What Do Patients Want to Know? Determining the Information Needs of Patients Undergoing Lumbar Microdiscectomy

by

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**Background:** No spine-specific educational tool has been developed using input from all relevant stakeholders, including patients.

**Purpose:** The objective of this study was to determine the information needs of lumbar microdiscectomy patients.

**Methods:** Qualitative methods with thematic analysis was used. Focus groups were conducted with: 1) preoperative microdiscectomy patients; 2) postoperative microdiscectomy patients; 3) spine surgeons; 4) spine fellows; 5) orthopaedic surgery residents; 6) anesthesiologists; 7) surgeons’ administrative assistants; and, 8) preoperative assessment team.

**Results:** Major information needs were related to: anesthesia, surgical procedure details and postoperative course. Patients desire information on postoperative course much more than surgeons perceive. Desired attributes of information tools as well as patient factors that influence the extent of information shared by surgeons were determined. Information resources should be given to patients as soon as they are deemed surgical candidates.

**Conclusions:** Microdiscectomy patients desire more information than currently provided to them – in particular postoperative-related information.
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Chapter 1
Introduction

Lumbar disc herniation is a prevalent condition and symptomatic patients present a significant socioeconomic and health burden (Katz, 2006). Spinal surgery in carefully selected patients who have failed conservative treatments can significantly improve quality of life (Katz, 2006; Weinstein et al., 2008). While the main indication for microdiscectomy is relief of leg pain, many patients also have concomitant back pain that can be severe (Hoffman et al., 1993). Unfortunately, while patients are relieved of their leg pain post-surgery, back pain usually does not improve (Hoffman et al., 1993). The false expectation that back pain will improve may result in patients perceiving a poor outcome in their level of pain related function after surgery. It is important to determine if an information resource would better align perceived and realistic expectations. Providing an education resource to patients pre-surgery may result in better self-rated functional outcomes post-surgery, as there is a better alignment of patient’s expectations with realistic anticipated outcomes. Such a resource would provide patients all the relevant information relating to the procedure and aftercare.

Information tools can reinforce the material covered by the surgeon during the consultation and include material not discussed or asked about. The quality of the existing educational tools are difficult to assess due to: 1) lack of adequate reporting of the methods used in their development; 2) lack of comprehensive stakeholder engagement in their development, particularly of the end users – surgeons and patients. Given these limitations to existing information tools, the first step in the development of
an education resource for microdiscectomy patients requires a needs assessment. The purpose of this thesis was therefore to determine the information needs of microdiscectomy patients.
Chapter 2
Literature Review and Thesis Objective

This chapter provides a brief clinical overview of lumbar disc herniation and microdiscectomy, a review of the patient information needs literature and current available resources, and the rationale and the objective of the thesis.

Lumbar Disc Herniation:

Herniated lumbar disc is a displacement of disc material (nucleus pulposus or annulus fibrosis) beyond the intervertebral disc space (Fardon & Milette, 2001). The diagnosis is usually made based on clinical signs and symptoms and can often be confirmed by radiological examination. Magnetic resonance imaging findings of a herniated disc are not always accompanied by clinical symptoms (Boden, 1996; Borenstein et al., 2001). The prevalence of symptomatic herniated lumbar disc is about 1–3% depending on age and sex (Andersson, 1997). The highest prevalence is among people aged 30–50 years with a male to female ratio of 2:1 (Friberg & Hirsch, 1949; Postacchini & Cinotti, 1999). In people aged 25–55 years, about 95% of herniated discs occur in the lower lumbar spine (L4/5 and L5/S1 level) while disc herniation above this level is more common in people aged over 55 years (Jensen et al., 1994; Schultz et al., 1982).

Radiographical evidence of disc herniation does not reliably predict low back pain in the future, or correlate with symptoms given that 19–27% of people without symptoms have disc herniation on imaging (Boden, 1996; Jensen et al., 1994). The natural history of
disc herniation is difficult to determine, but most patients improve clinically such that only about 10% still have sufficient pain after 6 weeks to consider surgery (Postacchini & Cinotti, 1999). Sequential magnetic resonance images have shown that the herniated portion of the disc tends to regress over time, with two thirds of the people showing partial to complete resolution after six months (Deyo & Weinstein 2001).

Surgery is indicated for those patients who have failed conservative treatment and remain symptomatic. Generally, patients have had 12 weeks of conservative care before they are considered for elective microdiscectomy (i.e., non-emergent). The aim of surgery is relief of neuropathic leg pain.

**Elective Outpatient Microdiscectomy: Process, Outcomes and Challenges**

Open microdiscectomy is the benchmark procedure with which percutaneous and other minimally invasive techniques are compared (Mathews & Long, 2002). At our institution it is the most common spine procedure. It utilizes a small incision and an operating microscope or loupe magnification. Open discectomy allows the surgeon to visualize the pathology and neurovascular anatomy. While performing a discectomy, the surgeon, often must gently manipulate the anatomic structures for optimal access to the disk-nerve root compression interface (Mathews & Long, 2002). Successful outcomes (i.e., relief of neuropathic leg pain) for microdiscectomy have been reported to range from 76% to 100% (Mathews & Long, 2002). Other studies demonstrate that the rate and type of complications are similar to those of minimally invasive spine surgery (Mayer & Brock, 1993). The most common complications are neurovascular trauma, discitis, and
cerebrospinal fluid leak (Mayer & Brock, 1993; McCulloch, 1998). With the advent of small incisions, microdiscectomy patients who otherwise have no major medical co-morbidities are discharged from hospital the same day as their procedure.

Typically, surgical candidates are seen in the spine clinic and, in discussion with the surgeon, a decision for surgery is made. The surgeon’s administrative assistant subsequently coordinate the pre-surgical appointments and schedule the operation. Thereafter, patients are seen in the preoperative/preadmission assessment clinic to undergo necessary investigations such as blood work and other tests depending on their medical history. The next interaction with the surgeon is usually immediately prior to surgery in the operative waiting area. Post surgery patients are transferred to the recovery room and once they meet the criteria they are transferred to the day surgery unit. In the day surgery unit their vital signs and pain are monitored as well as their neurologic function. Once they are able to stand up and walk, drink, and have good pain control they are discharged. Patients are asked to schedule a follow-up appointment with their primary care physician for two weeks. The first follow-up appointment with the surgeon is six weeks after surgery. The anesthesiologist initially administers the medications for pain relief immediately after surgery. A prescription for pain medication upon discharge is written by a member of the surgical team.

The primary goal of microdiscectomy is relief of pain, followed by improvement in function and, hence, quality of life (Mathews & Long, 2002). Secondary outcomes include return to work and decreased use of analgesia (Mathews & Long, 2002).
A study by Findley et al. (1998) demonstrated a 91% successful outcome at 6 months following microdiscectomy. At 10-year follow-up, this result declined slightly to an 83% success rate (Findley et al., 1998). Successful outcomes include pain relief, increased mobility and function, and improved quality of life. Hence, lumbar microdiscectomy achieves a high level of initial success, and this positive outcome is maintained at a 10-year follow-up (Findley et al., 1998).

Weinstein and colleagues (2008) published the four-year results for the Spine Patient Outcomes Research Trial (SPORT) on surgical versus nonoperative treatment for lumbar disc herniation. This was a multi-center study (13 spine clinics) that took place across 11 states in the United States. The eligible study participants were patients with lumbar intervertebral disc herniation who had persistent symptoms for at least 6 weeks. These eligible patients were subsequently enrolled into either a prospective, randomized (n=501) cohort or an observational cohort (n=743). The interventions of this study were open discectomy versus nonoperative care. The nonoperative protocol was “usual care”. In the usual care, patients were provided with physical therapy, education on home exercise, and nonsteroidal anti-inflammatory medications. The main outcome measures chosen for this study were changes from baseline in the Short Form-36 (SF-36) Bodily Pain (BP) and Physical Function (PF) subscales and the modified Oswestry Disability Index (ODI - AAOS/Modems version). Patients were assessed and completed the outcome questionnaires at 6 weeks, 3 months, 6 months, and annually thereafter. Based on the intent-to-treat analysis, the data showed no statistically significant difference in the aforementioned outcome measures between surgery and nonoperative care. Although not
statistically significant, the outcome measures did favour surgery. The most important finding of this study was that 41% of the patients randomized to nonoperative care received surgery by 1 year and 45% received surgery by 4 years. Similarly, in the observational cohort, 20% of patients in the nonoperative group had surgery at 1 year and 24% by four years. There was also crossover from the operative group to the nonoperative group. When the authors analyzed the 4-year combined as-treated data, they found the surgical patients demonstrated significantly greater improvements in all of the primary outcome measures. The authors concluded that the intent-to-treat analysis underestimates the true effect of surgery as demonstrated by the as-treated results. Ultimately many of the patients with severe pain from a herniated disc were unwilling to remain in the nonoperative care randomized cohort and as a result, there was a high crossover to the surgical group in this study. The authors expected some crossover and in planning the study, also included a prospective observational cohort in which the patients received the treatment of their choice. This study demonstrated that patient choice is an important consideration in the surgical decision-making process in this population. Research has shown that patient expectations are the main determinant of preference for operative versus nonoperative care among patients with lumbar disc herniation (Lurie et al., 2008). This necessitates that information resources contain explicit information on expected outcomes of both operative and nonoperative treatment. By knowing the predicted expectations, patients can make more informed choices.

With the advent of performing this procedure on an outpatient basis, there are fewer opportunities for patients to access their surgeon. Outpatient procedures decrease the
face-to-face time between patients and surgeons given the same day discharge. This change in practice process may result in less patient and surgeon contact in the immediate postoperative period and as a result patients may not have their information needs met.

**Patient Information Resources:**

Patients forget or misunderstand much of the information that is shared with them in a consultation with a physician (Kenny et al., 1998). One study showed that patients forget more than 50% of what they were told within 5 minutes of leaving the consultation (Kitching, 1990). Another study determined that generally people remember only 20% of what they hear and this may increase to 50% if additional written or visual information is added (Gauld, 1981). In particular, retention of information about postoperative recovery time frames and possible operative complications is poor (Turner & Williams, 2002).

Patients desire more information about their health status (Higgins et al., 2005; Kitching, 1990). Information tools can reinforce what has already been discussed by the physician, provide information on topics not covered during the consultation, and potentially reduce repeat consultation for the same problem. Better communication by written information has been shown to increase patient satisfaction and decrease anxiety (Kitching, 1990). Education can result in a well-informed patient, which has been shown to produce superior clinical outcomes (Kitching, 1990).

Although potentially improving patient outcomes, patient information tools should never be used as a substitute for the discussion that takes place between a patient and their
physician in a consultation or during the informed consent process. Medico-legally, there are three essential components of a valid informed consent: (i) the patient must be competent; (ii) the information provided to the patient must be adequate; and, (iii) the patient’s decision must be voluntary, without influence or coercion from other parties including health professionals or relatives (Evans, 2006). According to the Evans (2006) from the Canadian Medical Protective Association (CMPA), disclosure of information encompasses “an adequate explanation about the nature of the proposed investigation or treatment and its anticipated outcome as well as the significant risks involved and alternatives available. The information must be such as will allow the patient to reach an informed decision. In situations where the patient is not mentally capable, the discussion must take place with the substitute decision maker” (p.7). Most complaints and legal actions are a consequence of inadequate communication between the doctor and the patient (Evans, 2006). The information tool goes above and beyond the scope of the informed consent discussion and is an entirely separate entity.

A variety of media are used for the delivery of patient information. These include face-to-face interaction, pamphlets, audiotapes, telephone, the Internet, and audio-visual media such as videotape, DVD and CD-ROM (Chelf et al., 2001; McPherson et al., 2001; Ziebland et al., 2004). The limited literature on this topic suggests that a face-to-face interaction between health care providers and patients is most often preferred by patients. There is conflicting literature, however, on the next most desired format of an educational resource for patients (Higgins et al., 2005; Matter et al., 2009; Phelan et al., 2001). Higgins et al. (2005) surveyed patients after percutaneous coronary intervention on their
desired format for delivery of information on heart disease. Two thirds of the patients surveyed (n=208) preferred a face-to-face program with written media being the next most desired format. Matter and colleagues (2009) surveyed people with spinal cord injuries and found face-to-face dialogue with a health care provider as their most preferred format for obtaining information. Instead of this preferred format, the people surveyed were primarily using the Internet to obtain information on spinal cord injury. Face-to-face educational programs are not always feasible to offer given the time commitment required from health care providers and the need for additional visits by patients.

There also is conflicting literature on the most effective format of an educational resource for patients (Campbell et al., 2004; Done & Lee, 1998; Gagliano, 1988; Luck et al., 1999; McPherson et al., 2001; Olver et al., 2009; Phelan et al., 2001). The use of an interactive video program may facilitate patient decision-making about treatment of back pain according to a study by Phelan et al. (2001). Phelan and colleagues (2001) conducted a randomized trial in which the authors investigated whether an interactive video program would be superior to written material alone for informing patients about surgical versus non-surgical options for spinal stenosis and disc herniation. The study showed the addition of the video program improved knowledge to a greater extent than written material alone. Study subjects found the combination of video and written material more helpful for preparing them to make a treatment choice. The effectiveness of an interactive education tool was studied by Olver et al. (2009). The authors conducted a randomized controlled trial to evaluate the effectiveness of an interactive CD-ROM
information resource versus written information on cancer patients’ recall of chemotherapy treatment information. The study however found no significant differences between the written format and the CD-ROM format on patient recall of treatment information.

**Development of Patient Education Resources**

Audio-visual materials have been used in a range of patient educational applications such as treatment decision aids (Shepperd et al., 1995; Spunt et al., 1996) and delivery of information regarding cancer screening and treatment options (Ruthman & Ferrans, 2004). Such educational resources have been shown to reduce anxiety and depression among patients prior to chemotherapy (Thomas et al., 2000), reduce anxiety prior to procedures such as colonoscopy (Luck et al., 1999), and enhance recall of information about general anesthesia among surgical patients (Done & Lee, 1998). Several studies have shown a reduction in disability, pain, and other health-related measures after the application of educational intervention in rheumatoid arthritis patients (Nunez et al., 2006). However, some studies have failed to show the benefit of audiovisual information. For example, two studies that evaluated the impact of audiovisual information about radiotherapy showed no improvement in patient distress, knowledge, and self-efficacy (Dunn et al., 2004), or patient worry prior to treatment (Harrison et al., 2001). In view of conflicting results and limited evaluation, a systematic review of preoperative instructions for patients concluded that more research is needed into the role of audiovisual materials (Hodgkinson et al., 2000).
It is possible, however, that the conflicting results that are published on the effect of audiovisual resources on patient outcomes may be due to the inconsistent quality of the audiovisual resources tested. The quality of these educational materials is difficult to assess without adequate reporting of the methods used to develop them. To date, few studies have described the essential elements of the development process such as peer review of the information content (Cull et al., 1998) or the steps taken in the production of an information video (Williams et al., 1998). In addition, few studies provide a comprehensive and methodologically sound account of their development process. Furthermore, of the few studies that describe necessary elements of the development process, none specifically outlines a systematic process for the development of patient educational materials (Carey et al., 2007).

According to Carey et al. (2007) there are four key principles relevant to the development of audiovisual materials, which aim to prepare patients for potentially threatening procedures: (1) stakeholder engagement; (2) provision of carefully formatted information to prepare patients for the medical procedure; (3) use of evidence-based content; and, (4) promotion of patient confidence and adaptive coping.

The engagement of stakeholders is important in the development of an educational resource. The importance of stakeholder engagement was summarized by Carey et al. (2007) as: “consultation with stakeholders throughout the process of development helps ensure that the innovation meets stakeholders’ needs, reflects stakeholders’ values, and provides stakeholders with the experience of the innovation” (p. 419).
Language and style of presentation are influential on uptake of information. Adult learning theory suggests that adults are more likely to be engaged in the learning process if they perceive the information to be relevant (Knowles, 1978). Similarly, people are generally more eager to learn new information if they perceive that it will help them cope better with important real-life tribulations (Carey et al., 2007). Patient satisfaction with written information is enhanced when material is presented in simple language (Butow et al., 1998; Coulter et al., 1998). This illustrates the importance of the patient’s understanding the language used in the information materials. Coulter et al. (1998) examined consumer information needs and perceptions of information materials for 10 health conditions using focus groups involving 62 consumers. Results from this study indicated that consumers prefer information presented in a ‘down-to-earth’ and non-condescending manner with a tone that was ‘warm’, ‘chatty’, ‘friendly’ and had a ‘human touch’ (Coulter et al., 1998). Suls and Wan (1989) conducted a meta-analysis of studies concerning the preparation of patients for medical procedures. The authors concluded that interventions that included both sensory (what the patient will see, hear, taste or feel) and procedural information (what will happen) were the most successful in reducing negative outcomes, such as pain and distress. A second meta-analysis by Hathaway (1986) reviewed information provided to patients prior to surgery. Interventions with psychological content (for example, those which addressed patients attitudes and feelings) had a greater positive effect for highly anxious patients than for those with moderate or low levels of anxiety. Carey et al. (2007) in their educational resource for cancer patients focused on procedural elements by showing footage of chemotherapy being administered and showing the ward where treatment would be administered.
Patients’ descriptions of what having chemotherapy feels like were incorporated into the education resource. The resource also contained information on common misperceptions about chemotherapy and fears and concerns that people had while having treatment. This education tool was designed to normalize and reduce fears of chemotherapy among cancer patients.

Patient Information needs can represent a portion of their care or the entire spectrum of their care (e.g. operative versus preoperative, operative and postoperative). Themes or categories refer to a major heading that represents an information need (e.g. information need on surgery will have surgery as a heading). Subthemes or subcategories are subheadings and are thus related to the theme or category under which they appear. For the purposes of reviewing the limited literature in this area information headings or categories will be called themes (since they are often not named or termed categories or domains). Items refer to the populated content under each subtheme or subcategory.

The overall quality of patient information resources is dependent on the strength of the scientific evidence underlying its content (Coulter et al., 1998). Hence, evidence-based information is important as it provides credibility and consistency to the audience. McGregor et al. (2007) reviewed the published evidence on postoperative management of patients after lumbar discectomy or un-instrumented decompression. A systematic literature search was conducted and produced a best-evidence synthesis of information and advice for patients on postoperative restrictions, activation, rehabilitation, and expectations about outcomes. The authors used this evidence-based information and
developed patient-centered messages for an educational booklet. A draft text was synthesized and evaluated by experts and patients. This study used scientific evidence for deriving information themes. Derivation of themes using literature alone does not allow for stakeholder input into the themes, rather, it assumes the literature is representative of stakeholder needs. The importance of stakeholders in the development and the adoption of an information tool will be addressed in the discussion chapter.

Promotion of patient confidence can be accomplished by role modeling (Carey et al., 2007). According to Carey et al. (2007) role modeling refers to the provision of an example of someone successfully performing a desired behavior. Improvements in coping and a reduction in negative affect among cancer patients has been reported with the use of role modeling (to demonstrate coping with chemotherapy) as part of a comprehensive chemotherapy education package (Burish et al., 1991). Video role modeling in patient education may reduce anxiety, pain, and increase knowledge and coping ability (Gagliano, 1988).

Individualized or tailored information is associated with patient benefits (Damian & Tattersall, 1991; Hogbin et al., 1992; O’Connor et al., 1999). The balance between tailored and general information will likely depend upon the intended audience and the context in which the information is to be used. For example, a qualitative study received positive feedback on the use of an interactive multimedia tool to educate men with prostate cancer about the disease and treatment options (Diefenbach & Butz, 2004). This interactive format has the advantage of tailoring information to the patient’s need (i.e.
high information seeker or low information seeker), and allowing the patient to determine which information they wish to access.

**Information Resources for Patients Undergoing Surgery**

A recent study by Nunez et al. (2006) looked at the impact of an education program on quality of life and functional outcome for patients on a waiting list for knee arthroplasty. The education material was derived based on the available literature and expert opinion. The education material included content on consequences of disease on daily life; energy conservation; joint protection; pain management; treatments for osteoarthritis; demonstration for use of assistive device; and, exercises aimed to improve strength and range of motion in the knee as well as other joints. The authors concluded that access to a therapeutic education and functional readaptation program in addition to pharmacological treatment improved functional outcome in comparison to a control group who received only pharmacological intervention preoperatively. A randomized controlled trial of patients undergoing elective total hip replacement for osteoarthritis showed that the group receiving a collective multidisciplinary information session by the surgeon and anesthesiologist 2 to 6 weeks before surgery in addition to the standard verbal and written information had significantly less anxiety and pain just before surgery compared to patients in the control group who received standard care (i.e. verbal and written information) (Giraudet-Le Quintrec et al., 2003). The information session provided information on the following five major themes (or categories): 1) osteoarthritis of the hip; 2) surgery; 3) anesthesia; 4) rehabilitation and, 5) patient questions. A multidisciplinary team that included a surgeon, rheumatologist, anesthesiologist,
psychiatrist and physiotherapist conducted the session. These experts provided the information content during the session.

Keulers et al. (2008) derived eight domains (or themes) on the surgical process from their review of literature. The domains were: 1) disease; 2) examination; 3) preoperative period; 4) anesthesia; 5) operation; 6) postoperative period; 7) self-care; and, 8) general hospital information. The study showed that patients had significantly higher information need scores in most domains, including preoperative period, anesthesia, operation, postoperative period, self-care, and general hospital information compared with the surgeons. Women demonstrated a significantly higher need for information than did men. Patient information needs were independent of age or complexity of operation. Surgeons however believed that their patients desired more extensive information on cause, effect, and prognosis of the disease itself. This illustrates that there are differences between the stakeholders (i.e., patients and surgeons) when it comes to the information deemed valuable preoperatively. This study was limited to general surgery patients and did not include any patients undergoing spine surgery.

**Rationale for Thesis Proposal:**

Lumbar disc herniation is a prevalent condition and symptomatic patients present a significant socioeconomic and health burden (Katz, 2006). Spinal surgery in carefully selected patients who have failed conservative treatments can significantly improve quality of life (Katz, 2006; Weinstein et al., 2008). While the main indication for microdiscectomy is leg pain, often patients also have concomitant back pain that can be
severe (Hoffman et al., 1993). Unfortunately, while patients are relieved of their leg pain post-surgery, back pain usually does not improve (Hoffman et al., 1993). The false expectation that back pain will improve may result in patients feeling their level of pain-related function has become worse after surgery. It has previously been demonstrated in a similar population that patient expectation for surgery influences patient reported functional outcome (Yee et al., 2008). Providing an educational resource to patients pre-surgery may result in better self-rated functional outcomes post-surgery, as there is better-aligned patient’s expectations and realistic anticipated outcomes (Yee et al., 2008). Such a resource would meet the information needs of patients throughout their operative course.

Traditionally, a standard discussion is held between the spine surgeon and patient encompassing the indications, risks and benefits of the proposed surgery along with anticipated outcomes. Advancements in spine surgery such as minimally invasive techniques have led to same-day discharges of patients undergoing elective surgeries. In addition, shortages in spine surgeons across Canada have led to long waiting lists and crowded clinics. All of these factors can lead to less patient and surgeon face-to-face time during consultations. Moreover, with the volume of information available on the Internet, patients come armed with educated, technical questions and concerns further increasing the need of face-to-face time.

A variety of educational resources are available to counsel patients for elective surgery (Giraudet-Le Quintrec et al., 2003; Keulers et al., 2008; Nunez et al., 2006; Phelan et al.,
The traditional educational tools available to patients are derived by individual institutions and the topics and content of these were composed primarily by experts in the field (e.g., physicians, research coordinators) or other health care providers. Spine-specific educational material intended for patients who are contemplating elective spine surgery are not routinely used in practice. The existing spine-related educational materials are often from external resources such as websites or internally derived pamphlets. Although such sources do have “themes”, many have not been published in peer review journals. Where such resources are published, the themes in these educational materials have been derived from the literature and expert opinion. Using literature alone to derive themes does not allow for stakeholder input into the derived themes, rather, it assumes the literature is representative of stakeholder needs. Literature likely is best utilized to populate the content of the themes derived rather than deriving the themes themselves, thus providing credibility to the content of the information resource. Intricate to knowledge translation is the process of including the end users of the knowledge in the entire process to ensure that the knowledge and its subsequent implementation are relevant to their needs (Straus et al., 2009). This supports the importance of including all relevant stakeholders in devising the themes of an educational resource. A comprehensive literature search using MEDLINE and EMBASE databases yielded no spine-specific educational tool that was developed using input from relevant stakeholders, that is patients and members of the health care team such as spine surgeons, anesthesiologists.
Determining the information needs of patients undergoing microdiscectomy (i.e. preoperative patients) utilizing all relevant stakeholders including the intended end users – surgeons and patients – is the first step in the development of an educational tool in this population.

**Objective:**

The objective of the study is to determine the information needs of patients undergoing microdiscectomy.
Chapter 3
Methods

Study Design

This research utilized a qualitative design using focus groups. Such a design uses an inductive approach to make sense of complex processes and generates information in areas where the existing knowledge base may be inadequate. It maximizes the integrity of participant responses by drawing on issues important to individuals in their own words (Krippendorff, 2004). Additionally, as a resident in orthopaedic surgery whose subspecialty interest is in spinal surgery, I recognized that I needed to employ methods such as verbatim transcription of interviews, use of memos, multiple data sources and researchers along with a second data coder to enhance study the rigour and ensure that I was able to set aside any bias or preconceptions that might influence data gathering in the context of the focus groups and in data interpretation.

Focus groups

Focus group interviews were chosen as a qualitative method with the primary aim of describing and understanding beliefs, perceptions, and interpretations of a select population to gain understanding of a particular issue from the perspective of the group’s participants (Khan & Manderson, 1992). In this study, focus groups were used as a “self-contained method” serving as my main primary means of data collection.

There are several strengths to using focus groups as the method of data collection. Focus group interviews allow for interaction between participants. Focus groups are typically
conducted in an informal and relaxed setting using open-ended questions. This encourages participants to express opinions openly and spontaneously, free from the constraints that are typical to one-to-one interviews (Khan & Manderson, 1992). Focus group interviews were used to facilitate the research goal by acquiring a depth of knowledge about what patients and other relevant stakeholders deem important surgical information. A focus group interview has several important and distinct features (Liamputtong & Ezzy, 2001): 1) It enables in-depth discussions and involves a relatively small number of participants; 2) It is focused on a specific area of interest allowing participants to discuss the topic in greater detail; 3) It relies heavily on the interaction between participants; and, 4) The participants usually have shared experiences or shared areas of concern. In successful focus groups, the participants are able to talk to each other, rather than individually answering the moderator’s questions. This characteristic distinguishes the method from the individual in-depth interview. This group interaction has been termed “the group effect”, which is based on the idea that group processes assist participants to explore and clarify their points of view regarding their shared concern.

It has been stated that focus group participants need to be homogeneous in terms of this “shared experience” (Liamputtong & Ezzy, 2001). The homogeneity in our patient focus groups stemmed from their common experience of spine surgery. Within the patient focus groups a spectrum of age, sex, severity of symptoms, education, employment status and medical comorbidities was included. The other focus groups involving surgeons, fellows, residents, and anesthetists were homogeneous within the groups in terms of occupation, education, and between groups in the shared experience of educating preoperative spine patients.
In general, it has been established that focus groups work well with four to twelve people (Liampittong and Ezzy, 2001). The focus groups consisted of three to six participants. Given the topic of discussion, the use of small groups allowed ample time for participants to express their concerns while facilitating interactions between respondents that are essential to a successful focus group. Groups with more than six people may be difficult to manage and risk domination of the discussion by one or two participants (Liampittong & Ezzy, 2001). In addition most participants find it difficult to talk in a big group when everyone else is trying to speak. Loss of participant interest can occur as a result of having to wait a long time for their turn.

**The Moderator**

An experienced moderator was used to ensure effective elicitation of data. The primary investigator served as the note-taker in the focus group interview. This allowed us to record non-verbal responses such as facial expressions and body postures that may assist in understanding on how participants feel about particular issues (Liampittong & Ezzy, 2001).

**Semi-structured interview guide**

A semi-structured interview guide was developed for each focus group (Appendix 1-6). The moderator and the primary investigator designed each question in an open-ended format. For each open-ended question, a series of prompts were designed to elicit the desired answers if participants were off topic. The interview guide questions were then reviewed by two qualitative researchers for content and language and further modified.
As the focus groups went on, the questions changed over time to reflect the data of previous focus groups and thus became more refined. For example, in the second focus group involving postoperative patients, the questions were more specific and incorporated responses from previous groups. This allowed us to substantiate our findings.

All focus groups shared some fundamental questions. This allowed identification of information needs from all relevant and identified stakeholders. Questions specific to each participant group were also formulated. This allowed us to explore the unique experience of each group as it related to their role in operative experience.

**Participants**

Important stakeholders in the care of microdiscectomy patients were identified and approached to participate in the study. The two main stakeholders invested in the spine surgical decision-making process are surgeons and patients. Participants were chosen according to: 1) their perceived contact with the patient (residents, fellows, surgeons, administrative assistants); and, 2) their knowledge of the surgical process (surgeons, anesthesiologists) and their experience in the surgical consultation and procedure (preoperative and postoperative patients).

Residents are often the first to examine the patient and depending on their training level can often make a decision on the appropriateness of surgery for the patient. Surgical residents also are involved in the administration of informed consent and answer patient questions. The resident perception of the content of information to cover with the patient
information may be different than the surgeon. This may be due to their: 1) perceived lesser medico-legal responsibility; 2) less experience and knowledge of the planned procedure; and, 3) more available time with patient.

Surgical fellows have completed their residency but have not yet started independent practice. Fellows may thus fall in between the surgeons and residents in terms of experience and thus represent an additional stakeholder.

In this study, both the postoperative and preoperative patients identified the surgeon’s administrative assistant as well as the preadmission process as important sources of information. The patients were frequently in communication with the surgeon’s administrative assistant regarding preoperative issues and in addition postoperative concerns. The preadmission is an appointment that preoperative patients attend where they meet with an anesthesiologist as well as educators such as registered nurses. Details around the process of the operation, discharge as well as specific questions are addressed. This appointment occurs typically one to two weeks prior to surgery. Based on the emerging data additional stakeholders were identified and additional focus groups with the administrative assistants and the preadmission team were conducted.

Anesthesiologists are an important group as they are the most knowledgeable on topics related to the surgical process including anesthetic complications, sensation and awareness during surgery, and peri- and postoperative pain control. Hence, they were deemed a valuable resource for contribution to such an educational tool.
Although preoperative patients are the targets for an educational tool, this group does not have the same knowledge and experience as the postoperative patients. Postoperative patients were included as they are insightful as to information needs about the procedure having gone through the experience. They can thus articulate what information they wish they had preoperatively.

Allied health professionals including physiotherapists, occupational therapists, and social workers were considered for this study, but since they have no significant interaction with same day surgery microdiscectomy patients they were not deemed key stakeholders. Nurses working on the orthopaedic ward were also excluded given their lack of microdiscectomy patient interaction, which is limited to the day surgery unit. Nurses were included in this study as part of the preoperative assessment team due to their role in the education of preoperative patients.

To be eligible for the study, orthopaedic surgery residents must have completed at least two months of spine surgery training. Spine fellows are defined as orthopaedic surgeons or neurosurgeons who are currently enrolled in a spine surgery fellowship (i.e., spine surgery trainees). Spine surgeons are defined as orthopaedic surgeons or neurosurgeons who have completed a fellowship in spine surgery and their current practice involves spine surgery. Anesthesiologists are defined as physicians having completed residency training in anesthesia. Spine surgeons’ administrative assistants were identified through the spine clinic. The key preadmission personnel were identified and recruited by the perioperative services manager.
The eligible stakeholders who consented to the study were interviewed in a focus group format (as described) by a moderator and the primary investigator. Focus groups should be conducted in the native language of the participants or in a language that the participants are fluent in. Language or cognitive impairments were therefore considered an exclusion criterion. Furthermore, our focus groups were ideal in that participants did not know each other in advance thus allowing facilitation of a free dialogue (Khan & Manderson, 1992). The moderator for our study was a qualitative researcher with a doctorate. The study investigator is a senior orthopaedic surgery resident with 12 months of spine surgery training.

Inclusion criteria for patients were:

1. Age 18 or older and one of:

2. Eligible for and having consented to microdiscectomy (preoperative patients):
   a. Patients seen by a spine surgeon with clinical examination and history confirming back and neurologic leg symptoms relating to disk herniation for at least 12 weeks that have failed non-surgical therapies
   b. Confirmatory cross-sectional imaging demonstrating neurologic compression consistent with clinical presentation.
   c. Signed informed consent and on the waiting list for surgery.

Or

1. Postoperative from a microdiscectomy.

Exclusion criteria for patients were:
1. Emergency spinal conditions (i.e. cauda equina syndrome with acute bowel/bladder dysfunction).
2. Language or cognitive impairments that would prevent participation in interviews conducted in English.

The following cohorts were interviewed (Table 1):
1) Preoperative patients meeting inclusion criteria;
2) Postoperative microdiscectomy patients;
3) Fellowship trained spine surgeons;
4) Spine fellows;
5) Orthopaedic surgery residents with at least 2 months of spine training;
6) Anesthesiologists;
7) Surgeons’ administrative assistants; and,
8) Preadmission team personnel (i.e., nurses, educators, managers).

**Sampling**
One or two focus groups were planned with each of the stakeholder groups (Table 1). The final number of each stakeholder group was determined when saturation was reached, specifically when no new or relevant data seemed to emerge regarding a theme (i.e. category), the theme was well developed in terms of its properties and dimensions demonstrating variation, and the relationships among themes were well-established (Strauss & Corbin, 1998). Based on the analysis of the emerging data, we identified two additional stakeholders and conducted additional focus groups on the administrative
assistants and the preadmission team. In this study, both the postoperative and preoperative patients identified the surgeon’s administrative assistants as vital resources for information and their preferred person to address concerns and questions. This group was chosen to further explore themes relating to patient education and thus ensure saturation of those themes. Similarly, a second postoperative group was interviewed to ensure saturation of themes relating to postoperative care.

In selective sampling (Coyne, 1997) the researcher selects people according to the aims of the research. Variables such as age, gender or occupation will serve as starting points for choosing a selective sample. Patients, surgeons, residents, fellows, and anesthesiologists represent selective or purposive samples. These stakeholders are a selective sample because of their role in the care of microdiscectomy patients.

Triangulation, or the use of multiple methods, involves using a combination of methods, data sources and researchers in a study (Liamputtong & Ezzy, 2001). In this study, data source triangulation was used as relevant stakeholders (i.e. surgeons, anesthesiologists, patients, etc) represented multiple information sources. Researcher triangulation was also utilized in this study by combining the perspectives of qualitative researchers and clinicians.

**Procedures**

Approval from the Research Ethics Board of Sunnybrook Health Sciences as well as University of Toronto was obtained (Appendix 7). A written consent form was be completed by patients and all other participants.
Preoperative and postoperative microdiscectomy patients were recruited from the spine clinic at Sunnybrook hospital. These patients have been seen in consultation by a spine surgeon and have consented to having a microdiscectomy. Orthopaedic surgery residents and spine fellows at the University of Toronto, identified through their respective programs, were approached for study participation. Spine surgeons affiliated with the University of Toronto were identified and asked to participate.

**Data Collection**

Demographic information including age, gender, highest level of education obtained, employment status, worker’s compensations (WSIB), and duration of symptoms were collected via questionnaire (Appendix 8). A Visual Analogue (VAS) pain score was completed by patients individually rating their back and leg pain (Appendix 9). The preferred format of an education tool was specifically posed to patients as a question (Appendix 10).

**Data Analysis**

Transcripts will be analyzed using content analysis, a method for systematically making inferences from text (Krippendorff, 2004). Krippendorff (2004) describes content analysis as “a research technique for making replicable and valid inferences from texts (or other useful matter) to the contexts of their use” (p. 18). Content analysis involves a process of coding text into themes. Themes are categories that are inductively identified from the data. Subthemes or subcategories are related to the theme or category and aim to describe the properties of the theme thus forming more concrete explanations about the
concept the theme represents (Strauss & Corbin, 1998). Three main coding procedures were used in this study – open, axial and selective (Strauss & Corbin, 1998). Although each coding procedure is different in its process, the three coding procedures were done both sequentially and simultaneously as data emerged. Details of how coding was conducted are provided in Appendices 11 and 12.

Conditions are the events that create the issues or problems pertaining to a theme (Strauss & Corbin, 1998). Conditions can arise out of time, place, culture, rules, regulations, beliefs, economics, power, gender, social factors, organizations and institutions (Strauss & Corbin, 1998). Conditions are important to identify as they can give the researcher insight as to the responses of the participants. Conditions may be micro (i.e. close to the source of the action) or macro (i.e., far from the source such as administrative issues). Conditions can also change over time, affect one another or combine in different ways. Causal conditions – factors that influenced a theme – were identified in this study.

The focus groups conducted were within one to one and a half hours. The interviews were audio taped and transcribed verbatim, with the exception of identifying information, which was deleted. All transcripts were typed onto a Microsoft Word document. The moderator and two analysts (AZ, VP, CB) all with experience with qualitative research independently reviewed the first transcript. A line-by-line analysis method was used and transcripts were coded. Responses that were unique to certain patient demographics such as gender and age, resulted in further analysis and additional sampling based on those demographics. The codes were transferred onto a Microsoft Word memo document as
they emerged during analysis. Thereafter, each transcript was reviewed by the moderator and the primary investigator to ensure consistency and transparency. As described earlier, open, axial and selective coding was performed (Appendix 12). Word clusters that corresponded to discrete themes such as desired education topics, surgical information and delivery format were identified and placed in a memo document. Each analyst independently developed a list of identified themes and through comparison the analysts established consensus on a list of themes and subthemes. Each theme was developed and refined based on analysis of each focus group transcript in a continuous back and forth process. Focus groups were conducted until saturation was reached.

**Member Checking**

Member checks were carried out to increase the credibility of the study findings. This was accomplished by sharing the findings of the study with the participants involved. This allowed participants to critically analyze the findings and comment on them (Barbour, 2001; Byrne, 2001). The participants either affirmed or denounced that the findings reflected their views, feelings, and experiences. If the participants affirmed the accuracy and completeness, then the study is said to have credibility (Barbour, 2001). The synthesized themes and subthemes derived from all focus groups were shared with the following groups:

1) Spine surgeons;

2) The preoperative focus group used in our initial analysis who had subsequently undergone the surgical procedure; and

3) One-on-one interview with two preoperative spine patients.
The same group of spine surgeons in our original focus group was asked about the usefulness of the derived themes of the education tool as it related to their practice. The preoperative focus group – that had now undergone surgery – was brought back for another focus group and asked about the utility of this information in retrospect. A series of one-on-one interviews with new preoperative patients investigated the usefulness of such a tool for its target audience. The appropriateness of the content of the proposed education tool for its intended users was tested utilizing different preoperative patients not involved in the original focus groups. Member checking in a sample of patients that were not part of the original study (i.e. the preoperative patient group) can also be used to assess transferability. If the people who were not the original participants agree with the findings, then the results can be said to be transferable.

Member checks were also conducted informally during the focus group interviews by constantly checking understanding of the themes utilizing techniques such as paraphrasing and summarization for clarification.
Chapter 4
Results

Participants

Focus groups were conducted with the following health care providers: 1) fellowship trained spine surgeons (n=6, all males); 2) spine fellows (n=3, all males); 3) orthopaedic surgery residents (n=5, 4 males, 1 female); 4) anesthesiologists (n=4, 1 males, 3 female); 5) surgeons’ administrative assistants (n=2, all female); and, 6) the preoperative team (n=6, 1 male, 5 females) (Table 1). The patient focus group demographics are presented in Table 2. A total of 10 patients were interviewed (6 males and 4 females). The mean patient age was 42.6 years (range 20-67). Preoperative and postoperative patient leg and back pain as recorded by the Visual Analogue Scale (VAS, out of 10) is represented in Table 2. Mean preoperative patient VAS score for leg pain and back pain were 6.2 and 5.5 respectively. Mean postoperative patient VAS score for leg pain and back pain were 4.3 and 3.4 respectively. Employment status as depicted in Figure 1 illustrates the percentages of patients employed versus patients on worker place safety and insurance board (WSIB).

Themes from the data

When the data were specifically analyzed for responses unique to gender, education, Visual Analogue Scale (VAS) pain scores, and age, no dissents of opinion or new themes were found.
The following analysis aims to describe the themes that emerged from the data. The central theme was identified as: desired components to an education resource. Themes and subthemes derived from the latter were organized according to: 1) content areas of patient information needs; and, 2) desired attributes and format of an education resource for patients. Causal conditions with direct impact on the transfer of information to patients were identified. The identified causal conditions were: 1) patient factors influencing the extent of delivered information; and, 2) communication of information with patients.

1) Reported content areas of patient information needs (Themes):

A) Anesthesia information

One of the themes relating to content area of information need by participants was identified as anesthesia information (Figure 2). Subthemes of anesthesia-related information were anesthetic risks and postoperative pain management. Anesthesiologists were the predominant stakeholder in their contribution to this theme and its subthemes. I observed that of all types of information relating to spine surgery, patients had the least desire for information related to anesthesia. This was confirmed when anesthesiologists confessed that they are frequently asked questions related to the surgery and postoperative course instead of anesthesia-related topics. As a result, anesthesiologists often felt unqualified to answer such questions and suggested for the patients to revisit their surgeons.

i. Anesthesia risk
One subtheme related to anesthesia was the risk associated with anesthetic. The importance of the anesthesia to patients was conveyed in the interview by a postoperative patient, “I have to say I was really surprised by the anesthetic. I didn’t realize the anesthetic would have more of an effect on me than the surgery did.” When anesthesiologists were asked about patient’s desired information on anesthesia, they felt patients often say “I don’t know what to ask.” Anesthesiologists communicate to patients “what they think they should know” about the anesthetic. When patients did ask questions, anesthesia ‘awareness’ was frequently the topic of discussion. Anesthesiologists felt that “people have always been worried about being awake during anesthesia” and “if you give people an opportunity to ask questions, and a lot of them bring it [awareness] up.”

**ii. Postoperative pain management**

Postoperative pain management was another subtheme related to anesthesia. Both patients and anesthesiologists viewed this as an important content area of preoperative information. This was especially vital to patients with chronic pain or patients who had been on a high dose of pain medication prior to surgery. The challenge of postoperative pain control was summarized by one anesthesiologist as: “I don’t think they [patients] realize that it’s going to be a big problem to have their pain under control post-op. I don’t think they have any idea. They come to surgery with the hope that their pain will be made better, and in fact sometimes it’s really hard to control when they’ve been on large doses of narcotics.” When the topic of postoperative pain medication management was raised, postoperative patients had little to no information on this prior to surgery and deemed this as “information that I would really like to have had.”
**B) Procedure-related content**

Another content area of information need identified by all stakeholders relates to the surgical procedure (Figure 3). All stakeholders contributed to the emergence of this theme and its subthemes. The subthemes that emerged were: definition of terminology, diagnosis and treatment options, procedure overview, complications, surgical goals, outcomes, and length of hospitalization.

**i. Definition of terminology**

Both preoperative and postoperative patients were unfamiliar with the terminology that was used by surgeons to describe their condition and/or procedure. “I didn’t even know the term ‘microdiscectomy’ until after I’d left the building” admitted one postoperative patient. It was apparent that many patients were confused about the procedure they had given consent for due to their inability to understand the terms used to describe it. For example, one postoperative patient confessed “I’m not really sure what I’m agreeing to”, while another patient stated “even the word microdiscectomy I’d never heard before! I had no clue what that was.” Patients with familiarity with computers and access to the Internet would conduct their own research on the procedure after the consultation and in many instances after having given consent for surgery. This notion was corroborated by a patient who stated: “I had to have them write it down for me so I could do my research.” Administrative assistants also agreed that patients were often confused by the terminology surgeons used and when the administrative assistants discussed with patients the discectomy procedure, they described it as, “it’s to go in and pick out crab meat. That’s simple, they get it.”

**ii. Diagnosis and treatment options**
Surgeons convey to patients their diagnosis during the initial consultation based on the history, physical examination and imaging results. The diagnosis serves as the basis for the recommended treatments. Surgeons believe that, for the surgical candidates, “the main things are that they understand the diagnosis, they understand what the surgery’s going to treat, what it’s likely not going to treat.” A participant echoed the view of many when he said: “I didn’t even know what I was agreeing to [treatment].” A contributing factor to what seemed to be a lack of understanding of the treatment by patients was again related to confusion around the technical details of the procedure.

**iii. Overview of procedure**

The overview of the procedure was a subtheme identified by all stakeholders. The use of patient imaging or a spine model were examples of effective visual aids used to describe the procedure to patients by the surgical team. The spine models are used “to show them [patients] what exactly you’re doing, in a very simple way” expressed a spine fellow. Surgeons used a patient’s diagnostic images to illustrate their condition. Surgeons felt that patients “connect with you when they see their own image.” In the overview of the procedure, the data showed clearly that patients want to know the basics of what would be done, the incision location and size, and the length of operation. With regards to the duration of the procedure, a fellow stated that “people [patients] tend to care how long their surgery is going to be – they tend to equate that with either your level of skill or the complexity of surgery, I’m not sure which.” Interestingly, residents expressed that they would want to know the surgeon’s experience with the procedure if they were the patient and acknowledged that patients “want to know your experience, they want to know you’ve seen it before.”
Since patients awaiting spine surgery are often in severe pain, it is their desire to know the date of surgery as soon as possible making this question “one of the biggest and the most difficult questions” a resident admitted.

iv. Surgical goals and outcomes

With regards to the goal of surgery, surgeons emphasized the importance of managing patient expectations. The surgeons wanted to ensure that patient’s expectations regarding the surgical goal were consistent with their own view of the goals of surgery. One surgeon echoed the consensus among surgeons that “what to expect with the surgery, what’s the objective, what are the typical outcomes” are important for patients to understand prior to considering surgery. However, surgeons felt that despite efforts to set what they deemed to be realistic expectations for patients, getting that message across was not always successful since “patients hear what they want to hear.” Given that the goal of microdiscectomy is to relieve leg pain, surgeons agreed “the most frequent question, the number one question that they have, is ‘what’s going to happen to my pain…how much reduction can I expect.’” The importance of this content area was corroborated by a postoperative patient as, “I wanted to understand…what’s the percentile in terms of success rate that I’ll have? In terms of the pain I’m experiencing, how much will it be reduced? When will it be reduced by? Will it be a permanent reduction? Can I expect recurring problems?”

v. Surgical complications

Surgical risks and complications are often discussed during the initial consultation since it is considered to be an intricate component to obtaining informed consent. Surgeons, fellows and residents all indicated the importance of discussing surgical risks with
patients. Surgeons “spend a great deal of time looking at risk and possible complications, making it very clear to them [patients].” Residents felt only reasonable risks should be discussed. When prompted to explain what is ‘reasonable’, one resident stated: “I think what’s reasonable is what’s common, and also what’s reasonable is something devastating that can happen and there’s a possibility that it can happen. Rare events aren’t necessarily reasonable even though they may or may not be legally required to be covered.” Fellows views on the importance of discussing all complications resembled the surgeons, “Absolutely. Complications, every time. Most people don’t ask because they probably don’t really want to know what can happen.” Information needs on surgical risks were identified by patients but far less often in comparison to the surgeons, fellows and residents. A postoperative patient conveyed this notion saying, “I wasn’t interested in the technicalities…I didn’t care.”

vi. Length of Hospitalization

Although the majority of microdiscectomy procedures are performed as outpatient surgery, questions relating to the length of hospital stay were repeatedly brought up by patients and all other stakeholder groups. One fellow perceived the frequency of this question was related to the notion that “hospital, for them, is not their life: once they’re out of hospital, they get back to their life.”

C. Postoperative care

Postoperative-related content was identified as a main theme from the analysis of the transcripts from all stakeholder interviews. The patients contributed the most to data that derived the subthemes in postoperative-related care. Utilizing qualitative methodology a
gap in the continuum of care for microdiscectomy patients was identified. Analysis of the data from the pre- and postoperative patients, administrative assistants and the preadmission team focus groups identified postoperative-related content as the most deficient in terms of information available to patients prior to surgery. Figure 4 illustrates how this study finding is placed into a framework representing the continuum of care. The subthemes identified under postoperative care were: recovery time, expected symptoms including postoperative pain management, restrictions and limitations, wound care, need for a caregiver, and physiotherapy (Figure 5).

i. Recovery time

Of the postoperative care subthemes, recovery was the most desired content area. Postoperative patients felt that they were greatly unprepared for their postoperative care as they were told little to no information relating to it. “For me what was going to be most important – was recovery” and “I wish I knew how long the recovery was really going to be” stated postoperative patients, expressing a preponderant view. One surgeon’s administrative assistant also observed that “it’s more recovery [types of questions]” when asked about the most common types of patient inquires encountered.

ii. Expected symptoms

Patients often stated that they were unsure of what to expect after surgery in terms of pain. One patient shared their experience once they were home from surgery as “I had incredible pain that the pain-killers were not subsiding any of the pain, easing any of the pain at all.” Patients felt unprepared and wished they had “understood the extent of the pain [after surgery]” they may experience. The residents also admitted that the patients need more information, highlighting, “nobody’s told them [patients] that at six weeks
they can still expect swelling or they can still have pain when they walk.” The surgeons’ administrative assistants stated that they often receive phone calls from patients after surgery with concerns about their pain. One of them spoke about this saying: “some patients will phone immediately – like, a day or two after surgery – and ask, you know, ‘Why do I still have this leg pain?’”

### iii. Restrictions and limitations

Interviews with the postoperative patients emphasized the need for more information on patients’ restrictions and limitations postoperatively. Patients were frequently unsure and confused about what they were and were not able to do safely postoperatively. One surgeon cited that based on his research, “restriction in mobility from surgery” was a common concern for patients postoperatively. One postoperative patient stated “my only question was what kind of limitations I will have” when asked about desired information to know prior to the surgery. Another postoperative patient spoke about the confusion she experienced with instructions she received prior to discharge, “‘you’re going to be able to walk.’ What does that mean? How long can I walk for? Can I walk the whole day? Can I walk the dog? Can I jog a bit? What does that mean? Can I go up the stairs?” When surgeon’s were asked about the types of questions posed by patients, one stated: “they’ll ask about what they’re going to be able to do, their restriction of mobility, whether they can shower…and those kind of questions I tend to defer to their pre-admission visit.” However, it was apparent from our data that not all patients were sent for a preadmission or preoperative appointment. For those patients who did attend a preoperative appointment, the information provided was very nonspecific as corroborated by one nurse from the preadmission team, “but even the pamphlets we have doesn’t really
explain anything, ‘Oh, you’ll come on such a date, you’ll have your surgery second day, you’ll be discharged.’ It’s like there isn’t much detail in that pamphlet.” Another surgeon felt that such postoperative details such as showering was specific information best answered after the surgery stating: “with regards to a lot of the specifics, like when can you have a shower and when can you bathe after the operation and all that, I usually actually reserve that kind of conversation for when I see them in the day surgery unit.” The problem with this strategy was that patients had little or no recollection of the information received in the recovery area prior to discharge. One patient stated: “I was in a lot of pain so I couldn’t remember what anyone was saying to me… So when I came out of surgery I had no idea what I was supposed to do.” An anesthesiologist confirmed this by sharing his experience as a postoperative patient saying “the surgeon came and spoke to me in Recovery Room, I asked all the doctor questions that a doctor would…I was wide awake, but I had zero recall.”

iv. Wound care

The patients interviewed desired information on wound care. Patients seemed better informed, however, on managing their wound in comparison to other subthemes in postoperative care. The preadmission nursing staff discussed “any care of the incision” with patients during the appointment and instructions for wound care were given in the discharge pamphlet.

v. Need for a caregiver

Given most microdiscectomy patients are discharged the same day as their surgery, the topic of arranging for a caregiver was strongly emphasized by postoperative patients as their hindsight advice for future patients. “I really relied on my husband and my children,
but I mean just going to the washroom, rolling over in bed, getting out of bed, getting into bed, walking a short distance…I didn’t know it was going to be that bad” stated one patient and “I wish they had told me that for the next four days I needed somebody there” stated another patient. Another patient advised future patients of the need for a caregiver after surgery saying “if they have a partner, spouse,…somebody who’s going to help them.” The preadmission nurses did acknowledge that patients often asked if “I need a nurse to help me at home?” Patients reported they did not receive instructions on the need for caregiver after surgery.

vi. Physiotherapy

Residents were often asked by patients preoperatively and on follow-up about the need for and the role of physiotherapy in their rehabilitation. Residents admitted “nobody from us will tell the patient how much physiotherapy he will need.” The role of physiotherapy and its appropriateness was information that patients stated they desired preoperatively.

2) Desired format and attributes of a patient education resource (Figure 6):

A. Patient preferred format of an educational resource

All patients were asked about their preferred format of an educational resource once available for patients preoperatively. The majority of patients preferred a written pamphlet (Figure 7). Other formats of Internet, CD-ROM, DVD, and face-to-face education were less desired as an adjunct to the consultation with the surgeon. It became clear that “people learn in different ways” as one member of the preoperative team pointed out. The advantage to a pamphlet for surgeons was the potential for providing
consistent information to a patient and the ability to maintain this consistency by having patients carry this information with them throughout the surgical process. The other advantage to written information was the ability for the surgeon to customize the information to each patient further ensuring consistency in the care of the patient at all points. One surgeon summarized this by, “potentially having the patient have a document that may be helpful is to provide a tool of consistency…there’s areas where we can put in certain expectation questions… proposed return to date work… but this way that patient is carrying that around.”

All stakeholders wanted a Frequently Asked Questions (FAQs) component to the education resource that would be specific to the microdiscectomy patient population. This would ensure patients get “a personalized answer to questions” said one manager in the preoperative team.

The ability for patients to have a visual diagram of the procedure and/or anatomy in the pamphlet and website would help patients better understand their disease process especially given the complex nature of spinal anatomy. Some stakeholders wanted patients to be given a DVD that illustrates their operative course perhaps using real patients as narrators explaining the role of the health care team members and providing a visual of the environment they will be traversing. The use of audiovisual images in such an education resource was deemed a “very powerful educational tool” by one anesthesiologist.
Finally, a patient suggested the addition of an electronic message board or email where patients can post their specific questions that were not answered by the pamphlet or FAQs. This idea was favoured by many stakeholders and comments from patients included: “I’m in favour of an on-line message board which would be very, very helpful for me” and “that’s an excellent idea.” The response to the postings would, according to patients, come from any member of the surgical or spine care team.

**B. Desired attributes of the educational resource**

The most important attribute required for the postoperative care component of an educational resource is a time-specific or temporal outline according to the patients. Patients realized that their activities, restrictions and limitations would vary from the immediate postoperative to weeks or months after surgery. The need for postoperative information in a time-specific format was noted by one patient as “what can I expect [in my recovery] sort of a month, two months, three months out?” The postoperative information should be “divided into weeks” said one patient to provide guidance since patients often do not come back for their first follow-up visit until six weeks after surgery. “What can you do after the surgery and on the first week or two weeks or three weeks, that would be very helpful” conveyed one preoperative patient.

The other important attribute that was captured in the derived themes was the inclusive nature of such resource to cover information pertinent to the entire surgical process from beginning to the end (i.e. recovery). According to one resident this “really helps alleviate anxiety and puts things in perspective” for patients.

**C. Optimal time for patients to receive preoperative information**
When is the best time to hand out an educational resource to patients who have been deemed surgical candidates? According to pre- and postoperative patients, the consensus was “the earlier the better”. One patient described the consultation experience with the surgeon as “they bombard you with a lot of information all at once, and the questions don’t come until after [leaving the consultation].” Another patient admitted that “I didn’t ask any questions because I was so nervous, and I didn’t even remember what he was saying to me.” The administrative assistants receive the majority of the patient’s questions once a surgery date is assigned. It was apparent based on the data from all stakeholders that the most appropriate and desired timing for such information is at the initial consultation once a patient is determined to be a surgical candidate. This would allow the patient’s who consented to the surgery to reinforce the information at home and for those who are undecided to review the material and return for a second visit once a decision is made to proceed with surgery. For those patients who are given a preoperative appointment, that appointment is generally very close in proximity to the date of surgery. Providing information to patients during this appointment is suboptimal according to patients because “your brain is already saturated with so much, and plus you worry about the surgery.” The early timing of such resource is also important since often a lag time of many weeks to months exists from the initial consult to surgery. This would afford the patient ample time to review the contents of the resource.

3) **Causal condition: Patient factors influencing the extent of delivered information:**

Data from the participating health care providers showed that factors that influence the extent of the information provided to patients relating to the surgery are: patient’s age,
language, education/socioeconomic status, patient comprehension and presence of family members during consultation (Figure 8).

A. Age

Patient age was a variable that influenced the extent of information that was delivered to patients. This was due to the perceived notion that ‘younger’ patients are more inquisitive about their health status. This consensus was summarized by a spine fellow as “I find myself spending more time with the younger people. I guess, again, they’re [young patients] the people that want to know more and they want to understand what exactly you’re doing… whereas the elder population – I mean by over 60 – they’re less so interested.” This perception resulted in a more extensive information exchange with younger patients.

B. Language

A member from the preadmission team described language as a barrier to delivery of information by stating: “a lot of them [patients] don’t speak English, so they’re having an interpreter interpret…so you’re kind of thinking, ‘What is the patient actually taking in?’”

A resident described a strategy to overcome potential language barriers as, “you try to explain to them by talking slowly, emphasizing certain parts of the words.”

C. Patient education/socioeconomic status and patient comprehension/self-education

There were differing views on the impact that a patient’s education or socioeconomic status had on the extent of information delivered by health care providers. One fellow stated that “the socio-economic status [of the patient] reflects on their knowledge of their problem and their disease” and explained that patients “come with different levels of education, and then it depends, during your interaction with the patient you kind of gauge
your discussion with... how much information the patient would want to know.” Surgeons, however, disagreed with this notion, with one stating “the amount of information that’s transferred to the patient doesn’t vary based on socio-economic status or educational status, there is a certain amount of baseline information that gets transferred over… Everybody gets that.”

With further probing, it became apparent that patient ‘education’ was interpreted as the patient’s understanding of their condition rather than the highest level of education obtained by a patient. As the subtheme of patient education was further explored with spine surgeons, it was apparent that for them a patient’s comprehension during the consultation and insight into their condition influenced the extent of information they provided. Residents agreed with this assessment explaining that, the information they share depends on “whether the patient understands what you’re talking about and how well you think that they could process the information that you’re telling them. That goes a lot towards how much and what you say to a patient.” Surgeons also agreed with this notion that “there’s a high degree of variability with the amount of time that’s spent [with a patient]” and further explained that “there is difference with regards to the level of questioning [by patients] and... the depth of information that gets transferred in someone, say, who’s done a lot of research about it… sort of read around the topic.”

**D. Presence of family members**

Patients who had a spouse or a family member present during the consultation may receive more information from their provider by virtue of the fact that family members often asked surgeons questions related to the surgical procedure or process. A resident
noted that when family members are present during a consultation, more time is spent with patients because “they might have a family member there who might want to ask a few more questions.”

E. Previous surgical experience

Patients with previous experience with surgery and more specifically a negative experience or a complication, asked more questions relating to the surgery. As one anesthesiologist expressed, “because they’ve had previous experience. If they had a previous negative experience, we’ll be sure to get lots of questions – and that’s fine, it’s appropriate.”

4) Causal condition: Communication of information with patients

The importance of the use of simple and easy to understand language as well as defining the common medical terminologies used was highlighted above. The communication of information to patients prior to surgery is a causal condition that influences the described themes and subthemes. Important subcategories identified by all stakeholders under communication where identified as: reinforcement of information, time constraints, face-to-face communication, consistency of the provided information, need for a liaison between surgeons and patients, and role of the primary care physician in the continuity of patient care (Figure 9). The results for each subcategory are described below.

A. Reinforcement of information

Both pre- and postoperative patients recollected only a portion of the information that was given to them by surgeons at the consultation. “I don’t remember it being mentioned in the room” stated one patient about the name of the proposed surgery. Surgeons echoed
this concern expressing that “it’s well known that the patient will recall at best 20-30% of what you’ve told them.” The solution the surgeons had for this difficulty by patients to retain information was to “reinforce it, or to allow them to revisit.” The preoperative team in the preadmission clinic also voiced concerns that when patients see them prior to surgery, they ask many questions that presumably would have been covered at the time of consultation.

B. Time constraints: A contributing factor to the exchange of information by surgeons to patients

Time constraints such as large clinics or clinics running late affected how much information surgical residents and fellows provided to patients. This was also confirmed by some patients who experienced being rushed through by comments such as: “Dr. spine surgeon] came in and engaged in about 30 seconds’ worth of conversation and then left…I felt like a patient and that was it, a number…but it was all a little bit rushed.” When residents spoke about their interactions with patients in clinics, the lack of sufficient time was cited as the main reason for limiting the information that was given to patients. “The reality is in a busy clinic you’re really strapped for time, and you realize you should probably spend a few minutes talking about the risks and benefits of surgery” stated one resident while another resident confessed that “usually when you’re saying, ‘Do you have any questions?’ you’re one foot out the door.” Staff surgeons, however, were not influenced by time constraints and answered patient’s questions “until they’re finished asking.”

C. Establishing rapport and gaining patient’s trust is achieved through face-to-face communication
In order to establish rapport with patients and gain their trust, surgeons all agreed that spending face-to-face time with their patients was crucial. “Part of developing rapport with the patient... allowing them to trust you as a surgeon, means spending some time…” Even if they’re not catching it all, you’ve delivered it and they probably are developing a rapport with you and they’re comfortable signing on and having surgery with you” summarized one surgeon. All of the physicians agreed that there can be no substitute for the face-to-face time spent with patients and one anesthesiologist explained: “The beauty of the person-to-person discussion…you can hear what that patient needs to know…then that’s the best way.” The administrative assistants further agreed with this notion saying “I think people need to speak to one another… I want contact, I want a human being talking to me. It’s important.”

D. Delivered information must be consistent

A patient will see a number of health care providers during their care including, but not limited to the surgeon, fellows, residents, nurses and educators. Based on their experience, surgeons believe that the information that is conveyed to patients at different points of care was at times inconsistent creating confusion and anxiety for their patients. “I think people [patients] would feel more comfortable with that consistency [of information]” said one fellow and hence consistency was crucial in creating “less confusion, more trust.” A barrier to giving consistent information to patients was identified by the preadmission staff as, “one of the issues around giving information post-operatively is that it’s not standardized information. Some surgeons prefer this over that, and it’s difficult it to give a clear message.” This notion of inconsistent messages was also voiced by a postoperative patient, “I keep getting sort of almost conflicting
information from various people. Physio says one thing, surgeon says another thing, GP [General Practitioner] says another thing, and then some people say nothing, so then you’re like, ‘What am I supposed to do?’” According to surgeons, the major problem with this inconsistency in the message is that it “undermines the patient confidence.”

E. Providing patient information requires a liaison between surgeons and patients

Patients often relied on the administrative assistants for answering questions that would arise after the consultation and surgery. The role of the administrative assistants as a patient information resource was summarized by one postoperative patient as “they’re like the administrative assistants to CEOs [Chief Executive Officers], they are incredibly knowledgeable.” When patients were asked about their level of comfort in seeking answers related to their surgery from the administrative assistants, responses such as “I’m really comfortable asking the administrative assistant questions… I have a lot of trust and faith in how she responds to me” were voiced. The administrative assistants acknowledge that “secretaries gets a lot of the questions, pre and post [surgery]” and a sense of responsibility existed within them in ensuring to answer those questions.

Patients further identified that an information gap exists in the system stating: “between the patient and surgeon there’s no in-between.” Our data indicates that the administrative assistants serve exactly this “in-between” role helping to bridge the information gap that exists between the patient and the surgeon.

F. Engagement of primary care physician is essential for continuity of care

Patients often felt that they were bounced back and forth between their surgeon and the primary care physician after surgery. “I think that the gap between the family doctor and
the hospital needs to be closed somewhat” said one postoperative patient. Patients were often referred to their family physician by surgeons for pain management after the immediate postoperative period (i.e. after the first or second pain prescription). Patients complained that the primary care physician was often unaware of the pertinent details of the operation and lacked direction in managing them postoperatively. One solution to this problem according to one patient was that “there needs to be the hand-back to... my doctor.” This “gap” was further acknowledged by one anesthesiologist: “well, one of the biggest gaps – and this is particularly true of academic institutions which are tertiary care and not secondary care – is that there is little or no communication with the family physician, and the family physician might not even know that their patient’s gone for surgery, and... what’s been done to the patient.” “A lot of the operative notes aren’t copied to the family docs” acknowledged administrative assistants, further contributing and perhaps extending this communication gap between the surgeon and family physician. A patient shared his frustration with this lack of communication stating: “if you don’t provide that information to the family doctor then you don’t give them any chance whatsoever of being able to bring some value into the circle.” This ‘circle’ is the circle of care for patients encompassing the entire surgical process. Patients unanimously expressed the desire for continuity in their care from the beginning to end.

**Member-checking of the study findings:**

A written format of the derived themes and subthemes were shared with three stakeholders: 1) spine surgeons; 2) preoperative microdiscectomy patients; and, 3) postoperative microdiscectomy patients. Spine surgeons were emailed the derived
themes and subthemes (Figures 10, 11) and were specifically asked to comment on: a) the usefulness of such information to their patients; b) the appropriateness of the themes and subthemes; and, c) if they would use such a resource. Spine surgeons agreed with the appropriateness and inclusiveness of the derived themes and subthemes stating that it “covers all areas” while some admitted that they had not thought of some of the derived content areas previously. “I believe this [derived themes and subthemes] tool would be useful to patients” and “I find the tool useful” were among many reassuring comments from surgeons on the derived resource.

One-on-one interviews with preoperative patients confirmed the utility of such a resource once developed (Figure 11) and the main themes and subthemes appeared inclusive to these patients. “It would have been great to have this [derived themes and subthemes]” said emphatically one patient. Lack of such postoperative information for one patient awaiting surgery was summarized as: “Nothing has been told to me about recovery. Not been told about restrictions. I have received the least information on postop course.” With regards to the need for temporal outline of such a resource, a patient commented that, “for sure it’s great to have a temporal outline of what to expect and the restrictions. This saves resources by me not going to see my doctor to ask about it.” Patients also liked the idea of an email service for specific questions. It was clear that many of the derived subthemes had not been discussed with patients during the consult or at the preoperative appointment as evidenced by a patient statement, “never gave that a thought” regarding the potential need for caregiver for patients.
The derived themes of this educational resource (Figure 11) were shared with postoperative patients that were initially interviewed prior to their surgery. As with other groups, the themes were inclusive for their needs and highly valuable. Their experience confirmed the importance of postoperative pain management education for patients as discussed already. Patients, now with the hindsight of having had surgery, agreed with the timing of the educational resource at the initial consult. The need for postoperative information was again confirmed by a patient who received “no instructions at all.” When asked about what instructions were given to patients after surgery, the responses by patients included: “we were sent home with one page, and the top portion was how to care for your wound, and the second one was basically take your medication” and “I went home blind.” These findings validate the importance of providing patients with information relating to their entire spectrum of care with emphasis on the postoperative course.

**Summary: Placing the Identified Themes into a Framework**

The pathway of care for microdiscectomy patients is outlined in Figure 4. Patients with symptomatic disc herniation are typically first seen by the primary care physician. Thereafter, patients can be referred to community services such as physiotherapy. Patients with persistent symptoms despite conservative modalities (e.g. physiotherapy) are referred to a spine surgeon for surgical management. During the consultation with a spine surgeon, patients deemed surgical candidates are offered a microdiscectomy while those patients not meeting surgical criteria are referred back to the primary care physician
and/or community for conservative care (e.g. physiotherapy or rehabilitation at home with an exercise/strengthening program).

The data and the results from this study represents the segment of the care pathway related to the surgical care of these patients. Those candidates who elect for surgery after a discussion with the surgeon are placed on a surgical wait-list. The majority of surgical patients are seen prior to surgery by the preadmission/preoperative team, which includes nurse educators and anesthesiologists. The details of this appointment have already been stated in the introduction chapter. Post surgery patients are transferred to the recovery room and once they meet the criteria they are transferred to the day surgery unit. Patients are discharged home from the day surgery unit. The first follow-up appointment with the surgeon is six weeks after surgery.

The derived information needs of microdiscectomy patients in this study are relevant to the surgical portion of the care pathway (i.e. from consultation to follow-up). Figure 4 illustrates how the study finding contextualizes the identified information gap in postoperative care within the care pathway of microdiscectomy patients.
Chapter 5
Discussion

The objective of my thesis was to determine the information needs of patients undergoing microdiscectomy. The central theme identified from the data was “desired components to an education resource” (Figure 10). All themes and subthemes were representative of and relevant to the central theme. The major themes related to content areas of information need from the data were: anesthesia information, procedure-related content and postoperative care (Figure 11).

Main study finding

Using qualitative methodology a gap in information provision that informs education needs, particularly related to the postoperative period of the continuum of care, was identified for people undergoing microdiscectomy. This information gap was developed inductively from the data. Figure 4 contextualizes my finding within the continuum of care for microdiscectomy patients. The context within which my themes are embedded requires knowledge of the patient care pathway (i.e. environment), understanding the participant’s point of view and the interaction between the individuals within the care pathway (Benzies & Allen, 2001; Jeon, 2004). It was therefore important for me as an observer of the interviews to capture what information patients knew, what they deemed important to know and the context of this information need within the care pathway.

The major study finding was that microdiscectomy patients desire more information than currently provided to them especially on postoperative-related care. Additionally, member-checking the derived themes from the data with pre- and postoperative patients
confirmed this finding. Figure 4 illustrates how the study findings are placed into a framework. Currently, surgeons, fellows and residents spend the majority of their time-limited discussion with patients on information related to the procedure and its associated risks and benefits, not on the postoperative course. This is understandable given the medico-legal implications of not covering risks and benefits with patients in the informed consent process. With limited time available to surgeons during a consultation with patients, perhaps it seems unnecessary for them to be discussing postoperative care details such as need for caregiver so far in advance. However, with patients’ interest hinged on postoperative information, the current content areas covered during consultations leave their needs unmet. Patients interviewed wanted to get on with their lives and once relieved of their pain wanted to do everything possible to get back to ‘normal’. Unfortunately, as it stands, patients are ill prepared for many aspects related to their postoperative care, and identify lack of information as a barrier to recovery. Given that most patients undergoing microdiscectomy are discharged the same day as their surgery, there is no opportunity for a health care provider to discuss their recovery course with them prior to discharge. A discussion by surgeons with patients post-anesthesia in the recovery room is not optimal as conveyed by patients who had little recollection of such conversations. The interview with the preoperative team revealed patients receive a generic booklet prior to discharge outlining wound care with no specific details on recovery, ambulation and limitations. Patients corroborated this and as a result, left the hospital “blind” and unsure of what activities they were allowed and what limitations they had. This leaves patients in a state of uncertainty until their follow-up, which can be as long as six weeks after surgery.
I will now review the available literature on the implications of such an information gap for microdiscectomy patients. A Cochrane review by Ostelo et al. (2000) showed that activity after lumbar surgery was not harmful and intensive postoperative exercise actually improved functional outcomes. The systematic search of the literature on the postoperative management of patients undergoing discectomy by McGregor et al. (2007) found good evidence that: 1) encouragement of mobility and return to full activities as soon as possible after surgery produces better relief of pain, and an earlier return to work; 2) early postoperative rehabilitation programs improve patient’s ability to carry out activities of daily living; 3) early return to work after surgery results in faster recovery and better clinical outcomes; 4) the rate of recovery after surgery (both for clinical and vocational outcomes) is greatest in the first three months and any further improvement occurs more slowly; and, 5) patients’ recovery may be facilitated if they know what to expect (McGregor et al., 2007). The study by McGregor and colleagues (2007) also reported strong evidence that patients do not know what they should or should not be doing during recovery from surgery, which is consistent with my study finding. When patients were given information on their postoperative course, Magnusson et al. (1999) found inconsistencies in the recommendations to patients postoperatively with regards to activities and limitations. Lack of advice, or inconsistent and contradictory advice, creates uncertainty for patients as to what they should or should not do postoperatively. This uncertainty may result in fear by patients to mobilize after surgery, which can create anxiety, inhibit rehabilitation and potentially compromise a desired outcome (McGregor et al., 2007). Given that the rate of recovery from lumbar discectomy is greatest within the first three months of surgery, patients may benefit from an education resource that
provides the content of such information in a time-specific or temporal format. This is especially true of postoperative subthemes such as recovery and limitations. Patients realized that what they can or cannot do at week one after surgery is different than at week four. Patients did not see their surgeon until six weeks after surgery, yet no time-specific information was given to them prior to leaving the hospital on their recovery, restrictions and limitations. As a result, patients are often afraid to partake in any activity for fear of damaging their ‘spine’. Providing time-specific recovery-related information in an education resource to patients would provide them with guidance and likely decrease their fears and anxiety around ambulation and activity postoperatively which may lead to improved outcomes.

Based on my observations of the focus groups, I postulate that patients want ownership over aspects of their care that they have control over. This claim was supported by a comment by one anesthesiologist who stated: “the things that are uppermost in their mind [patients] are the things that they have control over or that are going to influence what they can and can’t do. You know, what’s happening during the surgery, they have no control over that, there’s really nothing they can do about that, it’s going to happen.” Patients have no control over their surgical procedure and hence many of them were not interested in the details surrounding the surgical procedure. A patient confirmed this notion stating: “I wasn’t interested in the technicalities of what was going to happen during the surgery, I didn’t care.” Patients, however, do have control over their postoperative care – especially recovery. Hence, patients need a resource that outlines the postoperative course in order to fulfill their needs and afford them with more
ownership in their care. Providing a complete overview of the surgical process to patients by way of an information resource would allow them to take ownership of their postoperative care and help plan their lives.

The need for more information by the patients interviewed in this study was consistent with the literature reviewed on this topic. A study by Ronnberg and colleagues (2007) sought to see if patients undergoing surgery for lumbar disc herniation were satisfied with their care and the information provided to them. In their study, surgeons provided patients information on surgical procedure, surgical risks, outcomes, post-operative regimes and expected sick leave verbally on two occasions. The information on these themes was provided based on surgeon opinion. A physiotherapist also provided instructions, according to a practice routine, on how to handle activities of daily living after surgery. Despite their efforts, only 46% of the 148 patients were satisfied with the information they received preoperatively. Patients were least satisfied with the given information relating to surgical risks, time for sick leave, and postoperative regimen. Keulers et al. (2008) administered a survey to assess the importance of surgical information to surgeons and patients. The authors derived eight domains on the surgical process from their review of literature. The result was an 80-item questionnaire based on disease, examination, preoperative period, anesthesia, operation, postoperative period, self-care and general hospital information. Preoperative patients rated the relevance of being informed on each item. Surgeons were also asked to rate the relevance of informing patients on each item. Patients rated items related to the postoperative domain as more important when compared to surgeons. Conversely, surgeons deemed domains
related to the operation and disease as more important in comparison to patients. Overall, patients desired more information than surgeons perceived on most domains including preoperative period, anesthesia, operation, postoperative period, self-care, and general hospital information. The derived items from this study were inclusive, however, they were crafted based on literature review and author opinion. Such an exhaustive list of 80 items can also be time consuming and overwhelming for patients and consequently deter them from reading the material. McGregor et al. (2007) performed a systematic literature search in order to produce best-evidence information and advice on postoperative restrictions, activation, rehabilitation, and expectations about outcomes. The authors used this evidence-based information and developed patient-centred messages for an educational booklet. A draft text was synthesized and evaluated by experts and patients. This approach used existing literature to derive the themes instead of interviewing the end users – surgeons and patients. Phelan et al. (2001) conducted a randomized trial in which the authors investigated whether an interactive video program would be superior to written material alone for informing patients about surgical versus non-surgical options for spinal stenosis and disc herniation. The video content included graphics on spinal anatomy, information relating to the specific surgical procedure, risks and benefits and patient narratives on the surgical experience. The booklet had a similar content along with complete information on all treatment options. The content of these resources were derived from databases and published trials. The information video and booklets were not derived utilizing relevant stakeholders and patient input was not integrated into the education information. Another major weakness of their derived education resource was that no information was provided on the postoperative course such as recovery and
limitations. Table 3 illustrates the derived themes by these aforementioned studies. The derived themes and subthemes in this study are inclusive and in keeping with the published themes which are derived from literature and expert opinion. The importance of information related to postoperative care in this patient population was not however represented in the available literature.

The cited studies by Keulers, McGregor and Phelan all used scientific evidence for deriving patient information themes. Stakeholder involvement in the process of developing an information resource for patients is crucial for knowledge translation and the adoption of such tool into practice. The literature likely is best utilized to populate the content of the themes derived by stakeholders rather than deriving the themes themselves, thus providing credibility to the content of the information resource. Using literature alone to derive themes does not allow for stakeholder input into the derived themes, rather, it assumes the literature is representative of stakeholder needs. The importance of stakeholders in the development and the adoption of an information tool will be addressed in the knowledge translation section of this chapter.

**Potential implications of other findings**

Data from the focus groups showed that patients had the least desire for information related to anesthesia. Anesthesiologists were frequently asked questions related to the surgery and postoperative course instead of anesthesia-related topics. As a result, anesthesiologists often felt unqualified to answer such questions and suggested for the patients to revisit their surgeons. Anesthesiologists are not the appropriate provider to
answer questions related to spine surgery. Yet the need for a patient to revisit their
surgeon to address such questions is often not practical as the preoperative visit with the
anesthesiologist takes place one to two weeks prior to surgery. This may cause patient
frustration and anxiety.

Surgeons, fellows and residents underestimated how much pain and disability a patient
experiences after microdiscectomy. This is likely due to their perception of the procedure
being minimally invasive and the fact that patients are typically discharged without
overnight hospitalization. Patients told us they could barely go to the bathroom and
needed help performing many basic activities of daily living. Patients had significant
impairments in completing self-care postoperatively and required the help of a caregiver.
The biggest impact an education resource would have for these patients would be
outlining what they could expect in terms of activity, restrictions, pain, wound care,
caregiver need and physiotherapy while providing a time-frame for recovery. Having this
information in advance would allow patients time to prepare and plan for a caregiver (e.g.
spouse) once they are at home.

The subtheme of postoperative pain management was identified under both the anesthesia
and the postoperative themes. Patients had little guidance on how to taper narcotic pain
medications after surgery. Anesthesiologists echoed these concerns highlighting that
patients are ill prepared to manage their postoperative pain. Based on patient and surgeon
interviews it was apparent that surgeons and in many cases, primary care physicians were
not the ideal experts for helping patients wean from pain medication. Since
anesthesiologists are experts in pain management, they should be designated to provide the content information under this subtheme for a preoperative education resource for patients. Currently the vast majority of patients are sent home after surgery with a standard pain prescription from their surgeons lasting them 7 to 10 days. It would also seem appropriate for any patient on prolonged and/or high doses of pain medication to be referred for a consult with the anesthesiologist preoperatively to specifically obtain guidance for management of postoperative pain.

It would seem logical that a common understanding of the terminology and spinal anatomy by patients would be necessary in order for them to participate in a meaningful discussion about their diagnosis and proposed treatment options. Nevertheless, despite the surgeon’s best efforts to speak using non-medical terms, patients often left the consultation confused and unsure of what they were told and what they had consented to. This potentially leads to a barrier to patient participation in their treatment. Patients with access to the Internet conducted research on the proposed treatment. Given the inconsistent and often inaccurate information available on the Internet, the potential exists for misinforming patients and creating anxiety. Patient participation was further hindered by patient pain and nervousness during their consultation with the surgeon. One preoperative patient conveyed this as: “I was so nervous that I didn’t remember what he [spine surgeon] was telling me about surgery… I was really in pain.” Given that under the best of circumstances patients retain only a fraction of the information during a consultation (Gauld, 1981; Kitching, 1990; Turner & Williams, 2002), one ponders on how much is retained by patients in excruciating pain due to sciatica. An education
resource that provides common definitions of spinal anatomy and procedure terminology administered to patients could improve their understanding and encourage participation in their care.

Surgeons spent a great deal of time with patients discussing the objective of surgery along with its success rate, risks and benefits. Surgeons conveyed the importance of aligning patient expectations with realistic goals and outcomes expected from the surgery. Despite their best effort to communicate to patients the aim of discectomy – relief of leg pain – patients often asked surgeons during the postoperative follow-up if their back pain was going to improve. Given the risks at stake in spine surgery, ensuring patient expectations are realistic and obtainable are essential. Yet given the limited face-to-face time surgeons have with their patients and the numerous health care providers that a typical patient interacts with, it is not surprising that the goal(s) of surgery can be misinterpreted. Providing the goals of surgery, outcomes, risks and other procedure-related details in a resource to surgical patients at the time of the initial consult would allow patients to study and reinforce this information. If nothing more, it at least highlights the discussion points during the consultation in the event of disagreements with regards to surgical goals and risks postoperatively between patients and surgeons.

This study identified several factors that determine the extent of information that is given to patients by surgeons. Younger patients were perceived to be more inquisitive about their condition and seemed more “educated” according to residents and fellows. Patients’ comprehension and knowledge of their condition influenced the amount of information
they were provided by surgeons. Patients with previous surgical experience had insight into the process and frequently asked more questions. Similarly, family members accompanying patients posed additional questions to surgeons during the consultation. There were differing views on whether a patient’s socioeconomic status influenced the amount of information they were provided at the consultation. Residents and fellows associated the types of questions posed by a patient and the level of knowledge a patient possessed on their condition with a higher patient socioeconomic status. It is conceivable that patients with a higher socioeconomic status would have more access to information resources such as Internet and thus appeared more self-educated on their condition. Surgeons, however, disagreed, citing patient knowledge and socioeconomic status as distinct entities. Spine surgeons, like residents, provided more detailed information to patients they deemed as having a better understanding of their condition.

There is literature that supports that patient age and level of education influence Internet access (Pautler et al., 2001; Peterson & Fretz, 2003). Pautler and colleagues (2001) investigated the use of Internet for self-education by a cohort of patients with prostate cancer. The study found that patients used the Internet for health information if they were: 1) younger in age; 2) had a higher education level; 3) owned a personal computer; and, 4) had prior computing experience. It is somewhat ironic from the current study that patients who educate themselves prior to the consultation appear more likely to be given more information and advice by their surgeon during a consultation.
The current study also suggests that patients’ comprehension of the English language is a barrier to the extent of information they receive. If all patients have the same right to information, regardless of their language skills, surgeons and other health providers (e.g. residents and fellows) should consequently ensure to communicate with patients using easy to understand language and provide a translator if necessary. Efforts to decrease language barriers can include the use of pre-translated materials, use of simple words and/or translator services.

In order to establish rapport with patients and gain their trust, surgeons must interact with their patients face-to-face (Gignac et al., 2006). There is no substitute for this format and no education resource should be used to decrease this face-to-face interaction. Patients signing consent for spine surgery must feel comfortable with the explanations given to them and should have all their questions answered. In academic hospitals, often residents and fellows partake in the majority of the face-to-face discussions with patients. Given the study findings that large clinics pose time constraints specifically on residents and fellows, it is imperative that surgeons, who are most responsible and accountable medically, spend ample time with patients and not assume their resident or fellow had already covered the pertinent information related to surgery.

The typical spine patient will interact with many health care providers during their circle of care and as a result, the information given to them may vary in consistency. This inconsistency in the provided information causes patient confusion and can potentially affect their ability to trust the information they received from their surgeon. Surgeons
unanimously agreed that such inconsistency is problematic for patients. The challenge is hinged on the variability that exists in the surgeon’s practices both within and between institutions. Therefore, it would be difficult to provide identical information to patients undergoing discectomy in a large academic centre with several spine surgeons. To overcome this, any communication tool using the identified themes from this study would need to have its contents populated by individual surgeons. This would ensure consistency for all patients in the surgeon’s practice. In addition, a hand-written component in the pamphlet for proposed return to work date and other patient-specific details could be formatted, allowing the information resource to be customizable to patients. Research has shown such tailored information is associated with patient benefits (Damian & Tattersall, 1991; Hogbin et al., 1992; O’Connor et al., 1999). The information resource would then be shared with other health care providers within the patient’s circle of care, and in turn, serve to educate them on the surgeon’s practice further reinforcing consistency.

The administrative assistants in this study setting functioned as a liaison between patients and surgeons providing answers to patient’s questions. Other providers such as nurse practitioners or physician extenders may fulfill this role at other institutions. Patients confessed that they felt comfortable communicating their concerns with the administrative assistants. This comfort stems from the rapport they established with them through multiple interactions and phone calls. Administrative assistants are typically very familiar with their surgeon’s practice and can accurately answer many of the patient’s questions. It seems that the assistants serve to close the information gap that
exists for patients in their operative course. Arming them with an information resource for microdiscectomy would provide them with more direction while lessening the burden of emails and phone calls they receive from confused and concerned patients. The administrative assistants can then incorporate novel patient inquires into the frequently asked questions component of the resource thus creating an information loop.

Face-to-face discussion between health care providers and patients is the most desired method of communicating information according to the limited literature available on this topic (Higgins et al., 2005; Matter et al., 2009). There is conflicting literature, however, on the next most desired format of an educational resource for patients (Campbell et al., 2004; Chelf et al. 2001; Gagliano, 1988; Higgins et al., 2005; Matter et al., 2009; McPherson et al., 2001; Olver et al., 2009; Phelan et al., 2001; Ziebland et al., 2004). Overall, a written layout in the form of pamphlet or booklet was highly desirable to all stakeholders interviewed in this study. Even among patients who preferred the Internet, the use of a pamphlet was still acceptable. Given the small sample size of the patients in my study this finding is only suggestive and needs to be investigated. The proposed contents to the derived themes from this study could be supplied in a booklet using simple language along with diagrams and/or images of the spinal anatomy providing a visual illustration – deemed to be beneficial by surgeons. A website reference could be provided within the written resource with identical content geared for those patients preferring an electronic medium. Terminology would be defined within the resource along with all relevant information pertaining to the surgical process form the beginning to the end. This electronic medium would allow patients to directly search the website and obtain the information they need.
Patients’ response to the optimal time of providing surgical information was unanimously “the earlier the better”. Having the primary care physician provide such information prior to the consult with the spine surgeon – the earliest time frame – would create unnecessary anxiety or give false expectations to nonoperative patients. Providing such information during the preoperative visit is also suboptimal given its close timing to the actual surgery (e.g. usually a week before surgery). This would not allow patients enough time for preparation. Furthermore, patients expressed that shortly prior to surgery they felt too anxious to comprehend such a volume of information. This was conveyed by one patient as: “your brain is already saturated with so much, and plus you worry about the surgery.” It was apparent from the interviews with patients that the majority of their questions were generated after leaving the consultation. This was attributed to their nervousness, lack of understanding of the proposed procedure (i.e. the terminology used), and the pain they experienced during the consult. My study strongly suggested that the optimal time for providing an information resource to surgical patients was at the initial consultation, as soon as they are deemed a surgical candidate. This would optimize the patient’s knowledge of the surgical process and allow for them to formulate questions based on their reading of the material provided. It would also allow them to discuss the surgery and review the provided resource with family members. A Frequently Asked Questions (FAQs) section to the booklet or website would allow patients to not only get answers to common questions they may have but also to read answers to questions they did no think of. Where patients have more specific or unanswered questions an email or electronic message forum can be created and monitored by a health care provider if the spine practice or institution deems feasible. Those patients whose information needs are
still unmet can be brought back for another visit with the surgeon to discuss their questions and concerns. Ideally every patient that is deemed an operative candidate during the surgical consultation should be given an education resource in addition to the standard face-to-face discussion with the surgeon. Selkowitz and colleagues (2006) did not use this strategy in their published protocol of a randomized controlled trial to evaluate the effect of a patient education and exercise program on the quality of life and functional outcomes of microdiscectomy patients. The protocol proposed to randomly assign patients to one of two groups: 1) one session of back care education; or, 2) a back care education session followed by the 12-week specifically designed spine exercise program. The education consisted of a one-hour session with a therapist to review a booklet with the patient 4 to 6 weeks after surgery. The booklet’s content was derived using information surgeons typically provided to postoperative patients in their practice. The booklet was divided into four sections: normal anatomy of spine; anatomy of disc herniation; strategies on how patients can protect their back; and, commonly asked questions. The timing of the proposed education intervention by this study occurs after surgery instead of prior. With this study’s timing of information intervention, patients would have no postoperative instructions such as recovery and limitations until 4 to 6 weeks after surgery. The problems associated with the lack of guidance for patients in the immediate postoperative period have already been discussed.

Member-checks with spine surgeons confirmed the utility of an information resource containing the study’s derived themes and subthemes (Figure 11). Surgeons were willing to use such an information resource, as they believed it would help their patients.
Patients – both pre and postoperative – and surgeons found the content themes inclusive and appropriate. In fact both patients and surgeons admitted to not “thinking” about many of the derived content areas.

Knowledge Translation in Health Care

The findings of my study suggest that patients are ill prepared for surgery based on possessing insufficient knowledge, mainly around their recovery and postoperative care. Some of the patients interviewed were also uncertain of the other essential information – surgical risks and complications. Implementing such an information resource requires understanding of how knowledge is translated in the health care setting. Although not the focus of this thesis, I will discuss the basic requirements that are needed in order to allow the transition of such a resource from research to clinical practice.

Ian Graham (2007) from the Canadian Institutes of Health Research (CIHR) defines knowledge translation as: "the exchange, synthesis and ethically-sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system." Straus et al. (2009) believe that knowledge translation is about ensuring that decision makers at all levels of the health system (i.e. consumers, patients, practitioners, managers, and policy makers) are aware of, and can access and use research evidence to inform health-related decision making. The authors emphasized that knowledge creation, distillation, and dissemination are not sufficient on their own to ensure evidence-based decision-making
in the health care setting. The reason for this is that an understanding of the decision makers, their needs and the context is necessary prior to implementing strategies for knowledge translation (Straus et al., 2009).

Implementing such an education resource would require a change in the behavior, practice and policy by providers and the institution. A conceptual framework developed by Graham et al. (2006) called knowledge-to-action cycle has been recognized by CIHR as the accepted model for promoting the application of research. This framework for the process of knowledge translation is an iterative, dynamic and complex process relating to knowledge creation and its application. Intricate to this process is including the end users of the knowledge in the entire process to ensure that the knowledge and its subsequent implementation are relevant to their needs (Straus et al., 2009). This supports my rationale of including all relevant stakeholders in devising the contents of an education resource. Specifically, the pre- and postoperative patients were involved not only to derive the information needs but also to verify the final themes to ensure it met their needs. Surgeons also were included in identifying information needs of patients and the validation of the findings. This is important, as surgeon buy-in is essential to the success of implementing such a resource into clinical practice. Surgeons also are viewed as leaders in their work environment and it has been shown that leaders can influence the adoption of new innovation (Rogers, 2003). Rogers’s (2003) theory of diffusion of innovation describes the processes by which an innovation is adopted into practice. It states that an innovation is more likely to be accepted if it is perceived to be: (a) superior to what it is to replace; (b) compatible with the values, experiences and needs of those
who will use it; (c) able to be trialed on a limited basis; (d) simple to understand and use; and, (e) the effects of the innovation can be easily observed (Rogers, 2003). Since currently no other information resources are routinely provided to microdiscectomy patients, implementing such a resource would likely be superior to the status quo. The involvement of all relevant stakeholders in deriving the patient information content areas ensured it met stakeholders’ needs, reflected stakeholders’ values, and provided stakeholders with experience of the innovation. Once such a resource is developed, its adoption should be done on a trial basis and its impact measured as part of a research study in the near future.

The creation of knowledge for patients requires populating the contents under each derived theme based on the best available evidence. The content of the information resource needs to be ‘filtered’ using the end users (i.e. patients) to continually refine the material until its content is felt to be useful in order to allow knowledge creation. The action phase can occur sequentially or simultaneously as the knowledge creation. I would suggest that it occurs simultaneously to expedite the implementation of such a resource into clinical practice given the current deficiencies in the available information to microdiscectomy patients.

According to Straus et al. (2009), in order to implement such an education resource into practice, the following processes are required: “identification of the problem; identifying, reviewing, and selecting the knowledge to implement; customizing the knowledge to the local context; assessing the determinants of knowledge use; selecting, tailoring,
implementing, and monitoring knowledge translation interventions and knowledge uptake; evaluating outcomes or impact of using the knowledge; and determining strategies for ensuring sustained knowledge use” (p.4). The literature supports the notion of patients’ desire for more information. Identifying and selecting the content areas of information to deliver to patients has been the focus of this research and as already stated, the population and refinement of the derived themes are the immediate next steps in the development of this resource. What remains to be done is customizing the knowledge to the local context. Given the variability that exists in hospital policies regarding postoperative care and individual surgeon’s practices, it is not practical or feasible to provide the same information to all patients. Instead, each institution and surgeon can provide their patients with specific information as it pertains to their practice for each content area. This would customize the knowledge to the local care setting. Academic spine institutions should champion the use of such an education resource into practice and measure the impact of such a tool on patient outcome, satisfaction and other important measures. If similar benefits for spine patients are demonstrated, as was shown in hip and knee replacement patients (Nunez et al., 2006; Giraudet-Le Quintrec et al., 2003), its sustained use by surgeons will be enhanced.

**Future Directions**

In order to address the existing gap on the need for postoperative-related information by microdiscectomy patients a better understanding of the meaning of recovery in this patient population is required. Beaton and colleagues conducted a qualitative study on the meaning of recovery among people with musculoskeletal disorders of the upper limb
The study found that the perception of “being better” is highly contextualized in the experience of the individual. In order words, having recovered or “being better” does not necessarily mean that the disease state has resolved. Interestingly, when the participants described recovery in terms of disease resolution, the participants differed in their definitions, both in the type of change that they deemed to be representative of improvement and in the importance of that change to them. Spine surgeons need to understand the full impact of disc herniation on a patient’s life in order to completely understand what recovery means. A study into the meaning of recovery for patients with lumbar disc herniation should thus be conducted.

Currently, there is a lack of consensus among surgeons in respect of the need for, and the nature and timing of postoperative restrictions. Despite the strong evidence that most postoperative restrictions are not necessary and delay recovery and return to work, imposition of such restrictions seems to relate to clinician/patient anxiety and uncertainty (McGregor et al., 2007). A formal systematic review on the best evidence for postoperative-related themes such as restrictions, limitations, physiotherapy and expected symptoms should to be undertaken. Gaps in the literature should be identified and investigated with subsequent research studies. For example, a randomized study to evaluate the impact of activity after microdiscectomy at various time frames (e.g. immediate versus one week versus two weeks postoperatively) versus a formal rehabilitation program may improve surgeon consensus on postoperative activity/rehabilitation recommendations.
The aim of this study was to identify the information needs of microdiscectomy patients. This study utilized all relevant stakeholders in deriving the important themes and subthemes to an educational tool for these patients. The content under each derived theme and subtheme from this study can be populated using the best available evidence. For content that is missing in the literature, expert opinion can be utilized. Therefore, the immediate next steps to this research are: 1) populating the defined themes and subthemes based on the best available evidence; 2) ensuring the provided information is specific to each institution and/or practice where necessary; and, 3) refining the final resource through feedback from its end users – patients. In the near future, the impact of using such an informational resource should be assessed on outcomes such as patient satisfaction and anxiety level. Future research should also investigate the impact of using this information resource on patient’s general and spine-specific outcomes. Utilizing an education resource to reinforce realistic expectations around surgery and providing an outline of the postoperative course to patients, may translate into better-perceived outcomes by patients as reported by outcome questionnaires.

**Strengths**

A methodologically sound qualitative study must ensure rigour by utilizing: 1) audit trail (i.e. raw data including transcripts, interview notes); 2) field notes; 3) memos; 4) triangulation; and, 5) member checks (McReynolds et al., 2001). Rigour was met for this study by ensuring the availability of an audit trail, field notes and memos that would allow for subsequent reviews by other researchers. Triangulation in this study involved the use of multiple stakeholders as the data source as well as the use of multiple
researchers (i.e. clinicians and qualitative researchers) possessing unique skills and perspectives. Member checks with patients and surgeons allowed feedback and provided credibility regarding the accuracy of established themes and subthemes. The use of at least two researchers in independently coding each transcript and sharing the study findings with stakeholders for appraisal also afforded the study rigour.

The use of focus groups as the primary methods of data collections had several advantages. Given the objective of my research was determining patient information needs, focus groups allowed for an in-depth exploration of participants’ knowledge. The flexible nature of focus groups, allowed for unexpected findings such as barriers to patient information, which have significant value in the development of an education resource. Determinants of a successful focus group include range, specificity, depth and personal context (Liamputtong & Ezzy, 2001). The range of the focus groups was reflected in their ability to reveal unexpected issues while exploring as much information specific to the participants’ experiences and perspectives as possible. Another successful feature unique to focus groups was their ability to produce information by promoting interaction. Hearing about other people’s experiences stimulated others to share their own experiences, which they may have not remembered otherwise. The small group size along with the shared experience between participants served to enhance the discussion. Focus groups also allowed for direct interaction between the researcher and the participants. This allowed for immediate clarification, follow-up and probing of responses in addition to direct observation of non-verbal responses from participants. This study also met the required determinants of a high quality focus group according to
Krueger (1994) that include: 1) clarity of purpose (i.e. a clear purpose to the focus group); 2) the appropriate environment of focus groups that allowed for maximum group interaction free of intimidation and conflict; 3) selection of appropriate participants; 4) use of effective questions; 5) respecting and honoring the participants; and, 6) use of a skillful moderator.

This study used two analysts to review each transcript independently using a line-by-line coding method. Despite the use of independent coders, studies have suggested that although coders identify similar themes, the interpretation of those themes can be different reflecting the coders general framework of understanding and training background (Armstrong et al., 1997). Certainly the ultimate interpretation of themes rested on my understanding of the data. Armstrong and colleagues (1997) believe that this variability in interpretation of themes yields insight into the complex interplay that exists between the coder’s understanding of the data and his or her biography (Armstrong et al., 1997). This interpretative process is integral to the establishment of rigour as long as external peers agree that those interpretations are accurate reflections of the data (Atkinson et al., 1991).

Other strengths of this study included utilization of all relevant stakeholders especially patients and surgeons for data generation and validation of findings.

**Limitations**
There are several limitations to my study. Information gathered from focus groups represent only the perspective of the participants. The gathered information thus represents the range of views amongst stakeholders and not their prevalence. The assumption of using the focus groups as a representative sample of the population maybe problematic. The study findings may not be generalizable to other surgical procedures and institutions, especially where the time frames between consultation and surgery differ from those in our institution.

Compared with other methods such as surveys, the focus group participant selection and the potential bias for selecting more self-confident and outgoing individuals may produce a less representative sample (Sim, 1998).

Another potential weakness is the external validity of focus group results. Focus group data are contextualized within a specific social situation (Sim, 1998). In other words, it cannot be assumed that what a person says in a focus group is a predictor of what he or she will say in another social situation.

The findings of this study are, however, appropriate for limited generalization (Sim, 1998). The data gained from this study do possess a sufficient degree of generality to allow for its projection to other situations, which are comparable to my study setting. For example, the use of the derived themes to devise an education resource for other less invasive and outpatient spine procedures such as lumbar decompression may be possible.
It is further not possible to generate in-depth information from individual participants in a focus group due to the nature of the group interaction and the limited nature of the time provided for each participant to speak. In addition, some participants make conform with the responses of other members of the group even though they may disagree (Sim, 1998). More assertive participants may dominate the discussion and members of the group who are less confident maybe inhibited from expressing alternative viewpoints. The use of a trained moderator in this study setting decreased the likelihood of such an occurrence. Another potential weakness was the conduction of one or two focus group per stakeholder in this study. Although saturation was achieved and no new themes emerged from the data, it was not possible to determine consensus across one particular stakeholder (e.g. surgeons) without conducting multiple focus groups. Finally, since focus group questions are directed and controlled by a moderator, a biased moderator may prevent the participants from expressing their true concerns about the topic. The moderator of this study was naive to the topic of this research which should have eliminated or minimized such bias.

**Conclusion**

The quality of existing educational materials is difficult to assess without adequate reporting of the methods used to develop them. Few of the studies reviewed disclosed how the content of the information resources were developed. The key weakness common to all existing education resources is the lack of involvement of all relevant stakeholders in their conception in particular, the intended end user – patients. To the best of my knowledge, this is the first study that has utilized all relevant stakeholders in
deriving the information needs of microdiscectomy patients. Involvement of stakeholders in devising an education resource is important in its acceptance by the end users and its success in translation to clinical practice. Involving patients in my study provided data that no other stakeholder possessed as concurred by one patient, “there’s knowledge that the patients have that only the patients have.” I derived the essential framework of an educational resource utilizing all relevant stakeholders for its conception.

Patients need ‘mechanisms’ to obtain information. Currently, the existing mechanisms to provide patients with information at our institution are limited to surgeons and other health care providers, administrative assistants and the Internet. This study has demonstrated that these mechanisms were not sufficient for the patients interviewed in this study setting particularly in providing postoperative-related information.
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Table 1: Stakeholder Focus Groups

<table>
<thead>
<tr>
<th>Category</th>
<th>Number and Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spine surgeons</td>
<td>6 Fellowship trained spine surgeons</td>
</tr>
<tr>
<td>Fellows</td>
<td>3 Spine fellows</td>
</tr>
<tr>
<td>Residents</td>
<td>5 Orthopaedic residents</td>
</tr>
<tr>
<td>Preoperative patients</td>
<td>3 Microdiscectomy patients awaiting surgery</td>
</tr>
<tr>
<td>Postoperative patients</td>
<td>4 post-operative microdiscectomy patients</td>
</tr>
<tr>
<td>Postoperative patients</td>
<td>3 post-operative microdiscectomy patients</td>
</tr>
<tr>
<td>Anesthesiologists</td>
<td>4 Anesthesiologists</td>
</tr>
<tr>
<td>Surgeon’s Administrative Assistants</td>
<td>2 Administrative assistants in the spine practice</td>
</tr>
<tr>
<td>Preoperative/Preadmission team</td>
<td>6 staff that included: Nurse educators, perioperative manager, and team leader</td>
</tr>
</tbody>
</table>
Table 2: Focus Group Patient Demographics

Preoperative Patients

<table>
<thead>
<tr>
<th>Age (mean)</th>
<th>Gender</th>
<th>Pain duration (range)</th>
<th>VAS back (mean)</th>
<th>VAS leg (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>43.7 (20-67)</td>
<td>1 Male 2 Female</td>
<td>6 weeks-30 yrs</td>
<td>5.5 (1-8.5)</td>
<td>6.2 (3-8.5)</td>
</tr>
</tbody>
</table>

Postoperative Patients

<table>
<thead>
<tr>
<th>Age (mean)</th>
<th>Gender</th>
<th>Pain duration (range)</th>
<th>VAS back (mean)</th>
<th>VAS leg (mean)</th>
<th>Weeks postop (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>42.1 (29-58)</td>
<td>5 Male 2 Female</td>
<td>7months-40 yrs</td>
<td>3.4 (0-8)</td>
<td>4.3 (0-8)</td>
<td>5 (2-12)</td>
</tr>
</tbody>
</table>
Table 3: Summary of Existing Themes in the Literature for Surgical Patients Versus this Study’s Derived Themes

<table>
<thead>
<tr>
<th>Published study</th>
<th>Targeted patient population</th>
<th>Methods used to derive themes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keulers et al. (2008)</td>
<td>General surgery</td>
<td>Literature search and expert opinion</td>
<td>Disease, examination, preoperative period, anesthesia, operation, postoperative period, self care, general information</td>
</tr>
<tr>
<td>Phelan et al. (2001)</td>
<td>Spine surgery (herniated disc and spinal stenosis)</td>
<td>Literature search and institutional database</td>
<td>Anatomy illustrations including causes of low back and leg pain, surgical and nonsurgical treatment alternatives, outcomes with surgical and nonsurgical care</td>
</tr>
<tr>
<td>McGregor et al. (2007)</td>
<td>Spine surgery (herniated disc and spinal stenosis)</td>
<td>Literature search and refined by expert opinion. Themes refined by health professionals, pre- and postoperative patients</td>
<td>Anatomy and pathology descriptions, surgical technique, postoperative tips (activity, restrictions, work, rehabilitation) wound care and complications</td>
</tr>
<tr>
<td>Study</td>
<td>Procedure</td>
<td>Methodology</td>
<td>Focus</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>------------------------------------</td>
<td>----------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Nunez et al. (2006)</td>
<td>Total knee replacement</td>
<td>Literature search and expert opinion</td>
<td>Consequences of disease on daily life, energy conservation, joint protection, pain management, treatments for osteoarthritis, demonstration for use of assistive devise, and, exercises aimed to improve strength and range of motion in the knee as well as other joints.</td>
</tr>
<tr>
<td>Giraudet- Le Quintrec et al. (2003)</td>
<td>Total hip replacement</td>
<td>Expert opinion</td>
<td>Osteoarthritis of the hip, surgery, anesthesia, rehabilitation and patient questions</td>
</tr>
<tr>
<td>Current study by Zahrai et al.</td>
<td>Spine surgery (herniated disc)</td>
<td>Qualitative methods utilizing all relevant stakeholders including the end users – patients and surgeons</td>
<td>Anesthesia-related, procedure-related and postoperative-related information</td>
</tr>
</tbody>
</table>
Figures

Figure 1: Postoperative Patient Focus Group Employment Status

Employment

- 67% Working
- 33% WSIB

WSIB
Working
Figure 2: Anesthesia Information Content Area Subthemes and Descriptors

**Anesthetic risks**
- "Awareness during anesthesia, and that’s a very frequent question... years ago there was a movie called *Coma* and everybody was worried if they were going into OR 8, and then there was the movie *Awake.*" (Anesthesiologist)
- "I didn’t realize the anesthetic would have more of an effect on me than the surgery did." (Postoperative patient)

**Postoperative pain management**
- “I don’t think they [patients] realize that it’s going to be a big problem to have their pain under control post-op. I don’t think they have any idea.” (Anesthesiologist)
- “They come to surgery with the hope that their pain will be made better, and in fact sometimes it’s really hard to control when they’ve been on large doses of narcotics." (Anesthesiologist)
- “[Postoperative pain] Information that I would really like to have had.”(Postoperative patient)
**Figure 3: Procedure-related Subthemes and Descriptors**

| Definition of terminology | • “I didn’t even know the term ‘microdiscectomy’ until after I’d left the building” (Postoperative patient)  
  • “I’m not really sure what I’m agreeing to” (Postoperative patient)  
  • “Even the word microdiscectomy I’d never heard before! I had no clue what that was.” (Postoperative patient) |
|---|---|
| Diagnosis and treatment options | • “So the main things are that they understand the diagnosis, they understand what the surgery’s going to treat, what it’s likely not going to treat.” (Spine surgeon)  
  • “The patients do enjoy seeing their own images, so there’s something to be said about reviewing the MRI with the patient and showing them.” (Spine surgeon) |
| Overview of procedure | • “To show them [patients] what exactly you’re doing, in a very simple way.” (Spine Fellow)  
  • “[Patients] want to know your experience, they want to know you’ve seen it before.” (Resident) |
| Complications | • “[I] spend a great deal of time looking at risk and possible complications, making it very clear to them [patients].” (Spine surgeon)  
  • “Absolutely. Complications, every time. Most people don’t ask because they probably don’t really want to know what can happen.” (Spine Fellow) |
| Surgical goals and outcomes | • “I wanted to understand...what’s the percentile in terms of success rate that I’ll have? In terms of the pain I’m experiencing, how much will it be reduced? When will it be reduced by? Will it be a permanent reduction? Can I expect recurring problems?” (Postoperative patient)  
  • “They [patients] understand what the surgery’s going to treat, what it’s likely not going to treat.” (Spine surgeon)  
  • “What to expect with the surgery, what’s the objective, what are the typical outcomes?” (Spine surgeon) |
| Length of hospital stay | • “How long they’ll [patient] be in hospital.” (Administrative assistant)  
  • “How long they’re going to be in hospital. Hospital, for them [patients], is not their life: once they’re out of hospital they get back to their life.” (Spine Fellow) |
Figure 4: Placing the Findings into a Framework

Microdiscectomy Patient Care Pathway

Patient

Primary care physician  Spine surgeon  Rehabilitation

Community

→ = Patient flow

Spine Surgeon Consultation  Pre-admit Clinic  Surgery  Day Surgery Unit  Follow-up Visit

Surgeons, Fellows and Residents

Information provided

- Procedure Overview, Indications, Risks and Benefits

Information need

- Postoperative-related Information

Patient Information Gap
**Figure 5: Postoperative-related Subthemes and Descriptors**

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Quotes/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recovery time</strong></td>
<td>• “For me what was going to be most important – was recovery.” (Postoperative patient)</td>
</tr>
<tr>
<td></td>
<td>• “I wish I knew how long the recovery was really going to be.” (Postoperative patient)</td>
</tr>
<tr>
<td><strong>Restrictions and limitations</strong></td>
<td>• “Restriction in mobility from surgery” (spine surgeon)</td>
</tr>
<tr>
<td></td>
<td>• “My only question was what kind of limitations I will have.” (Postoperative patient)</td>
</tr>
<tr>
<td></td>
<td>• “I think also what’s important for the patient to know is what exactly they should and shouldn’t be doing when they go home.” (Manager in preoperative team)</td>
</tr>
<tr>
<td><strong>Expected symptoms and pain management</strong></td>
<td>• “Nobody’s told them [patients] that at six weeks they can still expect swelling or they can still have pain when they walk.” (Resident)</td>
</tr>
<tr>
<td></td>
<td>• “I wish I understood the extent of the pain.” (Postoperative patient)</td>
</tr>
<tr>
<td><strong>Wound care</strong></td>
<td>• “Any care of the incision [is discussed with patient]” (Nurse in preoperative team)</td>
</tr>
<tr>
<td></td>
<td>• “Incision, size, shape of incision” (Team leader in preoperative team)</td>
</tr>
<tr>
<td><strong>Need for caregiver</strong></td>
<td>• “I really relied on my husband and my children, but I mean just going to the washroom, rolling over in bed, getting out of bed, getting into bed, walking a short distance…I didn’t know it was going to be that bad.” (Postoperative patient)</td>
</tr>
<tr>
<td></td>
<td>• “I wish they had told me that for the next four days I needed somebody there.” (Postoperative patient)</td>
</tr>
<tr>
<td><strong>Physiotherapy</strong></td>
<td>• “Nobody from us will tell the patient how much physiotherapy he will need.” (Resident)</td>
</tr>
</tbody>
</table>
Desired Format and Attributes of a Patient Education Resource

- **Format:**
  - Customized pamphlet to ensure consistency of information given to patients from different sources
  - Visual aids
  - Frequently asked questions (FAQs)
  - Email or on-line message board for specific patient questions

- **Attributes:**
  - Resource should follow the surgical pathway timing (i.e. in a temporal format)
  - Material must outline each step in the process

- **Timing:**
  - Must be given at the time of surgical consult if a candidate
Figure 7: Patients’ Preferred Format for an Information Resource

Preferred Format

- Pamphlet: 40%
- Internet: 20%
- Face-to-face: 20%
- DVD: 10%
- CD-ROM: 10%
Figure 8: Causal Condition: Patient Factors Influencing the Extent of Information Delivered by Surgical Team

Patient Factors Influencing the Extent of Information Delivered by Surgical Team

- Age
- Language
- Presence of Family members
- Level of education
- Socioeconomic status
- Patient comprehension and self-education on disease
- Previous surgical experience
Figure 9: Causal Condition: Communication of Information with Patients

Communication of Information with Patients

- Information needs reinforcement
- Affected by time constraints
- Establishing rapport and gaining patient’s trust is achieved through face-to-face communication
- Delivered information must be consistent
- Providing patient information requires a liaison between surgeons and patients (e.g. Administrative Assistants)
- Engagement of primary care physician is essential for continuity of care
Figure 10: Derived Themes

Central theme

Anesthesia info

Desired components to an education resource

Desired attributes and format of education resource

Postop info

Procedure related info
Figure 11: Derived Content Areas or “Themes” (in shaded blue boxes), and Subthemes (in clear boxes) of Patient Information Needs According to Stakeholders

- **Anesthesia Information**
  - Anesthetic risks
  - Postoperative pain management

- **Procedure-related Information**
  - Definition of terminology
  - Diagnosis and Treatment options
  - Overview of procedure
  - Complications
  - Surgical goals and outcomes
  - Length of hospitalization

- **Postoperative Information**
  - Recovery time
  - Restrictions and Limitations
  - Expected symptoms and Pain management
  - Wound care
  - Need for a caregiver
  - Physiotherapy
Appendices

Appendix 1:
Semi-Structured Focus Group Guide – Anesthesiologist

**Background Information**

General introduction to process – explain that one person only should speak at a time and do NOT identify themselves before speaking. Thank everyone for attending, go over consent form and have them verbally agree to participate, explain how confidentiality and anonymity will be protected at point of transcription, etc.

**Warm-up and establishing rapport**

Brief overview of the focus group study objective

**Experiences of Pre-Surgery Consultation(s)**

How would you describe the discussion that you have with surgical candidates at the time of preoperative consultation or prior to the surgery in the OR?
  - How much time do you spend answering patient questions prior to surgery?
In your opinion what do patients most want to know during your interaction?
  - What do patients most fear?
  - What do you tell them?
  - What would you want to know?
Do they seem well informed on their surgery or condition?
  - What are patients most likely to forget?
Do you feel patients are generally satisfied with the information given to them?

How often do you provide them information on their surgical procedure? What is your rational for doing this?

**Information Needs at Different Points of Care**

What resources if any are made available to them preoperatively on anaesthesia?

How much education are patients provided in terms of their pain post-op?

**Recommendations for Information Delivery**

In your opinion what would be the best format for providing patient information? (video, brochures, etc.)?
How likely would you be to make use of (go through various options here) it?

**Cool-Down/Wrap-up Questions**

Is there anything else I haven’t asked you about that you’d like to add?
Appendix 2:
Semi-Structured Focus Group Guide – Surgeons, Fellows, and Residents

<table>
<thead>
<tr>
<th><strong>Background Information</strong></th>
</tr>
</thead>
<tbody>
<tr>
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<td>Brief overview of the focus group study objective</td>
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</table>

<table>
<thead>
<tr>
<th><strong>Experiences of Pre-Surgery Consultation(s)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you describe the discussion that you have with surgical candidates at the time of consultation?</td>
</tr>
<tr>
<td>- How much time do you spend answering patient questions prior to surgery?</td>
</tr>
<tr>
<td>- Is this adequate? Is time a barrier to educating patients on their condition?</td>
</tr>
<tr>
<td>In your opinion what do patients most want to know?</td>
</tr>
<tr>
<td>- What do you tell them about the surgery and recovery?</td>
</tr>
<tr>
<td>- In your opinion what should they know about their surgery or condition?</td>
</tr>
<tr>
<td>- What would you want to know if you were a patient?</td>
</tr>
<tr>
<td>In your opinion who is the best person to deliver this information to patients?</td>
</tr>
<tr>
<td>What are the barriers to having someone else provide the information?</td>
</tr>
<tr>
<td>Do you feel patients are generally satisfied with the information given to them?</td>
</tr>
<tr>
<td>How often and to what extent do you rely on what has been told to them by other members in the team?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Information Needs at Different Points of Care</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>What resources do you think should be made available to them after the consultation?</td>
</tr>
<tr>
<td>- In your opinion is this feasible?</td>
</tr>
<tr>
<td>How much education are patients provided in terms of their return to ADLs, work?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Recommendations for Information Delivery</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>In your opinion what would be the best format for delivery of patient information? (video, brochures, etc.)?</td>
</tr>
<tr>
<td>How likely would you be to make use of (go through various options here) it?</td>
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</table>

<table>
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<tr>
<th><strong>Cool-Down/Wrap-up Questions</strong></th>
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<tbody>
<tr>
<td>Is there anything else I haven't asked you about that you'd like to add?</td>
</tr>
</tbody>
</table>
Appendix 3:
Semi-Structured Focus Group Guide – Preoperative/Preadmission staff

**Background Information**

General introduction to process – explain that one person only should speak at a time and do NOT identify themselves before speaking. Thank everyone for attending, go over consent form and have them verbally agree to participate, explain how confidentiality and anonymity will be protected at point of transcription, etc.

**Warm-up and establishing rapport**

Brief overview of the focus group study objective

**Experiences of Pre-Surgery Consultation(s)**

How would you describe the discussion that you have with surgical candidates at the time of preoperative visit?
- How much time do you spend answering patient questions?
- Is this adequate? Is time a barrier to educating patients on their condition?

In your opinion what do patients most want to know?
- What do you tell them about the surgery and recovery?

Do you feel patients are generally satisfied with the information given to them?

Do you feel patients are well informed of their operative procedure?

Do you feel patients understand the postoperative journey?
- Recovery
- Limitations
- Caregiver need

**Information Needs at Different Points of Care**

What types of resources do you think should be made available to them after the consultation?

How much education are patients provided in terms of their return to ADLs, work?

**Recommendations for Information Delivery**

In your opinion what would be the best format for delivery of patient information? (video, brochures, etc.)?
- FAQs
- Pamphlet
- Website
- Email question blackboard

**Cool-Down/Wrap-up Questions**

Is there anything else I haven’t asked you about that you’d like to add?
Appendix 4:
Semi-Structured Focus Group Guide – Preoperative patients

<table>
<thead>
<tr>
<th>Background Information</th>
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<tr>
<td>General introduction to process – explain that one person only should speak at a time and do NOT identify themselves before speaking. Thank everyone for attending, go over consent form and have them verbally agree to participate, explain how confidentiality and anonymity will be protected at point of transcription, etc.</td>
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<tbody>
<tr>
<td>Brief overview of the focus group study objective</td>
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</table>

<table>
<thead>
<tr>
<th>Expectations of Pre-Surgery Consultation(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please describe your experience at the initial consultation</td>
</tr>
<tr>
<td>- By whom was the information relating to your condition delivered?</td>
</tr>
<tr>
<td>- What information was given to you?</td>
</tr>
<tr>
<td>- How was this information communicated? (delivered versus discussion)</td>
</tr>
<tr>
<td>- Did he or she answer all your questions?</td>
</tr>
<tr>
<td>- Were you satisfied?</td>
</tr>
<tr>
<td>What was most important for you to know about your upcoming surgery?</td>
</tr>
<tr>
<td>What was most important for you to know about your recovery?</td>
</tr>
<tr>
<td>- Who provided you with information on your surgery?</td>
</tr>
<tr>
<td>- Who do you think should provide you with this information (i.e. who would you prefer)?</td>
</tr>
<tr>
<td>Why?</td>
</tr>
<tr>
<td>After leaving the clinic how much of what was told to you do you remember?</td>
</tr>
<tr>
<td>- What would help you better remember health information?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Information Format, Timing, etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td>When would be the most appropriate time to discuss different aspects of your surgery and recovery with you?</td>
</tr>
<tr>
<td>What is your preference for obtaining health information? (Audio, Video, etc)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cool-Down/Wrap-up Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there anything else I haven’t asked you about that you’d like to add?</td>
</tr>
</tbody>
</table>
Appendix 5: Semi-Structured Focus Group Guide – Postoperative patients group 1

<table>
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<tr>
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<tbody>
<tr>
<td>General introduction to process – explain that one person only should speak at a time and do NOT identify themselves before speaking. Thank everyone for attending, go over consent form and have them verbally agree to participate, explain how confidentiality and anonymity will be protected at point of transcription, etc.</td>
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<th>Experiences of Pre-Surgery Consultation(s)</th>
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<tbody>
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<td>Please describe your experience at the initial consultation</td>
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<tr>
<td>By whom was the information relating to your condition delivered?</td>
</tr>
<tr>
<td>What information was given to you?</td>
</tr>
<tr>
<td>How was this information communicated? (delivered versus discussion)</td>
</tr>
<tr>
<td>Did he or she answer all your questions?</td>
</tr>
<tr>
<td>Were you satisfied?</td>
</tr>
</tbody>
</table>

| What was most important for you to know about your upcoming surgery? |
| What was most important for you to know about your recovery? |
| Who do you think should provide you with this information (i.e. who would you prefer)? Why? |

| After leaving the clinic how much of what was told to you do you remember? |
| What would help you better remember health information? |

<table>
<thead>
<tr>
<th>Information Needs at Different Points of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Looking back, what do you now know about going through this surgery that you wish you had known beforehand?</td>
</tr>
<tr>
<td>What would you tell other patients about this surgery?</td>
</tr>
<tr>
<td>Were there any surprises about the surgery or recovery?</td>
</tr>
</tbody>
</table>

| What information should be provided to patients? |
| How were your information needs after the surgery provided? |

<table>
<thead>
<tr>
<th>Recommendations for Information for other patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>When would be the most appropriate time to discuss different aspects of your surgery and recovery with you?</td>
</tr>
<tr>
<td>What is your preference for obtaining health information? (Audio, Video, etc)</td>
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</table>
Appendix 6:  
Semi-Structured Focus Group Guide – Postoperative patients group 2

**Background Information**

General introduction to process – explain that one person only should speak at a time and do NOT identify themselves before speaking. Thank everyone for attending, go over consent form and have them verbally agree to participate, explain how confidentiality and anonymity will be protected at point of transcription, etc.

**Warm-up and establishing rapport**

Brief overview of the focus group study objective

**Experiences of Pre-Surgery Consultation(s) and postoperative course**

What was most important for you to know about your upcoming surgery?
- Other patients have stated that they were unsure of what questions to ask. This was due to lack of knowledge about the procedure and the medical terminology discussed with them. Did you have a similar experience?

Who had the most influence on your decision to have surgery?
- Other patients have suggested their family doctor had a major influence in their decision. Do you agree?

What was most important for you to know about your recovery?
- Other patients felt they were told very little about the postoperative course (e.g. limitations, return to activities, pain after surgery). Was sufficient information provided to you in this area?

How important is the role of the surgeon administrative assistant for obtaining information?
- Other patients felt more comfortable asking the assistants questions than the surgeons. Who would you prefer to give you information on your surgery and postoperative course?

What information were you given at your preoperative or preadmission appointment?
- Was the information consistent with what you had been told by your surgeon?
- Was the timing of this information appropriate? (e.g., too late)

**Information Needs at Different Points of Care**

Looking back, what do you now know about going through this surgery that you wish you had known beforehand?
- What would you tell other patients about this surgery?
- Were there any surprises about the surgery or recovery?

How were your information needs after the surgery provided?
- Was any feedback or information provided to your family doctor? Would this be useful?

**Recommendations for Information for other patients**

When would be the most appropriate time to be given a comprehensive information tool on your operation and postoperative journey?
- Other patients preferred to have it immediately at the initial consultation once they were deemed surgical candidates. Would you agree?

What is your preference for obtaining health information?
- Other groups have suggested a website or pamphlet with visual aids along with a FAQ.

Would this be a good idea?
- Patients have suggested an email blackboard to send and have your specific questions answered by qualified personnel. Would this be useful?

**Cool-Down/Wrap-up Questions**

Is there anything else I haven’t asked you about that you’d like to add?
Appendix 7: Approval Letters from Research Ethics Boards

MEMORANDUM

To: Dr. Albert Yee
Orthopaedic Surgery
Room MG 317

From: Dr. Philip Hébert

Date: August 4, 2009

Subject: Preoperative Information: What Do Patient’s and Surgeon’s Deem Important?

Project Identification Number: 146-2009
Approval Date: August 4, 2009

The Research Ethics Board of Sunnybrook Health Sciences Centre has conducted a Delegated Board review of the research protocol referenced above and approved the involvement of human subjects as specified in the protocol on the above captioned date. The quorum for approval did not involve any member associated with this project.

The approval of this study includes the following documents:

- Protocol dated June 30, 2009
- Appendix 1: Interview Guide dated June 30, 2009
- Appendix 2: Demographic form dated June 30, 2009
- Appendix 3: Visual Analogue Pain Score (VAS) dated June 30, 2009
- Appendix 4: Preferred format question dated June 30, 2009
- Patient Informed Consent Form dated June 29, 2009
- Surgeon Informed Consent Form dated June 29, 2009

The above Project Identification Number has been assigned to your project. Please use this number on all future correspondence.

Should your study continue for more than one year you must request a renewal on or before one year from the approval date. Please advise the Board of the progress of your research annually and/or any adverse reactions or deviations which may occur in the future.

The Research Ethics Board of Sunnybrook Health Sciences Centre Operates in Compliance with the Tri-Council Policy Statement, the ICH/GCP Guidelines and Division 5 of the Food and Drug Regulations.

Fully affiliated with the University of Toronto
Approval of this study by the Sunnybrook REB entails that this study complies with current legislation as outlined in the Ontario Personal Health Information Protection Act (PHIPA) and all policies and guidelines established by Sunnybrook Health Sciences Centre. All applicable contracts and agreements must be submitted to Sunnybrook Research Administration before this research may be initiated.

Philip C. Hibbert, MD PhD FCFPC
Chair, Research Ethics Board
To: Dr. Albert Yee  
Orthopaedic Surgery  
Room MG 317

From: Dr. Philip Hébert

Date: November 25, 2009

Subject: Preoperative Information: What Do Patient's and Surgeon's Deem Important?

*Project Identification Number: 146-2009*

The Research Ethics Board is in receipt of your amendment submission form dated November 18, 2009 and has reviewed and approved the following documents pertaining to the above referenced study.

- Summary of Proposed Changes – Amendment November 2009
- Amended Protocol Version date November 17, 2009
- Revised Information sheet/consent form Version date November 17, 2009

This study may continue at Sunnybrook Health Sciences Centre.

During the course of the research, any significant deviations from the approved protocol and/ or any unanticipated developments must be brought to the attention of the Research Ethics Board.

Thank you for keeping the Board informed.

Philip C. Hébert, MD PhD FCFPC  
Chair, Research Ethics Board

OR

Blair Henry  
Vice-Chair, Research Ethics Board

The Research Ethics Board of Sunnybrook Health Sciences Centre Operates in Compliance with the Tri-Council Policy Statement, ICH GCP Guidelines, Part C Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Products Regulations, and the Medical Devices Regulations. All Health Canada regulated trials at Sunnybrook are conducted by a Qualified Investigator.

Fully affiliated with the University of Toronto
University of Toronto
Office of the Vice-President, Research
Office of Research Ethics

PROTOCOL REFERENCE #24383

August 21, 2009

Dr. Albert Yee
Division of Orthopaedic Surgery
2075 Bayview Ave. RM MG-371
Toronto, ON M4N 3M5

Dr. Ali Zahrai
Division of Orthopaedic Surgery
2075 Bayview Ave. RM MG-371
Toronto, ON M4N 3M5

Dear Dr. Yee and Dr. Zahrai:

Re: Administrative Approval of your research protocol entitled, “Preoperative Information: What do Patients and Surgeons deem Important?”

We are writing to advise you that the Office of Research Ethics has granted administrative approval to the above-named research study. The level of approval is based on the following role(s) of the University, as you have identified with your submission:

- Graduate Student research – hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board. Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University’s involvement requires ethics review.

Best wishes for the successful completion of your project.

Yours sincerely,

Daniel Gyewu
Research Ethics Coordinator
Appendix 8 : Patient Demographics Questionnaire

Date questionnaire completed:                                        Day  Month  Year

ID #__________________  Age: ______

Sex
☐ Male
☐ Female

Please indicate if you have the following conditions:

☐ Other lower limb joint problems (Hip/knee)
☐ Diabetes
☐ Heart condition
☐ Lung problems
☐ Thyroid Conditions
☐ History of Stroke/ Hemiplegia
☐ Depression
☐ Cancer
☐ Peripheral Neuropathy
☐ Other

Please tell us a bit about yourself:

1. How much schooling have you completed?
   a. Less than high school
   b. Graduated from high school
   c. Some college
   d. Graduated from college
   e. Postgraduate school or degree

2. What statements describes your current employment situation
a. Currently working
b. On leave of absence
c. Unemployed
d. Homemaker
e. Student
f. Retired
g. Disabled and/or retired due to ill health
h. Other- specify: ______

3. Are you currently involved with, or planning to become involved with and of the following:
   a. Disability (eg. insurance, Canada Pension Plan)
   b. Worker’s compensation (WSIB)
   c. Litigation
   d. None

4. How long have you had back and/or leg pain?
   ______ Weeks
   ______ Months
   ______ Year(s)

THANK YOU
Appendix 9: Patient Reported Back and Leg Visual Analogue Pain Scales (VAS)

1. Please circle your current back pain level on this scale:

![Back Pain Scale]

2. Please circle your current leg pain level on this scale:

![Leg Pain Scale]
Appendix 10: Patients’ Preferred Format for an Information Resource
Questionnaire

Please circle your preference for the desired format for an educational tool:

1. Pamphlet
2. Internet
3. CD-ROM
4. Interactive Computer Program
5. One-on-one information session
6. DVD
7. Audiotape
Appendix 11: Types of Coding in Thematic Analysis

Coding is a continuous process
Appendix 12: Open, Axial and Selective coding

Open Coding:

- Open coding breaks the data down into discrete parts
- Examines the components for similarities and differences
- Conceptually similar in nature or related in meaning are grouped under more abstract concepts termed “themes”
- Place the same code or theme for similar components of data

Axial Coding:

- Puts the data together and makes connections between a theme and its subtheme
- Defines the properties of a theme and its dimensions
- Forms more complete and precise explanations about the concept or phenomena behind the theme
- Identifies conditions, actions/interactions, and consequences associated with a theme
Selective Coding:

Process of integrating and refining themes

First step: identify a central theme that represents the purpose of the research

Ensure derived themes are representative, relevant and deduced based on all of the data