provides an opportunity to explore how healthcare provider action can influence patient motivation in engagement in research and the use of self-efficacy patient’s expectations in engagement in upper extremity arthroplasty.

Health Belief Model

The Health Belief Model is a conceptual framework that has been used widely to understand health-related behaviour (Champion & Skinner., 2008), (Rimer & Glanz., 2005). It is a model that is typically used to explains or predict why people will engage or not engage in a health-related action such as prevention and maintenance by understanding or researching underlying beliefs systems (Champion & Skinner., 2008), (Janz & Becker. 1984). An understanding of this model has made it easier for researchers to understand patient’s motivations and participation in health-related actions (Olsen et al., 2008). The health belief model has been used to develop new health behaviour interventions. (Glanz et al., 2008; Turner et al., 2004). The health belief model has also been used to explain patient involvement in patient safety and it provided a theoretically grounded approach to explain patients’ past and present involvement in safety practices and factors that influence patients; engagement (Bishop et al., 2015).
**Health Belief Model Key Construct**

The HBM was developed initially in the 1950s; but over the past 60 years has evolved to include six constructs, which includes: (i) perceived susceptibility; (ii) perceived severity, collectively known as a perceived threat; (iii) perceived benefits; (iv) perceived barriers; (v) cues to action; and (vi) self-efficacy (Becker, 1974; Rosenstock, 1974).

Perceived susceptibility has been described as the belief an individual regards himself or herself as susceptible to acquiring an illness or being harmed due to engaging or not engaging in a behaviour (Rosenstock & Becker, 1994).

Rosenstock & Becker, (1994) described the other concepts as Perceived severity in which is the belief of someone who regards the extent of harm that can occur by performing or not performing a health behaviour. (for example, death, disability, and pain) and possible social consequences (such as effects of the conditions on work, family life, and social relations). The combination of susceptibility and severity has been labelled as a perceived threat. In patients’ expectations on arthroplasty for instance patients may be more likely to engage in arthroplasty when perceiving their inability to use their joints may deteriorate with time and make them more dependent on others for help with activities of daily living.

Rosenstock & Becker., (1994) further explained, even though perceived threat should motivate a person to take action to reduce the threat, but the decision to take action depends on the belief of a perceived benefit in taking the action related to reducing the threat. For instance, an obese patient who is not concerned with the perceived threat of the conditions associated with obesity may be willing to engage in research on obesity if the expected positive effect such as having a healthier lifestyle, or weight loss, will please a family member. These benefits are also weighted against the perceived barrier which is the potential negative effect in taking the health-related action that might be expensive, inconvenient or
unpleasant. For instance, if the cost of transportation to the research site is a concern for a patient, the patient is likely not to engage in that research. Cues to action refer to other factors particularly cues that can stimulate or instigate an individual to take action and can be internal or external. Internal cues such as a person who experienced or witnessed a medication error while external cues include reading about a medical error in a newspaper or a poster in a doctor’s office (Bishop et al., 2015).

Self-efficacy suggests that individual confidence in a health-related action is defined as “the conviction that one can successfully execute the behaviour required to produce the outcomes” (Bandura., 1997). Bandura distinguished self-efficacy expectations from outcome expectations, defined as a person’s estimate that a given behaviour will lead to certain outcomes. Outcome expectations are similar to but distinct from the HBM concept of perceived benefits.

**Current Gap in Literature**

Patient engagement is still an evolving area, and studies have been done in areas like dementia (Bethell et al. 2018), cardiovascular diseases (Finney Rutten et al., 2015), and musculoskeletal conditions (Pang, Clavisi & Chang., 2017). To our knowledge, there are no studies in the literature addressing patient engagement in upper extremity musculoskeletal research. In the study by Pang, Clavisi, and Chang (2017), conducted in Australia, they assessed what patients intend to gain in seeking to be involved in the research. Our aim in this research is to understand the factors that enable and hinder patient’s engagement in research in upper extremity musculoskeletal research. Our findings in this research will add to the body of evidence in the literature.
In this thesis, we present research conducted to explore the facilitators and barriers in patients' engagement in musculoskeletal research in Chapter 2 and we also present a systematic review of the evidence which explored patients' preferences/expectations and barriers in the outcomes of engagement in the upper extremity arthroplasty in Chapter 3. We summarised the thesis in the last chapter and concluded the studies.
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CHAPTER 2

Barriers and facilitators of patient’s engagement in musculoskeletal research

Kizito I. Enonbun

Health and Rehabilitation Science, Health Promotion, Western University, London, ON, Canada. Email: kenonbun@uwo.ca

Joy C. MacDermid

Health and Rehabilitation Science, Physical Therapy and Surgery, Western University, London, ON, Canada; Clinical Research Lab, Hand and Upper Limb Centre, St. Joseph’s Health Centre, London, ON, Canada. Email: jmacderm@uwo.ca

Trevor Birmingham

Health and Rehabilitation Science, Physical Therapy and Surgery, Western University, London, ON, Canada. Email: tbirming@uwo.ca

David Walton

Health and Rehabilitation Science, Physical Therapy and Surgery, Western University, London, ON, Canada. Email: dwalton5@uwo.ca

Corresponding Author: Address all correspondence to: Kizito I. Enonbun, Health and Rehabilitation Science, Health Promotion Field, Western University, Elborn College, London, ON, Canada. kenonbun@uwo.ca
Abstract

There is a growing interest in patient engagement in research because it ensures topics and outcomes relevant to patients are selected for study, which has increased the number of patients enrolling in research and also helps the researchers in securing funding. The purpose of this study was to assess the facilitators of patients' engagement in health research; identify significant barriers to the patient’s engagement in health research, and document factors that facilitate patient engagement in health research. A descriptive cross-sectional survey design was used in this study. The study population was musculoskeletal patients who were recruited online through social media platforms and by healthcare provider referrals. Descriptive statistics and percentages were reported for all the data on the barriers, facilitators and factors affecting patient engagement in research. A total of 204 patients consented and viewed the survey. However, only 102 patients responded to the survey. The barriers to patients’ engagement in research identified in this study included lack of awareness of patient engagement in research (50%), the inconvenience of travelling to research sites (59%), length of time for research participation (56%) and fear of the potential side effect of research engagement on their health (56%). Given that these research factors are deterrents to patients’ engagement in research; researchers should consider adapting research designs to be more inclusive of these factors by emphasizing at-home testing, online engagement and putting in place systems that can help the patients to report or cope with the effect of the engagement. Future research is also needed in creating evaluation frameworks and sufficient evaluation data to measure near, intermediate and long-term outcomes of engaging patients across the health research engagement continuum.

Key Words: Patient Engagement, Patient Participation
INTRODUCTION

Patient engagement in health research is the process of involving people who have personal experiences of a health issue and their family, friends, and caregivers in the research process, not just as study subjects but as partners, helpers in planning, executing and disseminating research outcomes (Bethell et al., 2018). While there is limited evidence with regards to the benefits and potential difficulties of integrating patients into the research process (Domecq et al., 2014), (Fergusson et al., 2018), there is a clear movement towards doing so, especially in Europe and North America (Harrison & Palmer, 2015), (Selby & Slutsky, 2014).

There is a growing interest in patient engagement in research because it ensures topics and outcomes relevant to patients are selected for study, which has increased the number of patients enrolling in research and also helps the researchers in securing funding (Domecq et al., 2014). As stated by the Canadian Strategy for Patient-Oriented Research, “patients bring the perspective as ‘experts’ from their unique experience and knowledge gained through living with a condition or illness” (Canadian Institutes of Health Research, 2014). Increased interest in patient engagement comes at a time when healthcare spending is steadily rising in Canada, and in 2019, total health spending in Canada was expected to reach $265.5 billion, or $ 7064 per person (Health spending | CIHI). According to the Canadian Strategy for Patient-Oriented Research, engaging patients in health research increases the quality of the research and, as healthcare providers integrate this research into care, the quality of care will also be increased (Canadian Institutes of Health Research, 2014).

Patient engagement presents a positive opportunity for patients, researchers and healthcare systems across the research continuum in improving the patient and healthcare outcomes altogether (Manafo et al. 2018a). Current efforts in patient engagement have been
limited to preliminary activities that do not cut across the research activity spectrum which mostly caused by some barriers in the research process such as awareness and understanding of patient engagement guiding framework, constraints in a resource like time and money for planning purposes and validated methods for patient engagement (Manafo et al. 2018b)

Patient engagement is still an evolving area, and studies have been done in areas like dementia (Bethell et al. 2018), cardiovascular diseases (Finney Rutten et al. 2015), and musculoskeletal conditions (Pang, Clavisi, and Chang, 2017). To our knowledge, there are no studies in the literature addressing patient engagement in upper extremity musculoskeletal research. In the study by Pang, Clavisi, and Chang (2017), conducted in Australia, they assessed what patients intend to gain in seeking to be involved in the research.

Recruitment into clinical studies is the single most challenging issue in the successful completion of research studies. However, understanding the factors that contribute to participation is important to optimizing recruitment. Our findings in this research will help to understand the experiences of patients and identify ways that can improve patients’ involvement in research, and it will also add to the body of evidence in the literature. Our aim in this research is to understand the factors that enable and hinder patient’s engagement in research in upper extremity musculoskeletal research either as a research subject or a partner/knowledge user (patient engagement). Our findings in this research will add to the body of evidence in the literature.

METHOD:

Study Design

A descriptive cross-sectional survey design was used in the research. A self-report questionnaire was used to collect data. The study population was surgical/rehabilitation
patients who were recruited online through social media platforms. The University of Western Ontario Health Sciences Research Ethics Board provided ethical approval for the study. Information letters and the consent form were provided online to potential participants to review and consent before completing the online questionnaire. Participants were allowed to ask questions and clarification at every point of the consent process. Only participants who were willing and comfortable and had consented were invited to complete the questionnaire.

**Eligibility Criteria**

Patients were aged 18 years or over and were fluent in English. They were also surgical/rehabilitation patients recruited online and by healthcare providers’ referrals who had consented to participate in the research.

**Data Collection**

**Survey**

A questionnaire was designed by adapting a survey from a study that assessed the facilitators and barriers to clinical trial participation among the patients' community (DasMahapatra et al., 2017), which is very similar to this study. About 60% of the original survey was changed to suit this study. The changes included removing some demographic information, clinical trial-specific questions, health condition trial preferences, reformatting the questionnaire, and creating more questions to capture the patient engagement continuum, from conception to dissemination and implementation of research outcomes.

The adapted questionnaire was reviewed by members of the advisory committee and all suggested changes were incorporated into the question-wording. The questions were designed to elicit the context, experiences of challenges, preferences,
enablers, and perceived needs of patients involved in research. The survey consisted of 7 questions with sections related to research awareness, research participation, research experience, attitude to research, research interest, research factors (barriers and facilitators) and basic socio-demographic information (age, marital status, education, employment) of respondents.

We conducted a pilot testing of the questionnaire among 15 graduate students at Western University, London ON. to establish an estimate of survey length, clarity of questions, the ease of completion, ease of understanding, time of completion, and confidentiality (the extent to which they felt able to answer the questions honestly).

The adapted survey was used to collect data from the participants. These participants were recruited through advertisements on social media platforms such as musculoskeletal patients, support and caregiver groups on Facebook, Twitter, Kijiji and on the main website of the Roth McFarlane Hand and Upper Limb Centre (HULC) at St. Joseph’s Health Care Hospital in London, Ontario. Email requests were also sent to healthcare providers to send the survey to the patients in their care. All the advertisements included a link that directed potential participants to view the letter of information and complete the online survey after providing their consent. The survey questions are presented in Appendix 3.

Data Protection

No participant identifying information was collected in this anonymized survey. Data were kept at the HULC clinical research laboratory where only authorized personnel have access. Electronic files were stored in an encrypted file and apart from the study investigators and Western University Health Sciences Research Ethics Board and Lawson Quality Assurance and Education Program, no other person had access to the electronic records.
Data Analysis

Quantitative

Descriptive statistics and percentages were reported for all the data about the barriers, facilitators and factors around musculoskeletal research. Data analyses were completed using SPSS Software.

Sample Size Calculation

According to Chadha (2006), in estimating a population proportion with specified absolute precision, the anticipated population P is needed, and a rough estimate of P is sufficient. The observed value of the outcome measure gives the best estimate of the true value, and it is useful to have some indication of the precision of this estimate, which is done by attaching a confidence interval to the estimate in a range of plausible values for the true value of the outcome measure, conventionally quoted as 95 percent confidence interval (Chadha, 2006). We estimated that 20% of the patients are involved in the research. If the outcome measure is a proportion estimated from the sample data as P, the 95 percent confidence intervals (C.I) will be:

\[
C. I = P +/- 1.96 \times S.E
\]

S.E denotes standard error of the estimate

\[
C.I = (P-M.E, P+M.E)
\]

\[
C.1 = \{(20-5), (20 +5)\}
\]

\[
C.1= (15\%, 25\%)
\]

d = absolute precision required on either side of the proportion which is the total percentage of point of error is 0.05

\[
Z = Value \text{ corresponding to the level of confidence. At a 95% level of confidence (0.05: a Z value equals 1.96)}
\]
M.E (Marginal Error) = 1.96 x S.E

\[ \text{M.E} = 5\% = Z^2 \times \sqrt{p(1-p)} \]

According to Chadha, (2006), sample size can be estimated using the following formula:

\[ \text{Sample Size (n)} = \frac{Z^2 \times p(1-p)}{d^2} \]

\[ = \frac{1.96^2 \times 0.20 (1-0.20)}{0.05^2} \]

\[ = \frac{0.615}{0.0025} = 246 \]

Sample size = 246

**Qualitative**

Some of the survey questions (Questions 2, 3) were open-ended. For these questions, qualitative data analysis techniques were used. Data were analyzed by response line to identify emerging codes. Relationships and similarities among codes were discussed leading to the formation of themes. Themes were particularly identified to provide new information to the quantitative responses, to better understand the barriers and facilitators of patient engagement in research.

**RESULT**

**Participants Characteristics**

A total of 202 patients consented to participate and viewed the survey. Among those who viewed the invite (n = 202), 90 completed the survey, 80 opted out, and 12 provided partial data, yielding participation rate (n of participation/n of views) and completion rate (n
of completers/n of participation) of 50% and 88%, respectively. The completion rate was in line with the Internet-based surveys of similar length (approximately 70%) (Galesic, 2006).

Demographic variables included age, gender, marital status, and employment. Out of the 102 survey participants, 47 (46%) were men, 52 (51%) were women. There was three major sections in the survey: (1) experience with engagement in research; (2) attitudes and interest towards engagement in research; and (3) perceived factors that might influence engagement in research. Of the 102 participants in this study, 68.4% have participated in some form of health research with 31.6%, who have never participated in any research (Table 2). The majority of participants were aged 25 to 55 years old representing 89% of the sample of this survey. The majority of the participants, 70 (68.6%) had a university degree education, 18 (17.6%) had some college or university degree. The demographic description of the included participants is presented in Table 1.

**Research Awareness**

In this study, the majority of the participants (49%) found out about research from friends and family, 41% from the internet or online, 35.3% from doctors/healthcare providers, 14.7% from advertisements (Table 2). Forty-three of the participants (42.6%) have had a member of the health care team talked to them about health research. Fifty-one participants (50%) have never been spoken to by a member of the healthcare team (Figure 1). When a health professional informed participants about research, 38 (38%) participants were very likely to participate, 50 (50) were somewhat likely to participate, 7 (6.9) were not likely to participate while 5 (4.9) were not sure if they would participate (Figure 2). Table 2 describes research awareness and participation in health research. A total of 31 (31.6%) participants have never participated in any health research in their lifetime, 17 (16.7%)
participated once, 16 (16.3%) participated twice, 12 (11.8%) have participated thrice, 2 (2.0%) participated 8 times, 10 (10.2%) participated 10 times. Of those who participated in the research, 90 (88.2%) did not consider dropping out of the study, while 7 (6.9) participants considered dropping out of the study (Figure 1).

**Reasons for not participating in Health Research**

The reasons reported by the participants as barriers to their participation in research are described in Table 3. Forty-two (45%) percent reported that it was inconvenient for them to travel to the research sites, 10 (10.8%) reported work commitments as a hindrance, while 10 (10.8%) reported that they were concerned about the potential side effect of the research on their health. With regards to dropping out of the study, 18 (25.7%) had other commitments at the time of research, 7 (10%) were no longer interested, 6 (8.6%) reported the research was taking too much time (Table 3).

**Factors Affecting Patients’ Engagement in Research as Study Participant**

Factors reported by the participants as “very important” and “somewhat important” to engage in research are described in Table 5. These factors may act as facilitators to engagement in research when provided/available and can also act as barriers when not provided/available. As study participants, these factors regarded as “very important” included; research team training (55.6%), compensation for my expenses e.g parking (47%), length of time for research participation (56%), researcher’ attitude toward participants (66%), meeting the expectations of the participant (54%), compensation for time (41%), how important the research question was to the health condition of the participant (56%), Other factors included; participants’ perception that the research would make a difference (64.9%),
the length of follow-up time (46%), the amount of time each visit takes (45.8%), and participant's relationship with the healthcare team (42%).

**Factors Affecting Patients’ Engagement in Research as Team Members/Partner**

As research team members/partners, the factors that affected patients' engagement in the research were also considered to be “very important” and “somewhat important”. These factors when provided or available would act as facilitators and when not provided or available would act as barriers to patient engagement in research. They included; training provided for the role in the research team (59.8%), participants prior experience with research (41%), participants’ relationship with the healthcare team (52%), time for study the completion (50%), time that each meeting would take (60.8%), the amount of travel they would have to do to participate (58.8%), participants’ belief that the team would listen to their ideas that could influence the research project (64.7%), the relevance of the research question to the participants' health problems (54.9%), and the importance of the research question to help others (52%). All the research engagement factors are presented in Table 5.

**Interest in Engagement as a Research Team Member/Partner**

Results regarding participants’ interest in engaging in research as a team member/partner are presented in Figure 3. The “very interested” and “somewhat interested” were considered as very important to their engagement in research. The “very interested” options included sharing your experience with the problem (41%), deciding on what questions are important to be answered (38%), listed as a team member on a grant (35%), acting as a member of the research team (29%), helping to choose important study outcomes (27%), helping with recruitment into a study (26.5%). Some other participants’ interests in
engaging in research are described in Table 4. These interests were expressed by a “yes” or “no” by the participants, they included to; write or rank the importance of potential research questions (57.8%), pick study outcomes (57%). The aspect of research the participants were not interested or not sure about was indicated with a “no” or “not sure”. The aspect of research the participants expressed a “no” included: planning the research process (38%), apply for a research grant (47%), interpret and spread research results (45%).

**Participants’ Attitude to Research Engagement**

Participants' attitude towards research was indicated by the Likert scale of “strongly agree” and “agree” as presented in Table 6. The “strongly agree” and “agree” were very important positive attitudes to research. The “agree” option included: I am interested in learning more about taking part in research (41%), I would like to take part in research in the next 12 months (49%), it would be easier if I could go to a website and find studies that were a good match for me (40%), in the future, I would be interested in helping researchers to design better research by answering questions about the design of their research studies (49%).

**Qualitative Data**

A total of 60 participants provided additional information in open-ended responses which were mostly 1–3-word phrases to describe their barriers and facilitators to engaging in research. Three major themes emerged: personal factors; health factors, and research information factors. The personal factors included; time commitment or work commitments, social and moral support from family or friends to participate in research. Health Factors included; fear for personal injury, concerns about the potential impact the research can have
on their health, concerns about medical bills being covered in case of an accident during the research.

Research information factors include thorough information on what the research is all about, Intensive training, a detailed description of research objectives and milestones, open communication with the researcher, electronic research information preference, application process guidance, access to a device that has the system configuration and specification to make the task attainable and community awareness of research.

**DISCUSSION**

This study found that there was a lack of awareness of patient engagement in healthcare research. About 50% of the participants had never been spoken to about research by doctors or healthcare professionals. The others who have participated in some form of research found out about research from other sources such as the internet, and family/friends. The awareness of healthcare research by these other participants may be due to their exposure to some form of research in the university or college since 68.6% of the participants had a university education and 17.6% had some college or university degree. In this study, a lack of awareness of patients was found to be a barrier to research engagement. This barrier was in line with the study conducted by DasMahapatra et al. (2017), where one of the major barriers to patients’ participation in clinical trials was awareness of the research. The other barrier to patients' engagement in research was the inconvenience of travelling to the research sites once they were offered participation. Other reasons they declined participation in the research were concerns about the potential side effect of the research on their health and work commitments. This is also similar to the findings by DasMahapatra et al., (2017).
Many research factors were found in this study to either facilitate patient engagement in research or acts as a barrier. The study found that most patients will more likely be engaged in research if adequate training was provided for them not just as a participant (55.6%) but also as a team member or partner (59.8%). The researcher’s attitude to the patients played a very important role (66%) also in determining if the patient would engage or drop out of the study. It was also found that patients would be more willing to participate in research as a team member or a partner if the researcher was offering some compensation for time/knowledge (45.1%), and if the research team member meeting did not take too much of their time (60.8%). One major barrier or consideration to patient engagement as a team member or partner in research was privacy and confidentiality issues (75.5%). Other patients’ considerations include whether their medical bills will be covered in an injury from the study (71%) and if the research will provide an opportunity to possibly improve their health (68.6%) and the health of others (72.5%)

When a patient is interested in engaging in research but considers the cost of transportation to the research site or taking time off from work, the patient may not likely engage in that research. This is in line with the perceived barrier construct in the Health Belief Model, which says that if the perceived barrier is higher than the benefits patients are less likely to participate in that particular health action (Bishop et al., 2015). Reducing these barriers such as offering financial incentives to patients for their time/knowledge and transportation to the research site may help to increase patients’ engagement in that research.

According to Baquet et al., (2006), healthcare providers play an important role in discussing potential research opportunities with patients and, Getz, (2017) also added that patients will even more likely to engage in the research when their attending physician is confident and has well-grounded information about the study. This study found that 50% of
the participants had never been spoken to about research by doctors or healthcare professionals. Only about 35% of patients were informed about research by their healthcare provider and 50% of the participant reported that they would have participated in research if they were informed by their doctor or healthcare provider. Lack of awareness of research of 50% of the participants was quite higher than expected and may reflect a lack of access to research projects, a lack of awareness by their doctors or healthcare providers who should have been recommending research or their lack of interest in participating in it. Therefore, informing and engaging health care providers in research projects so they can provide informed recommendations to patients in their care is very crucial to reducing the barrier of lack of awareness and patients’ concern of the potential effect of their engagement in research could have on their health, which was a concern for about 11% of our study population. Providing training for potential research participants will increase their self-efficacy and willingness to participate in research. This is also in line with the self-efficacy construct in the HBM, which suggests that the researcher can also verbally reassure participants during the study, which can increase self-efficacy thereby reducing the drop-out rate (Bandura, 1997), (Rosenstock & Becker, 1994).

The method of delivery of the research project also plays an important role in patient engagement. This study found that one single method of delivery is not likely to meet all needs of patients as the variation in preferences was clear. Only 33% of the participants preferred a face-to-face meeting. Other preferences included: video chats (31%), websites with protected chat rooms (29%). The majority of the participants (93%), which included some of those who would also want to participate face-to-face, preferred engagement in research through listserve or email list. It is, therefore, crucial to note that preferences prior to
engagement are important since this is the time when patients make decisions about engaging in the research.

The participants identified several challenges to engaging in research. This suggests that researcher flexibility is a critical factor in research planning in how/when patients engage in the research. Patients placed high importance in engagement in research on their perception that the research will make a difference and improve their health conditions and that of others in the community. Some others placed importance on the research meeting their expectations and the belief that the research team would listen to their ideas and the likelihood their ideas could influence the research project. Since all of these factors are important to patients, research engagement may be increased by clear explanations of the benefits that could be derived in engaging in the research both at the conceptual level and in the engagement continuum. This is in line with the Health Belief Model in which benefits are weighed against the perceived barrier by the patients which may be the potential negative effect in taking the health-related action that may be expensive, inconvenient or unpleasant (Bishop et al., 2015).

Given that these research-related factors might be a deterrent to patient engagement, researchers could consider more patient-centred research designs that emphasize at-home testing, online engagement and putting in place systems that can help the patients to report or cope with the potential side effect of the engagement in research and creating patients’ engagement frameworks. A more adaptive way to incorporating these research factors in designing research is therefore needed to facilitate more patients engagement.

Future research should place much emphasis on patient engagement in musculoskeletal research as it is currently understudied. Musculoskeletal conditions have the biggest burden on general practitioners when considering conditions commonly associated
with quality of life (Grimaldi-Bensouda, et al., 2011). Future research is also needed in creating evaluation frameworks and sufficient evaluation data to measure near, intermediate and long-term outcomes of engaging patients across the health research engagement continuum.

**Study Limitations**

Our study had several limitations. In the planning phase of this study, the study was intended to be conducted face to face with hand and upper limp patients at St Joseph Hospital but due to Covid-19 pandemic lockdown, the study was adapted for online recruitment. Unfortunately, only 102 participants responded to the survey as against the anticipated 246 respondents. Since the survey was designed for those who are fluent in English who were musculoskeletal patients, people speaking other languages were not represented. Furthermore, musculoskeletal health issues mostly affect older people, however, only 10% of the research participants were between the ages 65-85. So this study may not have been representative of this age group.

**Future research and clinical implications**

While this survey is a first step to understand what factors affecting patient engagement in musculoskeletal research, studies that would collect patients' perceptions and preferences are needed to create patient-oriented engagement research projects. Future studies that would specifically target patients who are 56 years and older will be needed to collect the preferences and perceptions of the population group. Our survey identified some principles that patients considered very important and when present will facilitate their engagement in research among musculoskeletal patients. One of the most important findings
of our work is the patients’ lack of awareness about the research engagement continuum as the majority of the patients participated in research as a participant. Education and engagement of healthcare professionals and improved accessibility to the research project are also indicated to improve patients' engagement in research.

Conclusions

Awareness of the potential benefits of patient engagement in the research engagement continuum, and prior experience with it were very low. Common potential patient-reported barriers to engagement in future research included: transportation cost, work commitments, distance from home to research site and times for research participation were provided. These barriers might be addressed by compensating participants, modifying the method of patient engagement and education and involvement of healthcare professionals in the research process. These are needed for improved patient engagement in research.

Conflict of Interest Statement

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Statement of Informed Consent

This study involves no human subjects, so informed consent was not sought or required.

Statement of Funding

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References


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<tr>
<td>Questions</td>
<td>N (%)</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td><strong>When you were asked to be a participant in a study, what did you decide?</strong></td>
<td></td>
</tr>
<tr>
<td>I am currently in a study.</td>
<td></td>
</tr>
<tr>
<td>I took part and completed the research.</td>
<td></td>
</tr>
<tr>
<td>I took part but withdrew before the end.</td>
<td></td>
</tr>
<tr>
<td>I wanted to take part but was not eligible.</td>
<td></td>
</tr>
<tr>
<td>I wanted to take part but it was not possible due to health or any other physical challenges</td>
<td></td>
</tr>
<tr>
<td>I declined to take part in the research.</td>
<td></td>
</tr>
<tr>
<td>Can’t remember.</td>
<td></td>
</tr>
<tr>
<td><strong>In your lifetime, how many research have you taken a part in?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Number of Times:</strong></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1.0</td>
</tr>
<tr>
<td>1.0</td>
<td>2.0</td>
</tr>
<tr>
<td>3.0</td>
<td>4.0</td>
</tr>
<tr>
<td>5.0</td>
<td>6.0</td>
</tr>
<tr>
<td>8.0</td>
<td>10.0</td>
</tr>
<tr>
<td><strong>What were the best things about taking part in this research?</strong></td>
<td></td>
</tr>
<tr>
<td>I felt very important and valued in the research.</td>
<td></td>
</tr>
<tr>
<td>I learned more about my own health condition.</td>
<td></td>
</tr>
<tr>
<td>I learned some new things about research and the topic of research.</td>
<td></td>
</tr>
<tr>
<td>I felt I was contributing to the health and welfare of the community.</td>
<td></td>
</tr>
<tr>
<td>Can’t Remember</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td><strong>How do you find out about health research?</strong></td>
<td></td>
</tr>
<tr>
<td>Online/internet</td>
<td></td>
</tr>
<tr>
<td>Media</td>
<td></td>
</tr>
<tr>
<td>Advertisements</td>
<td></td>
</tr>
<tr>
<td>Doctor/healthcare provider</td>
<td></td>
</tr>
<tr>
<td>Friends/Family</td>
<td></td>
</tr>
<tr>
<td>Patient Organization</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td><strong>What role did you take in the research?</strong></td>
<td></td>
</tr>
<tr>
<td>I was a participant in the research.</td>
<td></td>
</tr>
<tr>
<td>I helped the researcher in planning or creating the research question.</td>
<td></td>
</tr>
<tr>
<td>I was part of the team that coordinated the participant for the research.</td>
<td></td>
</tr>
<tr>
<td>I was part of the team that interviewed the participants.</td>
<td></td>
</tr>
<tr>
<td>I was part of the team that disseminated (spread) the research result or outcome</td>
<td></td>
</tr>
<tr>
<td><strong>How would you like to participate in a research team?</strong></td>
<td></td>
</tr>
<tr>
<td>Face to face meeting</td>
<td></td>
</tr>
<tr>
<td>A website with a protected chat room</td>
<td></td>
</tr>
<tr>
<td>Listserv or email list</td>
<td></td>
</tr>
<tr>
<td>Individual email</td>
<td></td>
</tr>
<tr>
<td>Phone calls from research staff</td>
<td></td>
</tr>
<tr>
<td>Regular mails</td>
<td></td>
</tr>
<tr>
<td>Video chats on the internet (e.g. Zoom or Skype)</td>
<td></td>
</tr>
<tr>
<td>Variables</td>
<td>N (%)</td>
</tr>
<tr>
<td>-----------</td>
<td>-------</td>
</tr>
<tr>
<td>I am not interested in taking part in any research at all</td>
<td>6 (6.5)</td>
</tr>
<tr>
<td>I was not interested in that particular research</td>
<td>7 (7.5)</td>
</tr>
<tr>
<td>I work so I didn't think I could get the time off work</td>
<td>10 (10.8)</td>
</tr>
<tr>
<td>I was worried about the side effects of the research</td>
<td>10 (10.8)</td>
</tr>
<tr>
<td>I did not trust the motivations of the study sponsor/product manufacturer</td>
<td>7 (7.5)</td>
</tr>
<tr>
<td>It did not offer enough financial compensation for my time and expenses</td>
<td>3 (3.2)</td>
</tr>
<tr>
<td>I felt too unwell to take part</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>My friends or family advised me not to</td>
<td>3 (3.2)</td>
</tr>
<tr>
<td>It was inconvenient for me to travel to the research sites</td>
<td>42 (45.2)</td>
</tr>
<tr>
<td>Not applicable</td>
<td>4 (4.3)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
### Table 4. Interest in Engagement as a Research Team Member/Partner

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes N (%)</th>
<th>No N (%)</th>
<th>Not Sure N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you be interested in helping the research project if you are provided with the opportunity to:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Write or rank the importance of potential research questions?</td>
<td>59 (57.8)</td>
<td>43 (42.2)</td>
<td></td>
</tr>
<tr>
<td>Plan the research process?</td>
<td>11 (10.8)</td>
<td>39 (38.2)</td>
<td>52 (51.0)</td>
</tr>
<tr>
<td>Pick study outcomes?</td>
<td>57 (57.0)</td>
<td>43 (42.2)</td>
<td></td>
</tr>
<tr>
<td>Participating in a research team as a knowledge user?</td>
<td>10 (9.8)</td>
<td>45 (44.1)</td>
<td>47 (46.1)</td>
</tr>
<tr>
<td>Share with the researcher the most important things to you they should be doing to ensure that patients' perspectives are considered.</td>
<td>10 (9.8)</td>
<td>46 (45.1)</td>
<td>46 (45.1)</td>
</tr>
<tr>
<td>Apply for a research grant?</td>
<td>7 (6.9)</td>
<td>48 (47.1)</td>
<td>47 (46.1)</td>
</tr>
<tr>
<td>Interpret and spread research results?</td>
<td>8 (7.8)</td>
<td>46 (45.1)</td>
<td>8 (47.1)</td>
</tr>
</tbody>
</table>

### Table 5. Factors Affecting of Patients' Engagement in Research

<table>
<thead>
<tr>
<th>Research Factors</th>
<th>Very Important N (%)</th>
<th>Somewhat Important N (%)</th>
<th>Not very Important N (%)</th>
<th>Not at all Important N (%)</th>
<th>Not sure N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important are the following with respect to your participation in a research study as a study participant?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research team training</td>
<td>62 (55.6)</td>
<td>19 (19.2)</td>
<td>8 (8.1)</td>
<td>4 (4.0)</td>
<td>6 (6.1)</td>
</tr>
<tr>
<td>Compensation for my expenses e.g parking</td>
<td>46 (47.4)</td>
<td>28 (28.9)</td>
<td>12 (12.4)</td>
<td>6 (6.2)</td>
<td>5 (5.2)</td>
</tr>
<tr>
<td>Length of time for research participation</td>
<td>55 (55.6)</td>
<td>31 (31.3)</td>
<td>8 (8.1)</td>
<td>1 (1.0)</td>
<td>4 (4.0)</td>
</tr>
<tr>
<td>Researcher' attitude toward you</td>
<td>64 (66.0)</td>
<td>22 (22.7)</td>
<td>5 (5.2)</td>
<td>3 (2.0)</td>
<td>4 (4.1)</td>
</tr>
<tr>
<td>Meeting my expectations of the research</td>
<td>53 (54.1)</td>
<td>33 (33.7)</td>
<td>6 (6.1)</td>
<td>1 (1.0)</td>
<td>5 (5.1)</td>
</tr>
<tr>
<td>Compensation for my time</td>
<td>40 (41.2)</td>
<td>32 (33.0)</td>
<td>11 (11.3)</td>
<td>7 (7.2)</td>
<td>7 (7.2)</td>
</tr>
<tr>
<td>How important the research question is to my health condition?</td>
<td>55 (56.1)</td>
<td>27 (27.6)</td>
<td>9 (9.2)</td>
<td>2 (2.0)</td>
<td>5 (5.1)</td>
</tr>
<tr>
<td>My perception that the research will make a difference.</td>
<td>63 (64.9)</td>
<td>21 (21.6)</td>
<td>7 (7.2)</td>
<td>1 (1.0)</td>
<td>5 (5.2)</td>
</tr>
<tr>
<td>The length of follow-up time</td>
<td>45 (45.9)</td>
<td>40 (40.8)</td>
<td>7 (7.1)</td>
<td>2 (2.0)</td>
<td>4 (4.1)</td>
</tr>
<tr>
<td>The amount of time each visit takes.</td>
<td>44 (45.8)</td>
<td>36 (37.5)</td>
<td>10 (10.4)</td>
<td>2 (2.1)</td>
<td>4 (4.2)</td>
</tr>
<tr>
<td>My relationship with the healthcare team</td>
<td>40 (42.1)</td>
<td>37 (38.9)</td>
<td>11 (11.6)</td>
<td>2 (2.1)</td>
<td>5 (5.3)</td>
</tr>
<tr>
<td>How important are the following factors in your decision on taking on a role in research?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training provided for the role in research team.</td>
<td>61 (59.8)</td>
<td>25 (24.5)</td>
<td>7 (6.9)</td>
<td>4 (3.9)</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>My prior experience with research</td>
<td>42 (41.2)</td>
<td>33 (32.4)</td>
<td>17 (16.7)</td>
<td>5 (4.9)</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>My relationship with the healthcare team</td>
<td>53 (52.0)</td>
<td>31 (30.4)</td>
<td>11 (10.8)</td>
<td>2 (2.0)</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>The time that it would take to complete the study.</td>
<td>51 (50.0)</td>
<td>31 (30.4)</td>
<td>14 (13.7)</td>
<td>1 (1.0)</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>The time that each meeting would take.</td>
<td>62 (60.8)</td>
<td>26 (25.5)</td>
<td>9 (8.8)</td>
<td>2 (2.0)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>The amount of travel I would have to do to participate.</td>
<td>60 (58.8)</td>
<td>29 (28.4)</td>
<td>9 (8.8)</td>
<td>1 (1.0)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>My belief that the team would really listen to my ideas and I could influence the research project.</td>
<td>66 (64.7)</td>
<td>25 (24.5)</td>
<td>6 (5.9)</td>
<td>2 (2.0)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>Relevance of the research question to my health problems</td>
<td>56 (54.9)</td>
<td>28 (27.5)</td>
<td>10 (9.8)</td>
<td>2 (2.0)</td>
<td>6 (5.9)</td>
</tr>
<tr>
<td>The importance of the research question to help others.</td>
<td>53 (52.0)</td>
<td>26 (25.5)</td>
<td>17 (16.7)</td>
<td>1 (1.0)</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>The involvement of other patients</td>
<td>65 (63.7)</td>
<td>23 (22.5)</td>
<td>8 (7.8)</td>
<td>1 (1.0)</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>Compensation for my time/ knowledge</td>
<td>49 (48.0)</td>
<td>30 (29.4)</td>
<td>15 (14.7)</td>
<td>4 (3.9)</td>
<td>4 (3.9)</td>
</tr>
<tr>
<td>Compensation for my costs of participating</td>
<td>50 (49.0)</td>
<td>35 (34.3)</td>
<td>11 (10.8)</td>
<td>2 (2.0)</td>
<td>4 (3.9)</td>
</tr>
<tr>
<td>Authorship on publications or grants</td>
<td>33 (32.4)</td>
<td>28 (27.5)</td>
<td>24 (23.5)</td>
<td>9 (8.8)</td>
<td>8 (7.8)</td>
</tr>
</tbody>
</table>
Recognition in acknowledgement on publications or grants
Authorship when the research is presented.
Recognition in acknowledgement when the research is presented.
Members of the research team recognized the importance of my contributions during the conduct of the work.

How important would the following factors be in your consideration to join a new study?

<table>
<thead>
<tr>
<th>Factor</th>
<th>Strongly Agree N (%)</th>
<th>Agree N (%)</th>
<th>Disagree N (%)</th>
<th>Strongly Disagree N (%)</th>
<th>Not sure N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The potential negative impact the research on my health</td>
<td>72 (70.6)</td>
<td>16 (15.7)</td>
<td>8 (7.8)</td>
<td>3 (2.9)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>Keeping my current doctor during the research</td>
<td>50 (49.0)</td>
<td>29 (28.4)</td>
<td>17 (16.7)</td>
<td>3 (2.9)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>The friendliness of the clinicians and researchers</td>
<td>61 (59.8)</td>
<td>30 (29.4)</td>
<td>8 (7.8)</td>
<td>1 (1.0)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Being given the results of my research after my participation</td>
<td>63 (61.8)</td>
<td>30 (29.4)</td>
<td>7 (6.9)</td>
<td>2 (2.0)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Reputation of people or the institution conducting the research</td>
<td>73 (71.6)</td>
<td>17 (16.7)</td>
<td>8 (7.8)</td>
<td>2 (2.0)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Whether my medical bills is covered in an injury from the study</td>
<td>71 (68.6)</td>
<td>22 (21.6)</td>
<td>6 (5.9)</td>
<td>2 (2.0)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>An opportunity to possibly improve my own health</td>
<td>77 (75.5)</td>
<td>16 (15.7)</td>
<td>7 (6.9)</td>
<td>2 (2.0)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>Privacy and confidentiality issues</td>
<td>74 (72.5)</td>
<td>22 (21.6)</td>
<td>3 (2.9)</td>
<td>1 (1.0)</td>
<td>2 (2.0)</td>
</tr>
<tr>
<td>The opportunity to improve the health of others</td>
<td>52 (51.0)</td>
<td>29 (28.4)</td>
<td>15 (14.7)</td>
<td>2 (2.0)</td>
<td>4 (3.9)</td>
</tr>
</tbody>
</table>

Table 6. Participants’ Attitude to Research Engagement

Consider each statement below and rate how strongly you agree or disagree.
I am interested in learning more about taking part in research.
I would like to take part in research in the next 12 months.
It would be easier if I could go to a website and find studies that were a good match for me.
In the future, I would be interested in helping researchers to design better research by answering questions about the design of their research studies.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree N (%)</th>
<th>Agree N (%)</th>
<th>Disagree N (%)</th>
<th>Strongly Disagree N (%)</th>
<th>Not sure N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am interested in learning more about taking part in research.</td>
<td>39 (38.2)</td>
<td>44 (43.1)</td>
<td>11 (10.8)</td>
<td>1 (1.0)</td>
<td>7 (6.9)</td>
</tr>
<tr>
<td>I would like to take part in research in the next 12 months.</td>
<td>15 (14.7)</td>
<td>50 (49.0)</td>
<td>13 (12.7)</td>
<td>5 (4.9)</td>
<td>19 (18.6)</td>
</tr>
<tr>
<td>It would be easier if I could go to a website and find studies that were a good match for me.</td>
<td>37 (36.3)</td>
<td>41 (40.2)</td>
<td>15 (14.7)</td>
<td>2 (2.0)</td>
<td>7 (6.9)</td>
</tr>
<tr>
<td>In the future, I would be interested in helping researchers to design better research by answering questions about the design of their research studies.</td>
<td>32 (31.4)</td>
<td>50 (49.0)</td>
<td>7 (6.9)</td>
<td>4 (3.9)</td>
<td>9 (8.8)</td>
</tr>
</tbody>
</table>
Figure 1. Research Awareness

- Did you ever consider withdrawing your consent, dropping out, or leaving the study early?
- Has a member of the health care team ever talked to you about a health research study?

Figure 2. Likelihood to Participate in Research

If your doctor or other health care professional informs you of a health research study, how likely would you be to participate?

- Very likely: 38.00%
- Somewhat likely: 50.00%
- Not likely: 7%
- Not sure: 5%

55
Figure 3. Interest in Engagement as a Research Team Member
CHAPTER 3

Patient Expectations for Outcomes of Upper Extremity Total Joint Arthroplasty: A Systematic Review

ABSTRACT: Joint arthroplasty leads to a dramatic improvement in outcomes of pain, function, and satisfaction for many patients. Patient expectations have been increasingly linked to these treatment outcomes, with positive expectations being associated with better outcomes and greater patient satisfaction. However, the majority of the literature focuses on lower, not upper, limb extremities. The purpose of this study is to identify and summarize studies that determine the extent to which preoperative expectations are predictive of postoperative outcomes in patients undergoing any arthroplasty of joints in the upper extremities. A comprehensive systematic online literature search was performed in Embase, Medline, CINAHL, PsycINFO, Cochrane Library, and Web of Science. Articles addressing joint arthroplasty in the upper extremities that measured preoperative expectations affecting postoperative treatment outcomes (pain, function, and satisfaction), as well as their relationships, were included, with a result of eight studies reviewed. The methodological quality of the included articles ranged from 53%–89%. Studies differed substantially in definitions and measurements of patient expectations. Only two reported a correlation analysis between patient expectations and outcomes. SF-12 function ($p = 0.01$), VAS pain ($p = 0.05$), and ASES function ($p = 0.05$) showed significant correlations with preoperative patient expectations. Findings show that research on upper limb arthroplasty is limited, unlike lower limb results. Future studies should focus on using preoperative patient education to modify expectations and on creating a framework to standardize patient expectations for arthroplasty of upper limb extremities.
KEYWORDS: preoperative patient expectations, postoperative outcomes, total shoulder arthroplasty

INTRODUCTION

Thousands of patients undergo total joint arthroplasty surgery yearly, yet do not experience the same level of recovery that lower limb arthroplasty patients experience. In a total joint replacement, the damaged parts of the joint (shoulder, elbow, or finger) are removed and replaced with artificial components. This procedure allows the restoration of function at the replaced joint, leading to a dramatic improvement in outcomes for pain, function, and satisfaction for many patients, becoming an effective procedure for managing various chronic disorders like osteoarthritis. Nevertheless, there is a proportion of patients with unsuccessful outcomes and low satisfaction despite imaging showing no abnormalities after surgery.

Numerous studies have demonstrated that when preoperative patient expectations are in line with postoperative outcomes, patient satisfaction with surgery improves. Therefore, there has been a shift in understanding patient expectations as an integral part of assessing surgical outcomes. Patient expectations are subjective estimates of the likelihood that behaviour will influence outcome.

When defining preoperative expectations, outcome expectations, process expectations, and self-efficacy expectations from Bandura’s self-efficacy theory are often used. Outcome expectations are subjective estimates of how likely it is that a specific behaviour will be
followed by particular consequences; process expectations are beliefs about the content and process of interventions, and self-efficacy expectations are individual beliefs in the capacity to execute behaviours to produce specific performance. Understanding patient expectations of what constitutes successful treatment and the factors that influence those expectations can facilitate shared decision-making\(^3,\,8\) and guide patients in deriving realistic expectations for recovery.\(^9\) However, the majority of patient expectation research has been focused on lower limb extremities,\(^10,\,11\) leaving limited research focus on upper limb extremities.\(^5,\,10\)–\(^14\)

In assessing patient expectations for lower limb joint replacement, Haanstra et al.’s\(^3\) systematic review reported that self-efficacy and outcome expectations of pain and function favour an actual relationship. Additionally, a study by Berliner et al.\(^6\) assessed patients undergoing knee and hip arthroplasty and showed that, despite the effectiveness of the procedure, some patients with lower preoperative mental and emotional health still experienced chronic pain and postoperative dissatisfaction. This resulted in high medical costs and low quality of life for those patients.\(^6,\,15\) While prior systematic reviews evaluating the relationships between outcomes and joint arthroplasty have focused on the lower extremities, we cannot necessarily generalize these findings to the upper limb. There are substantial functional differences between joint structure and function in the upper and lower extremities, with the lower extremities more weight-bearing and the upper extremities more often moving objects in space. This might limit generalizability across these different subgroups of joint arthroplasty.

Therefore, the purpose of this systematic review was to identify studies that evaluate relationships between expectations and the outcomes in patients undergoing upper extremity arthroplasty. In this review, we focus on the outcome, process, and self-efficacy expectations, mirroring Haanstra et al.\(^3\) The objective is to identify and synthesize evidence that determines
the extent to which these expectations are predictive of postoperative outcomes (pain, function, and satisfaction) in patients undergoing total shoulder, elbow, or radial head replacement and metacarpophalangeal (MCP) joint arthroplasty. We closely compare Haanstra et al.’s outcomes for lower extremities with our outcomes for upper extremities—hence, our choice of this adapted tool for our systematic review in order to make justifiable conclusions.

MATERIALS AND METHODS

Eligibility

The inclusion criteria for this systematic review were:

- Design: cohort or randomized control trials
- Participants: > 50% of the study’s patient population had total joint arthroplasty of an upper extremity
- Intervention: measured preoperative expectations for postoperative outcomes and their relationship with postoperative outcomes
- Outcomes: one or more of pain, function, and satisfaction

In accordance with review guidelines, our protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on April 8, 2017 (CRD42017062318).

Strategy

Articles from Embase, Medline, CINAHL, PsycINFO, Cochrane Library, and Web of Science were searched from the earliest record to March 2019. Search items included “Patient* preoperative expectation*,” “Total arthroplasty*,” and “Upper extremity*
(shoulder, elbow, wrist, hand, upper limb, proximal interphalangeal, radiocarpal, carpometacarpal, metacarpophalangeal).” Furthermore, we identified additional studies by examining the initially selected studies’ reference lists.

**Study Selection**

Two authors independently performed electronic searches and screened articles by title and abstract for inclusion. They also screened full-text reviews independently to assess the final eligible articles. One senior author was available to mediate any conflicts through discussion.

**Assessment of Quality**

The methodological quality of each study was evaluated using Hayden et al.’s methodological assessment instrument as adapted by Haanstra et al. (see Appendix 1). The instrument’s 19 quality assessment questions were answered using “yes,” “no,” or “?.” A “yes” signified that the criterion was met; a “no” signified that the criterion was not met, and a “?” meant that it was not clear if the criterion was met. A total score for each study was derived by dividing all positives by the number of items in the study that were relevant.

**Data Synthesis and Analysis**

We had planned a meta-analysis for each of the included studies. However, it was not possible because of the heterogeneity in the studies and the difficulty of statistically pooling the result because the measurement of patient expectations differed across studies.

The $p$-values presented in the original articles were regarded as statistically significant when less than 0.05. In assessing the relationship between preoperative expectation scores and postoperative outcome scores in each study, a table was created to summarize the data. A
“+” signified a positive relationship or correlation, meaning that high expectations related to better outcomes; a “−” signified a negative relationship, meaning that higher expectations related to worse outcomes; an “x” signified no relationship.³

RESULTS

Database searches resulted in 2,083 references. Screening of titles and abstracts produced articles for further assessment of which 8 met the inclusion criteria (Fig. 1). Characteristics of the included studies are shown in Table 1 (only one¹⁴ did not report the percentage of male and female participants). Patient populations for the shoulder were reported in 5 studies¹⁴,¹⁸–²¹; for the hand, in 3.⁹,¹³ Reported locations were the US for ⁷,⁹,¹³,¹⁴,¹⁸–²¹ The reported study design was prospective cohorts in 6 studies⁹,¹³,¹⁴,¹⁸,²⁰,²² and retrospective cohorts in 2.¹⁹,²¹

Relationship between Patient Expectations and Treatment Outcomes

Table 2 summarizes the various preoperative expectations for the outcomes of satisfaction, pain, and function. Expectations were further broken down as outcome, reported by six studies, and self-efficacy, reported by three studies. The timing of measurement was reported as a baseline for preoperative expectations and usually at two to three years for postoperative outcomes; one study reported measuring outcomes at six months. No explanations were provided for the chosen timelines. All studies used validated measurement instruments for expectations,²³,²⁴ function,¹⁹,²¹,²⁵–²⁹ pain,²⁵,²⁶,²⁸,²⁹ and satisfaction.²⁵,²⁶ The expectations and outcome questionnaires used in two⁹,²² studies had not been previously validated.
Regarding MCP joint replacement, no study reported the outcome of satisfaction pre- or postoperatively. Bogoch et al.\textsuperscript{22} reported total postoperative but not preoperative satisfaction with the procedure. Patients who preoperatively reported high expectations regarding pain and function experienced better postoperative outcomes. Sears et al.\textsuperscript{13} reported moderate preoperative expectations for pain, which resulted in moderate pain improvement postoperatively. In all three studies of MCP joint replacements, hand appearance was one of the top three preoperative expectations.

Five studies reported that patients who had undergone shoulder joint replacement did not assess satisfaction as a primary outcome. However, they reported that shoulder patients had higher expectations for function, pain, activity levels, and general health prior to surgery. Those who had moderate to high expectations for preoperative function and pain reported higher function and reduced pain postoperatively. A reduction in pain was one of the top outcomes that motivated patients to have shoulder joint replacement surgery; this included relief from pain both day and night. These expectations differed between genders, as males expressed higher expectations for functional outcomes; females, for pain.

Methodological Quality Assessment

Table 3 summarizes the quality assessments for each study. Methodological quality assessment scores were between 53\%\textsuperscript{14} and 89\%,\textsuperscript{18,22} with an average score of 75\%. Three studies\textsuperscript{9,14,18} reported indeterminate findings.

Correlation of Preoperative Expectations with Postoperative Outcomes

Table 4 summarizes reported associations between patient expectations and treatment outcomes in the two\textsuperscript{14,19} studies that included correlation analysis of preoperative patient
expectations and postoperative outcomes. Rauck et al.\textsuperscript{19} reported significance between the SF-12 subscale of physical function ($p = 0.01$) when measuring preoperative patient expectations. Multivariate analysis showed no association between the total number of “very important” expectations and two-year ASES, SAS, or VAS scores. However, higher expectations for relieving nighttime pain were associated with better ASES ($\beta = 7.0, p = 0.048$) and VAS pain ($\beta = -5.9, p = 0.04$) scores. According to Swarup et al.,\textsuperscript{14} ASES scores ($p = 0.02$) were significant in understanding preoperative patient expectations for functional outcomes. Shoulder pain, physical function, and general health were not significant pre- to postoperatively.

**DISCUSSION**

Eight studies that identified the relationship between expectations and outcomes in patients undergoing upper limb joint arthroplasty were reviewed. We found evidence of some significant positive associations between outcome expectations and actual outcomes. As hypothesized, upper and lower limb expectations could not be compared because of anatomical differences. These findings were consistent with those of Haanstra et al.,\textsuperscript{3} indicating a lack of consistency in associations of preoperative expectations and treatment outcomes. For more accurate research synthesis, future studies should establish a theoretical framework for definitions, consensus measurement instruments, and classification of patient expectations to inform clinicians and policymakers who desire to integrate patient’s reported outcomes into surgical quality.

We identified preoperative expectations as falling into three categories: outcome, self-efficacy, and process. The majority of the reviewed studies assessed outcome and self-efficacy, but none assessed process. Process outcomes are defined as beliefs about
interventions. Understanding patient beliefs about surgery and rehabilitation will help clinicians tailor treatments for better recovery. Glattaker et al.,\textsuperscript{30} in a study on patient beliefs about lower back pain intervention and medication use, introduced a feedback form for patients to report their beliefs before and after the intervention. Results showed that satisfaction moderately increased in those who filled out the feedback form compared to those who did not. Another study, investigating return to work after total knee arthroplasty, reported that more positive patient beliefs were associated with higher functional outcomes, highlighting the need to study process expectations.\textsuperscript{31} Process expectations were not reported by Haanstra et al.,\textsuperscript{3} indicating a lack of evaluation of process outcomes of joint arthroplasty. Future studies should incorporate measures of process expectations when assessing patient expectations, as this has shown to be successful in improving treatment outcomes.

We assessed postoperative outcomes of function, pain, and satisfaction; however, only one study reported satisfaction, and only postoperatively. Patient satisfaction continues to show varying levels of evidence when understanding preoperative expectations in upper extremity surgeries. There continues to be uncertainty when defining “patient, injury, and treatment-specific factors” that influence outcomes of satisfaction.\textsuperscript{32,33} One of the biggest challenges when measuring satisfaction stems from response shift—that is, the shift in a patient’s subjective measurement of symptoms, which is fluid over time. Response shift can confound patient-reported outcomes measuring satisfaction because patients may have, in retrospect, felt worse preoperatively than they actually did.\textsuperscript{32,33} Therefore, there is a need to create PROs that can better predict satisfaction or use qualitative methods to address this issue. Qualitative research can better illuminate the unique perspective patients may have on their own satisfaction, and how that perspective can shift. Researchers need to improve methods to capture satisfaction before and after joint arthroplasty surgery.
Because the upper extremities incorporate a variety of joint surgical procedures, we decided to classify our studies by shoulder joint or MCP replacement to better appreciate how preoperative expectations vary between the two procedures. Results indicate that patients having undergone MCP replacement had high preoperative expectations for postoperative appearance, while those undergoing shoulder joint replacement had higher preoperative expectations for postoperative function. Hand appearance is subjective and so can be difficult to quantify, but it is consistently a high motivator for surgery. While hand aesthetics is not a frequently discussed topic, there is evidence that some patients link satisfaction to a successful aesthetic outcome. MCP replacement mustn't be cosmetic surgery but rather a procedure to restore function, reduce pain, and correct deformity, which can result in a more normal appearance. To understand why the top preoperative expectation for shoulder replacement surgery is a function, we must understand patient demographics. A younger cohort indicated that a desire for physical activity and participation in sport leads to function as the motivator for surgery. In general, female participants tend to perform more overhead lifting and repetitive tasks in their occupations, meaning that shoulder function is the motivator. Conversely, as reported by Jawa et al.,\textsuperscript{20} sometimes men have higher expectations for shoulder function. In either case, it is important for clinicians to understand the demographics of their patients and match both their own expectations and those of their patients to achieve improved postoperative outcomes.

Additionally, our review indicates a gap in the literature when assessing self-efficacy and outcome expectations for postoperative outcomes in upper limb arthroplasty. Only two studies used correlation analysis to measure the relationship between outcome expectations and actual outcomes, and the associations were not promising. One reason for this is that our primary studies rated average methodological scores, meaning that their results should be
interpreted with caution. In Haanstra et al.’s tool, which we used, final scores were summed from all items positively scored. However, this assumed that all items were weighted the same, which is not always true. For example, some studies scored high in describing their intervention, and although this is essential, it does not necessarily indicate that the intervention employed was valid or appropriate for measuring patient expectations. For this reason, researchers and clinicians should be cautious when interpreting the findings of primary studies.

As aforementioned, patient and surgeon expectations need to match in order to have a successful surgery. However, we saw that patient literacy and education regarding joint arthroplasty surgery were very low, which creates a huge challenge. Patients who are not knowledgeable about their surgery will not understand the importance of explaining their expectations to their surgeon. Further, as shown in lower limb arthroplasty studies, patient expectations are linked to patient knowledge, which results in the possibility of modifying patients’ preoperative expectations through education. Future research is warranted to fill this gap and understand how modifying preoperative education can lead to more realistic expectations in upper limb arthroplasty.

Lastly, when comparing our results to those of Haanstra et al. for lower extremity arthroplasty, we found them to be in agreement that there is no consistency in the association between patient expectations and treatment outcomes. This streams from the inconsistencies in definitions and terminology used to classify patient expectations. Patient expectations are a multifaceted and complex construct that has not been strictly defined for either lower or upper limb arthroplasty. Therefore, as Haanstra et al. pointed out, a framework for both lower and upper limb expectations is needed to create uniformity. As previously mentioned, upper and lower limb surgeries vary due to anatomy and patient expectations. Haanstra et al.
reported expectations of overall improvement and stiffness as highly common, while our review indicates that function is the most common patient expectation measured and reported. To better inform clinicians, then, separate frameworks should be created for each population. This would also better inform patient counselling and shared decision and policy making in integrating patient-reported outcomes into surgical quality.\textsuperscript{8}

While we reviewed many primary studies for inclusion in this study to understand associations between patients’ treatment expectations, some limitations existed. First, we discovered that studies that included patient expectations as one variable among others made it difficult to narrow our choices by just title and abstract. Therefore, we screened the methods and results of some previously excluded articles if they discussed patient expectations. We also adjusted the search strategy and did multiple searches of the databases in an effort not to miss any article. Second, it was not possible to conduct a meta-analysis of the given primary studies due to heterogeneity. A meta-analysis could have given us more precise results and better helped us to understand the strength of the association between expectations and outcomes.

In conclusion, this study improves understanding of the impact of preoperative expectations on outcomes of arthroplasty of the upper limbs. Some significant associations between preoperative expectations and postoperative outcomes for total shoulder arthroplasty exist, but the evidence is limited. Future studies should focus on preoperative patient education to modify expectations and on the creation of a framework to standardize patient expectations for upper limb extremity arthroscopy.
ACKNOWLEDGMENTS

Joy MacDermid was supported by a CIHR Chair in Gender Work and Health and the Dr. James Roth Chair in Knowledge Translation in Musculoskeletal Measurement.
REFERENCES


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<td>Timing of preoperative Expectations</td>
<td>Timing of outcome Measures (years of follow-up)</td>
<td>Relationship of Preoperative Expectations with Outcomes (satisfaction)</td>
<td>Relationship of Preoperative Expectations with Outcomes (pain)</td>
<td>Relationship of Preoperative Expectations with Outcomes (function)</td>
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<td>- Extension, arc of motion, - Ulnar deviation - MIQ Function &amp; ADL - SHC</td>
<td>Prior to surgery</td>
<td>1 year</td>
<td>Not reported</td>
<td>66% of patients had high levels of expectations at preop. 42% of patients reported an improvement in pain postop</td>
<td>93% of patients had high expectations and 60% reported improved function postop after 1 year</td>
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<td>Outcome expectations</td>
<td>- Wrist, - Pain - Activities - Appearance</td>
<td>- Questionnaire</td>
<td>Prior to surgery</td>
<td>3 years</td>
<td>Not reported</td>
<td>73% of patients had high levels of expectations and 65% of patients reported an improvement in pain postop</td>
<td>Not reported</td>
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<td>Jawa et al. (2016)</td>
<td>Self-Efficacy expectations</td>
<td>- Function - Pain - Physical - Mental - Outcome Expectations</td>
<td>- ASES Pain - VAS Pain - SF-12</td>
<td>Prior to surgery</td>
<td>3 years</td>
<td>Not reported</td>
<td>Men (6.4) had lower preop expectations than Women (7.3). Preop outcomes were the same for both genders (1.0)</td>
<td>Men (35.3) had higher preop expectations than Women (30.4). Preop outcomes were high for both genders (87-85)</td>
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<td>Self-Efficacy expectations</td>
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<td>- ASES - VAS Pain - SF-12 Physical - SF-12 Mental</td>
<td>Prior to surgery</td>
<td>3 years</td>
<td>Not reported</td>
<td>Patients had a moderate level of expectations preop. (50%) But reported high levels of reduced pain postop</td>
<td>Patients had lower levels of function expectations preoperatively but reported higher levels of function postop</td>
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Table 2. Preoperative expectations and the relationship with the outcomes of satisfaction, pain and function. n = 8 studies
<table>
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<th>Study</th>
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<td>Function, Pain, Health, Activity level, Satisfaction</td>
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<td>No relationship towards preoperative expectations and satisfaction (p&gt;0.05)</td>
<td>High levels of expectation postop (p=0.001)</td>
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MHQ = Michigan Hand Outcomes Questionnaire, HSSSES = Hospital for Special Surgery’s Shoulder Surgery Expectations Survey, VAS = Visual Analogue Scale, SF-36 = 36 Item Short-Form, ASES = American Shoulder and Elbow Surgeons questionnaire, SF-12 = 12-Item Short-Form Health Survey, PSS = Penn Shoulder Score, SAS = Shoulder Activity Scale, SHC = Sollerman hand function, AIMS = Arthritis Impact Measurement Scale, CMCA = Carpometacarpal joint Arthroplasty, PSEF = Patient Shoulder Expectancy Fulfillment, PSOE = Patient Shoulder Outcome Expectancies
Table 3. Scores of the methodological quality of included studies. n = 8 studies

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Hayden et al. adapted by Haanstra et al. were: ‘+’ sufficient; ‘−’ insufficient; ‘?’ indeterminate
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<td>36.5</td>
<td>75.7</td>
<td>-39 (-0.4)</td>
<td>0.04</td>
<td>0.88</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SF-36 Physical Function</td>
<td>55.8</td>
<td>51.5</td>
<td>4.3 (-1.5)</td>
<td>0.74</td>
<td>0.014</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SF-36 Mental Health</td>
<td>70.9</td>
<td>76.5</td>
<td>-5.6 (3.7)</td>
<td>0.40</td>
<td>0.25</td>
</tr>
<tr>
<td></td>
<td></td>
<td>VAS Pain</td>
<td>62.9</td>
<td>7.6</td>
<td>55.3 (12.3)</td>
<td>-0.03</td>
<td>0.75</td>
</tr>
<tr>
<td></td>
<td></td>
<td>VAS Fatigue</td>
<td>44.5</td>
<td>12.6</td>
<td>31.9 (9.3)</td>
<td>0.04</td>
<td>0.69</td>
</tr>
<tr>
<td></td>
<td></td>
<td>VAS General Health</td>
<td>43.9</td>
<td>15.9</td>
<td>28 (3)</td>
<td>0.08</td>
<td>0.36</td>
</tr>
<tr>
<td>Swarup et al. (2017)</td>
<td>53</td>
<td>SF-36 Physical function</td>
<td>62.9 (21.6)</td>
<td>66.3 (27.3)</td>
<td>3.4</td>
<td>0.13</td>
<td>0.34</td>
</tr>
<tr>
<td></td>
<td></td>
<td>VAS Shoulder pain</td>
<td>72.0 (16.6)</td>
<td>13.2 (20.0)</td>
<td>58.8</td>
<td>-0.22</td>
<td>0.09</td>
</tr>
<tr>
<td></td>
<td></td>
<td>VAS General health</td>
<td>72.8 (16.2)</td>
<td>71.0 (18.3)</td>
<td>1.8</td>
<td>-0.011</td>
<td>0.94</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ASES Score</td>
<td>37.9 (13.9)</td>
<td>78.8 (19.6)</td>
<td>40.9</td>
<td>0.43</td>
<td>0.02</td>
</tr>
</tbody>
</table>
Figure 4: Flow diagram of the literature search
CHAPTER 4

General Discussion and Conclusion

Overview of this dissertation

The purposes of this thesis were to better understand patient engagement in musculoskeletal research and how patient expectations influence outcomes of upper extremity arthroplasty.

The patient engagement survey addressed patients’ preferences, perceptions, barriers and facilitators. Several factors may affect the patients’ engagement in research. The first study was a survey that aimed at understanding patients’ expectations, preferences, barriers, facilitators to engagement in musculoskeletal research. An important finding was that half of the people that participants have never been spoken to nor participated in any health research and the majority of those who had participated in health research participated as subjects in the research. Only a few (10.8%) have ever been involved in the research engagement continuum as team members. This finding was very important because it highlights that there is a major gap in the implementation of patient engagement in the research. Several other barriers were identified in the study such as cost of transportation to the research site, length of time for research participation, and patients’ concerns about the potential effect of research on their health. The participants also expressed their preferences and some factors that could facilitate their engagement in research. Some of these factors included; the perception that the research will make a difference in their health and in the community, meeting the patients’ expectation of the research, compensation for patients’ time/knowledge and the researchers’ attitude towards patients. Other factions included: Patients’ concerns on privacy and confidentiality issues and concerns that research will actually listen to their ideas and opinions on the research.
In the second study, we conducted a systematic review of patients’ expectations on the outcomes of upper extremity total arthroplasty. This was an important systematic review of literature as we explored how patients’ preferences, expectations or beliefs on arthroplasty motivated them in engaging in the procedure. The literature search was done with a search strategy designed to enable us to conduct an evidence synthesis of all the available studies on upper extremity total arthroplasty for people with rheumatoid arthritis and osteoarthritis of the hand. We identified and synthesized evidence that determines the extent to which these expectations are predictive of postoperative outcomes (pain, function, and satisfaction) in patients undergoing total shoulder, elbow, or radial head replacement and metacarpophalangeal (MCP) joint arthroplasty. We closely compared Haanstra et al., (2012)’s outcomes for lower extremities with our outcomes for upper extremities. We found in the study some significant associations between patients’ preoperative expectations and postoperative outcomes for total shoulder arthroplasty but the evidence was limited. We were, however, unable to conduct a meta-analysis of the given primary studies due to the heterogeneity of the studies.

Clinical and Research Implications

In our first study, we found some factors acted either as barriers or facilitators to patients’ engagement in research. It becomes inevitable that future research should be flexible and adapted to reduces these barriers and to increase patient engagement in research. Other research factors were also identified that could act as barriers or facilitators to patient engagement in research depending on its availability or non-availability, this included recommendations by healthcare providers. Therefore, education and involvement of
healthcare providers on the importance of patients’ engagement in research would potentially improve outcomes of patients’ engagement in research.

In our systematic review, we found limited certainty evidence that patients’ preoperative preferences/expectation influences and affect their engagement and outcomes in arthroplasty. This important finding will supply the tool clinicians need to help and guide patients in deriving realistic expectations which will result in greater satisfaction in engagement in total arthroplasty. The fact that we could not conduct a meta-analysis justifies the rationale for future studies in this area to get more homogeneous studies from which the effects of such studies could be deduced in a meta-analysis. Future studies should focus on using preoperative patient education to modify expectations and creating a framework to standardize patient expectations for the field of upper limb extremities arthroscopy.

In applying the Health Belief Model in understanding patient’s behaviour in engagement in research and medical procedure such as upper extremity joint arthroplasty, it came clear that patients’ beliefs/self-efficacy expectations, barriers and potential benefits influenced both patients’ engagement in research and in the outcomes of electing to undergo total joint arthroplasty.

**Limitations**

In this dissertation, we conducted 2 studies. Although, we have some interesting findings our work has several limitations that need to be taken into account when interpreting our findings.

Firstly, in our survey, we did not have sufficient participants as anticipated and the majority of our study population were between the ages of 25 and 55 years. Understanding
that musculoskeletal health challenges affect more patients who are 65 years and older, this study has not adequately represented this study population.

Secondly, it was not possible to conduct a meta-analysis of the given primary studies due to heterogeneity. A meta-analysis could have given us more precise results and better helped us to understand the strength of association between patients’ preoperative expectations and postoperative outcomes of upper extremity total arthroplasty.
Appendix 1: Ethics Approval From Western University

Date: 6 October 2020
To: Dr. Joy MacDermid
Project ID: 115096
Study Title: Barriers and facilitators of patient’s engagement in musculoskeletal research
Application Type: HSREB Initial Application
Review Type: Delegated
Meeting Date / Full Board Reporting Date: 20/Oct/2020
Date Approval Issued: 06/Oct/2020
REB Approval Expiry Date: 06/Oct/2021

Dear Dr. Joy MacDermid

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above-mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Document Type</th>
<th>Document Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Plan 2 New Version</td>
<td>Protocol</td>
<td>02/Oct/2020</td>
</tr>
<tr>
<td>Redcap Survey New 3</td>
<td>Online Survey</td>
<td>02/Oct/2020</td>
</tr>
<tr>
<td>Authorization Request to Group Administrators</td>
<td>Recruitment Materials</td>
<td>02/Oct/2020</td>
</tr>
<tr>
<td>Facebook Post 2- Barriers and Facilitators</td>
<td>Email Script</td>
<td>02/Oct/2020</td>
</tr>
<tr>
<td>Request to Healthcare Providers</td>
<td>Email Script</td>
<td>02/Oct/2020</td>
</tr>
<tr>
<td>Appendix D - Letter of Information and Consent New Version 1</td>
<td>Written Consent/Assent</td>
<td>02/Oct/2020</td>
</tr>
</tbody>
</table>

Documents Acknowledged:

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Document Type</th>
<th>Document Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rationale References 2</td>
<td>References</td>
<td>02/Oct/2020</td>
</tr>
</tbody>
</table>

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to
eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Patricia Sargeant, Ethics Officer on behalf of Dr. Philip Jones, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
Appendix 2: Letter of Information and Consent

Project Title: Barriers and Facilitators to Patient Engagement in Musculoskeletal Research

Investigators

Dr. Joy MacDermid, PT Ph.D. (Principal Investigator)
Department of Physical Therapy, Western University

Dr. Trevor Birmingham, PT Ph.D. (Co-investigator)
Department of Physical Therapy, Western University

Dr. David Walton, PT Ph.D. (Co-investigator)
Department of Physical Therapy, Western University

Mr. Kizito Enonbun, MSc. candidate (Co-investigator)
Department of Health Rehabilitation Science, Western University

What is the purpose of this study?
The purpose of this study is to understand patients’ preferences and experiences in participation in research. Your response will help us to gain a better understanding of the factors that enable (facilitators) or hinders (barriers) patients’ participation in health research. This survey can help us understand how we can do a better job of getting people involved in patient-focused research. What we learn from your answers could be useful for the development of future patient engagement research.

Recruitment
Individuals who are aged 18 or over, can speak fluent English and are musculoskeletal rehabilitation or surgical patients.

Study Procedures
Please read through this letter of information. If you are interested in the study and are willing to participate, you will be asked to click on the link below to consent and complete the survey. The survey should take approximately 10 - 15 minutes.

Participation in the Study:
Participating in this study is voluntary. It is a student project. You do not waive any of your legal rights by signing the consent form. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future care. You are only required to complete Questions 2h, 4, 5, 6 and 7 of the survey. If you decide to stop your participation in our study, simply close the browser and do not submit the survey. Since it is an anonymous survey without identifiers, we cannot remove your survey after submission. If you have concerns about the study, you can contact the principal investigator, Dr. Joy MacDermid, or research assistant, Katrina Munro.

What are the benefits of this study?
There are no direct benefits to you associated with your participation in this study. But your study participation will help the researchers to understand how to best involve people in our research
program and the factors that encourage or discourage people from participating in research. When we share the results with others, it may help them do a better job of including patients in research studies.

**Are there any risks or discomfort associated with this study?**
There is a minimal risk of a breach of personal information being revealed. We do the following to prevent this:

1. We do not ask for your name.
2. We do not ask for your date of birth (only age) or any other personal identifiers.
3. No names or emails are ever used in any presentation of the study results.

**How many people are in this study?**
There will be approximately 300 people in this study.

**Is there any compensation if I participate?**
There is no monetary reimbursement for participation in this study.

**Will my results be kept confidential?**
Your results will be held in strict confidence, and no person, other than the study team will have access to it. Upon completion of the survey, participants will be given a unique numerical identifier (Participant ID) that will be entered into the survey. This identifier will be randomly generated and will not include any personally identifying information. The study investigators will keep a master copy of the unique identifier assigned to each participant. This list will be stored in an encrypted file on the St. Joseph Health Care London ON (SJHC) secure G drive in a password-protected computer on the secure hospital network. A summary of this study will be put on our lab website for public viewing; however, this would not identify you in any way. However, direct quotes may be used in the publication and the media, but again no identifiers will be linked to the quotes. Representatives of the University of Western Ontario Health Sciences Research Ethics Board and Lawson Quality Assurance and Education Program may contact you or require access to your study-related records to monitor the conduct of research and to ensure that proper policies and guidelines are being followed. Under Lawson’s data retention policy, the study investigators will retain the study data for 15 years.

**Sharing Findings**
We hope to share the patients’ opinions in presentations and publications. We will also write a readable summary for patients and post them on our website. We can provide you with a card on how to access the website area where the findings will be posted or if you keep this letter, you can look at the website listed below.

**Whom may you contact to find out more about this study?**
You can keep a copy of this letter. If you have questions about taking part in this study, you can directly contact:
Dr. Joy MacDermid, Principal Investigator, can be contacted at
Katrina Munro, Study Research Assistant at
Steve Lu, Study Research Assistant
Website: [https://www.lawsonresearch.ca/hulc/our-research](https://www.lawsonresearch.ca/hulc/our-research)

**If you have any other questions about your rights as a research participant or about the conduct of the study, you may contact:** St Joseph’s Health Care London Patient Relations Consultant at 519-646-6100 ext 64727
Consent to Participate In: Barriers and Facilitators to Patient Engagement in Musculoskeletal Research

Investigators:
Dr. Joy MacDermid, PT Ph.D. (Principal Investigator)
Department of Physical Therapy, Western University

Dr. Trevor Birmingham, PT Ph.D. (Co-investigator)
Department of Physical Therapy, Western University

Dr. David Walton, PT Ph.D. (Co-investigator)
Department of Physical Therapy, Western University

Mr. Kizito Enonbun, MSc. candidate (Co-investigator)
Department of Health Rehabilitation Science, Western University.

I have read the letter of information. All questions have been answered to my satisfaction, and by checking "Yes", I agree to participate in the survey.

□ Yes
□ No
Appendix 3: Survey Questionnaire

Survey of barriers and facilitators of patient’s engagement in musculoskeletal research

By completing this questionnaire, you will be helping us to understand your preferences and experiences in participation in research. Your answers will also help us to identify some of the factors that can/have helped encouraged you or can/have hindered you from being part of the research studies. What we learn from your answers could be useful for the development of future patient engagement research.

1. Research Awareness

   a. Has a member of the health care team ever talked to you about health research?
      - Yes
      - No
      - Not sure

   b. If your doctor or other health care professional informs you of a health research study, how likely would you be to participate in it?
      - Very likely
      - Somewhat likely
      - Not at all likely
      - Not sure

   c. In your lifetime, in how many research studies have you taken part in?
      Please enter numbers only, your best guess is fine ____________

   d. Did you ever consider withdrawing your consent, dropping out, or leaving a research study early?
      - Yes
      - No
      If yes; why?

      

   e. If you did not want to participate in a research study, please check from the list below why?
      - I am not interested in taking part in any research at all
      - I was not interested in that particular research
      - I work so I didn’t think I could get the time off work
      - I was worried about the side effects of the research
      - I did not trust the motivations of the study sponsor/product manufacturer
      - It did not offer enough financial compensation for my time and expenses
      - I felt too unwell to take part
My friends or family advised me not to
It was inconvenient for me to travel to the research sites
Not applicable
Other

*If you checked “Other”, please explain.*

f. If you dropped out of a study, please tell us why you dropped out

- I was no longer interested
- It was taking too much time
- Travel was inconvenient
- It was not worth it to me
- Study procedures were uncomfortable
- I did not like the staff
- I did not like the research question
- I did not like the location of the research
- I did not think my participation would be useful
- I was too ill
- I had other commitments
- Other

*If you checked “Other”, please explain.*

2. Research Participation

**The following questions ask about your experience participating as a study subject.**

In each of the following questions, we will ask you to remember several aspects of the research - your best guess is absolutely fine, or if you don’t remember, please check “can’t remember”

a. When you were asked to be a subject in a study, what did you decide?

*If you have participated in more than one study, please think about the most recent study and check the box.*

- I am currently in a study
- I took part and completed the research
- I took part but withdrew before the end
I wanted to take part but was not eligible
I wanted to take part but it was not possible due to health or any other physical challenges
I declined to take part in the research
Can’t remember
Other

If you checked “Other”, please explain

b. What were the best things about taking part in this research? Check all that applies to you
I felt very important and valued in the research
I learned more about my own health condition
I learnt some new things about research and the topic of research
I felt I was contributing to the health and welfare of other people
Can’t remember
Other

If you checked “Other”, please explain

C. How do you find out about health research?
Check all that apply
Online/internet
Media
Advertisements
Doctor/healthcare provider
Friends/Family
Patient Organization
Not sure
Other

If you checked “Other”, please write your response in the space below
d. How likely would you be to recommend taking part in this specific research to another potential participant or patient?


e. Are there other experiences you would like to share? If so please describe briefly below


f. Overall, how satisfied were you with the research?


g. What role did you take in the research? Please check all that applies to you

☐ I was a subject in the research
☐ I helped the researcher in planning or creating the research question
☐ I was part of the team that coordinated the participant for the research
☐ I was part of the team that interviewed the participants
☐ I was part of the team that disseminated (spread) the research result or outcome

h. Apart from participating as a subject in research, would you be interested in helping with the following?

<table>
<thead>
<tr>
<th>Role</th>
<th>Very Interested</th>
<th>Somewhat Interested</th>
<th>Not very Interested</th>
<th>Not all Interested</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helping to decide on what research questions are important</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Helping with recruitment into the study</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Sharing your experience with the problem</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Acting as a member of the research team throughout the entire project</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Being listed as a team member on a grant</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Helping to write study results for other patients ended</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Helping to present study findings to patients or media
Participating in a research study as a knowledge user helping to implement study findings
Helping to choose important study outcomes

i. How would you like to participate in a research team??
   Check all that applies
   - Face to face meetings
   - A website with a protected chat room
   - Listserv or email list
   - Individual emails
   - Phone calls from research staff
   - Regular mail
   - Video chats on the internet (e.g Zoom or Skype)

3. Research Experience
   How important are the following when making your decision about participation in research study as a subject?

<table>
<thead>
<tr>
<th></th>
<th>Very Important</th>
<th>Somewhat Important</th>
<th>Not very important</th>
<th>Not all important</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Research team training</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b. Compensation for my expenses e.g parking</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c. Length of time for research participation</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>d. The researcher’s attitude toward you</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>e. Meeting my expectations of the research</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>f. Compensation for my time</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>g. How important the research question is to my health condition</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>h. My perception that the research will make a difference</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
i. The length of follow-up time
j. The amount of time each visit takes
k. My relationship with the healthcare team

4. Attitude to Research
We are interested in your attitudes towards taking part in the research. Please consider each statement below and rate how strongly you agree or disagree.

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I am interested in learning more about taking part in research</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>b. I would like to take part in a research trial in the next 12 months</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>c. It would make it easier for me if I could go to a website and find studies that were a good match for me</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>d. In the future, I would be interested in helping researchers to design better research by answering questions about the design of their research studies</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

5. Research interest
Would you be interested in participating in research if you are provided with the opportunity to:

i. Write or rank the importance of potential research questions?
- Yes
- No
- If yes, what supports would you need to do this?

- If no, why would you not be interested?
ii. Help plan the research process (how to recruit participants, test procedures) or research designs?

- Yes
- No
- If yes, what supports would you need to do this?

- If no, why would you not be interested?

iii. Help pick study outcomes?

- Yes
- No
- If yes, what supports would you need to do this?

- If no, why would you not be interested?

iv. Participate in a research team as a knowledge user (who helps the team understand the patient’s perspective and or how to implement the findings when the studies are complete)?

- Yes
- No
- If yes, what supports would you need to do this?
v. Share with the researcher the most important things they should be doing to ensure that patients' perspectives are considered doing to ensure that patients' perspectives are considered?
   - Yes
   - No
   - If yes, what supports would you need to do this?

vi. Apply for research grants?
   - Yes
   - No
   - If yes, what supports would you need to do this?

If no, why would you not be interested?

vii. Interpret and spread research results?
   - Yes
   - No
   - If yes, what supports would you need to do this?
If no, why would you not be interested?

<table>
<thead>
<tr>
<th>6. Research Factors</th>
<th>Very Important</th>
<th>Somewhat Important</th>
<th>Not very important</th>
<th>Not all important</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The training provided for the roles that patients can play on the research team</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>b. My prior experience with research</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>c. My relationship with the healthcare team</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>d. My relationship with the research team</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>e. The amount of time that it would take to complete the study</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>f. The amount of time that each meeting would take</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>g. The amount of travel I would have to do to participate</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>h. My belief that the team would really listen to my ideas and I could influence the research project</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>i. The relevance of the research question to my health problems</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>j. The importance of the research question to help others</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>k. The involvement of other patients (that I would not be the sole patient representative)</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
</tbody>
</table>
b. If you were thinking about joining a new study, how important would the following factors be in your consideration?

<table>
<thead>
<tr>
<th>Factor</th>
<th>Very Important</th>
<th>Somewhat Important</th>
<th>Not very important</th>
<th>Not all important</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. The potential negative impact the research could have on my health</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>b. Keeping my current doctor or other health professionals during the research</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>c. The friendliness of the clinicians and researchers</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>d. Being given the results of my research after my participation had ended</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>e. The reputation of people or the institution conducting the research</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>f. Whether I would have medical bills covered if I had an injury from the study</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>g. An opportunity to possibly improve my own health</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>h. Privacy and confidentiality issues</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>i. The opportunity to improve the health of others</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
<tr>
<td>j. My physician’s recommendation</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
<td>☒</td>
</tr>
</tbody>
</table>
7. Demographics

a. Age ________ years

b. Gender

☐ Man

☐ Woman

☐ Other

☐ Prefer not to answer

c. Educational Background

*Please check the box for the highest level of education you have completed:*

☐ Some high school

☐ High school graduate or diploma

☐ Trade / technical / vocational training

☐ College diploma

☐ Some college or university degree

☐ University Degree

d. Employment

☐ Full-Time

☐ Part-Time

☐ Home Maker

☐ On social assistance

☐ Unemployed

☐ Student

☐ Retired

Thank you for taking the time to participate in this study. If you have any other comments about this survey or your experience with health research, in general, please enter them in the box below otherwise submit complete the study. Thanks again!

If you want to talk to someone about this survey, please contact Kizito Enonbun or contact Dr. Joy MacDermid.
APPENDIX 4. METHODOLOGICAL QUALITY ASSESSMENT TOOL

Study Participation

1. Is the source population adequately described (primarily in terms of indication for the operation)?
2. Is it clear how participants are recruited (consecutive, random, or selective sample)?
3. Are inclusion and exclusion criteria described?
4. Is the chance of selection bias small (is the study population an adequate representation of the source population)?
5. Are at least five out of six key baseline characteristics of the study population reported (gender, age, type of operation, indication for TSA, CMCA baseline pain and function, satisfaction)?

Measurement of Determinant

6. Is there a clear definition or description of the type of expectations measured (outcome, self-efficacy, process)?
7. Is it clear how expectations are measured (questionnaire/interview, number of items, continuous/ordinal/dichotomous)?
8. Does an adequate proportion of the (eligible) study sample have complete data for the expectation measurement (> 80% is adequate)?

Outcome Measurement

9. Is a clear definition of the outcome of interest provided?
10. Is it clear how the outcome is measured (questionnaire/interview/functional assessment, number of items, continuous/ordinal/dichotomous)?

11. Is the response rate for the outcome adequate (> 80% is adequate)?

12. Is it plausible that there is no selective drop-out during follow-up?

13. If data are missing, are they dealt with in the appropriate way?

14. Is the outcome measure blinded for exposure status?

Confounding Measurement and Account

15. Are at least three out of four important categories of confounders measured (patient characteristics, surgery characteristics, baseline disease characteristics, psychosocial characteristics)?

16. Are appropriate methods used to account for confounders in the analyses?

Analysis

17. Is an appropriate statistical method used for the analyses?

18. Are continuous variables (determinant or outcome) not dichotomized in the analyses?

19. Is the number of observations in the final multivariable model at least 10 times the number of independent variables in the analysis?
Curriculum Vitae

Name: Kizito Enonbun

Post-Secondary Education and Degrees:

Western University. London. ON
Health Promotion
2020-2021 MSc In view

Central Michigan University, Mt. Pleasant. MI. U.S.A
Health Service Administration,
2008-2010. MSA

University of Ilorin, Ilorin, Nigeria
Medical Microbiology
2003-2006. MSc.

Ambrose Alli University, Edo State, Nigeria
Microbiology

Publications:


