

Oh! Canada: Southeast Asian Immigrants' Experience of Osteoarthritis (OA) Surgery

Patient Engagement Research Study Report

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*Patients Matter: Engaging Patients as Collaborators
to Improve Osteoarthritis Care in Alberta*

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Introduction

This qualitative study is the research component of an internship in the *Patients Matter* Project¹, and is one of the three studies that we, as interns, are completing to inform the Bone and Joint Strategic Clinical Network (BJSCN) about patients with osteoarthritis (OA). The concept of patient engagement research, in which patients (or family members) work as researchers with other patients who have a similar disease, is taken from the work outlined in *Grey Matters* (Marlett & Emes, 2010). We, Rashika Kalia and Rooh-Afza Khan, are the two primary researchers working on this study. I, Rashika, was recruited by my university professor, Nancy Marlett, because of my close ties and involvement with my (ethnic) community. I chose to participate because I want to widen my horizons and become proficient in qualitative research. I, Rooh, have a family history of osteoarthritis and am now experiencing the early symptoms of this condition. My primary interest is in finding solutions for the day-to-day management of the disease. Marlyn Gill, one of our colleague patient engagement researchers, joined our team at later stages and contributed to our analysis and write-up. Two academics from the University of Calgary, Nancy Marlett and Svetlana Shklarov, are teaching research methods in the project, while Mary Sheridan, who has experience in the *Grey Matters* project, is the mentor.

During the six-month academic training portion of the internship, we became interested in the experience of people with OA who had reached “the end of the road” and had to have joint replacement surgery. Our curiosity was initiated and grew as a result of much discussion among the original interns in the program, as well as information gleaned during practice focus group and interview sessions. The literature that we consulted indicated that post-surgery patients, most often seniors, experienced vulnerability and uncertainty (Alami et al, 2011) and that such patients needed guidance and reassurance

¹ The *Patients Matter* Project has been completed in partnership between Alberta Health Services and the University of Calgary (Community Rehabilitation and Disability Studies and the Institute for Public Health). The project was funded through a two year grant from the Canadian Foundation for Healthcare Improvement (CFHI).

(Smythe, Larmer & McNair, 2012) so we decided this was an experience we wished to explore with these patients. To add an extra layer to the research, since we are both multi-lingual, we decided to focus the research on the Southeast Asian Community. The inquiry we undertook was to investigate the experience of Southeast Asian immigrants with joint replacement surgery.

Background and Literature Review

While this study is the first peer-to-peer qualitative research into the experience of Southeast Asian older patients following a hip or knee replacement or other OA related surgery, much work has been documented around the difficulties such immigrants to Canada encounter. Despite Canada being recognized as a multicultural society where “each wave of new immigration has added to the nation’s ethnic and cultural composition” (Statistics Canada, 2011, p. 6), much literature is devoted to outlining the difficulties that immigrants are facing. The most recent flow of immigrants into Canada, 57% of whom originate from Asia (Statistics Canada), are noted as having some difficulties adopting a Canadian lifestyle and seem to have problems successfully accessing available services including satisfactory health care (Zanchetta & Poureslami, 2006).

The difficulties facing immigrants, especially elderly men and women, are many and varied. Ahmed et al (2008) noted that women from India have trouble accessing and understanding health information as they are more used to “informal means of obtaining information such as social networks, mass media and written materials in their mother tongue” (p. 22). They also encounter language problems when trying to communicate with health professionals and are dissatisfied with “the doctor-patient relationship, particularly about the doctor’s quality of care, poor listening skills, lack of explanation and limited time” (Ahmed et al, p. 28). Such language problems reveal other problems for the elderly when they are forced to use “educated young members of the family” as interpreters. Culturally it is not acceptable to talk about health issues and the use of younger family members as interpreters may lead to incomplete disclosure of problems as well as “lead to complications because of role reversal” (Weiss et al, p. 282). This has a

twofold detrimental effect on the family as the elders are put in a subordinate role causing discomfort for both them and the young family member.

Weiss et al (2006) noted that there might be a disparity between the Canadian health care system and that of their home of origin. In many Southeast Asian countries there is a strong private fee-for-healthcare system and “patients of high social status are treated as social equals and in a socially intimate manner” (Weiss et al, p. 282), so some immigrant patients may perceive that they are not being well served by a Canadian system. The authors also note that traditionally, in the immigrants’ country of origin, if money is scarce, priority for medical treatment is given to the male breadwinner and any sons leaving women, girls and elders to manage as best they can.

In addition to all the cultural problems facing immigrant women, there are the acknowledged needs of all older patients who choose to undergo hip or knee replacements. Stephens (2002) tells us of the importance of social interaction and support following joint replacement surgery when he states, “social and personal contexts of surgery can provide resources that aid recovery by facilitating approach-appetitive striving” (p. 378). The level of engagement with psychosocial supports before, during and after surgery are often key predictors in recovery; the higher the engagement the better the recovery as both mood and activity levels often depend on the interaction with others (Stephens).

It has also been noted that social support appears to motivate patients to engage in rehabilitation of their prosthetic joints as “social support has a strong independent positive association with greater quality of life improvement” (Fitzgerald et al, 2002, p. 108). Furthermore, women tend to score lower in physical functioning after joint replacement than men, a finding that Stephens (2002) ascribes to a tendency for women to delay surgery lest they burden their families. If one takes the factors necessary for a good recovery from joint replacement, it would appear that Southeast Indian immigrant women are facing fairly stiff odds in receiving timely treatment and ideal recovery situations.

Given the above information, we think that there is a need for Canadian health care systems to engage in cultural competence. This means we need to “create a healthcare system and workforce that is capable of delivering the highest care to every patient regardless of race, ethnicity, culture or language proficiency” (Betancourt et al, 2005, p. 499). We hope that this study will illuminate any difficulties in this respect and help a movement in Alberta “to improve outcomes and help control costs by making care more effective and efficient” (Betancourt et al, p. 500).

This qualitative study, using patient engagement research, is one of the first steps in becoming familiar with the challenges facing immigrant patients who require joint replacement surgery.

Engagement Methods

Our study, as is common with many qualitative research endeavors, started off encompassing a very broad scope. We thought we knew what we needed to investigate and what questions we should ask. Our first or SET focus group, described below, soon had us changing our minds. We had forgotten that the power of patient engagement research lies in the hands of the participants, not the researchers. Our participants had very clear ideas about what was important to them and the topics they saw as central to their experiences of joint replacement surgery. We saw this as an opportunity for us to uncover the hidden pathways to self-recovery; a way to discover how, as noted above, against great difficulties, members of the Southeast Asian community managed their post-surgery recovery in a country far, in all respects, from their familiar homeland.

The choice of engaging participants from the Southeast Asian immigrant community was very personal for us. As partners in research we have the ability to reach out to patients whose first language is Punjabi, Hindi, and Urdu, a population largely ignored by most researchers because of language and cultural barriers. We are connected at multiple levels with this group, and a high level of connection through a shared experience is integral to patient engagement research. We were able to connect with our participants at a deep and meaningful level, not only through our OA experiences, but also because we

understood, and were understood by our participants, to have intimate knowledge of shared cultural norms and appropriate language. We understood the importance of relationship ethics and the multiple differing meanings of words and concepts. This freed both the participants and ourselves, so that we were able to reach a trusting level of relationship that allowed us to enter the reality our patient-participants lived. We found engaging with the diverse Southeast Asian participants both exciting and challenging. It required flexibility, an ability to move from their language of choice into English and then back, as we kept them informed and engaged. Engagement meant being available at any time to answer questions, address concerns and generally stay on top of keeping our participants informed about the research process.

We followed the SET COLLECT REFLECT structure and philosophy outlined in *Grey Matters* (Marlett & Emes, 2010), using narrative interviews lasting between 45 and 70 minutes for the COLLECT component. We analyzed the interviews using the narrative format described below to allow the stories to emerge ensuring that we had “the commitment to get close, to be factual, descriptive and quotative [which] constitutes a significant commitment to represent the participant in his or her own terms” (Patton, 2001, p. 28).

Recruitment

For all three sections of the study we recruited our participants from the Southeast Asian community through posters in appropriate languages at Temples, Gurdwara, Mosques, a local community centre, ethnic restaurants, and by word of mouth. We were fortunate in being able to have most of the same participants for both the SET and REFLECT focus group components. All of the participants were from the Southeast Asian community, had experienced knee replacement surgery within the last five years, and were willing to talk about their post-surgery experiences. The ages ranged from 50 to over 70, and it was notable that most of these participants were dependent on family members for transport, so we picked them up and drove them to and fro the focus group locations. We interviewed each narrative interviewee in his or her home. We translated the consent forms into Punjabi, Hindi and Urdu as we went through them with the group, making sure

everyone fully understood what they were signing, following the same procedure with each of the nine individuals in the narrative interview section of the study.

SET Focus Group

The SET focus group, as noted above, had seven participants, including six women and one man. All had experienced knee surgery within the last five years. We were fortunate in our location for this session as one of the Southeast Asian businesswomen in the community gave us part of her restaurant for the meeting. This meant that we were able to provide a comfortable relaxing atmosphere and milieu for our participants.

After the necessary form signing we explored the participants' post surgical experience, using the following guidelines for our investigation:

- Tell us about your experience with OA.
- Could you tell us a time when you felt helpless after surgery?
- What could have improved your post-operative experience?
- What is one thing you would like to change about your experience prior to surgery?

This was a very participatory group and we were soon fielding answers in Punjabi and Urdu, which we translated into English for inclusion on the flip chart notes. The flip chart made it easy for them to come up with a great deal of additional information as the majority of the participants read and understood English. We also had a process recorder following and noting all the interaction.

The research question that we initially proposed was focused on peer support and the immigrant patients' sharing their experience with their peers. We were interested to know what patients with OA post-surgical experience learn from each other. However, when we came to analyze the flip chart notes and process recording in order to find out what was most important for the participants, we discovered, despite our efforts to focus on peer relationships, the discussion kept coming back to their experiences "back home." This is where the power of patient engagement research came through; our participants

were telling us what was significant in their lives. We knew we had to use this information about the differences between their lives in India and the ones they now led in Canada; the SET focus group set the stage for our work in the narrative interviews.

COLLECT: The Narrative Interviews

Our narrative interview component had nine participants, eight females and one male; eight of the nine had both knees replaced within the last five years. All of the interviews were carried out in the participant's first language. The interviews were taped, and the tapes were then analyzed as described below in the Data Analysis section.

Participants

Krishna is a very active 75-years-young woman who immigrated to Canada forty years ago with her loving husband and two sons. She is now a widow living with one of her sons, the other having married and moved to the U.S.A. She has had both knees replaced, one eight years ago, the other three years ago, and indicated that she believes her OA is a result, among other things, of her active participation in jazzercise and running. "I believe that the reason my knees became so weak is because of the way I used to walk where I would not lift my foot high enough and would stumble. Also another reason as to why my knees deteriorated was because I would do jazzercise without the right footwear."

Darshan came to Canada, sponsored by her elder son, on August 18, 1999. Prior to moving to Canada she had enjoyed an active, outgoing life in India with her husband, two sons, her daughter and their families. Her first surgery took place in 2003 followed by her second in 2011. "I never worked outside the home after coming to Canada. My knees would hurt a little bit in India and pain increased once coming to Canada because I wouldn't go out a lot, or lack of walking here."

Kalash, age 70, with two sons and two daughters, came to Canada with her husband in 1994. She had three surgeries and numerous tests before being diagnosed with spinal arthritis. Moving to Canada meant giving up a very active lifestyle, working on her farm. "I think my condition was caused because of the weather here in Canada, because I could

not go out as much and I did not work. I was much more active back in India with the farm work.”

Nashan, Kalash’s husband, age 73, came to Canada along with Kalash in 1994, both being sponsored by their elder son. They are currently living together separately from their children. Nashan had both knees replaced at different times in 2012. He worked as a farmer in India. “Prior to my wife being sick I used to be more active and worked at a furniture factory for seven years, until I retired in 2004. Because of my wife’s illness I could not go out as much, which caused my knees to be in pain. Since my wife’s illness I have not been able to look after my health as much because I was busy taking care of my wife.”

Kartar, who was sponsored twenty years ago by her daughter, lives with her husband, two sons and their families. She was a housewife in India. Mostly performing household chores. At the time of her interview she had one knee replacement done in 2011. When we contacted her in July of this year she was recovering from a June surgery on her other knee. “When coming to Canada I felt alone because I was used to living in an open space and now I had to stay indoors. Sons did not allow me to work outside the home, although my husband worked for a few years.”

Parkash, age 77, came to Canada more than 25 years ago, with her husband and their remaining dependent daughters; all were sponsored by her eldest daughter. Parkash is an educated and active woman who raised four daughters. Her first knee surgery was performed in July, 2010 and she and her husband currently reside with her married daughter’s family. “Pain in knee started after coming to Canada. [I] worked in a hat factory for ten years and quit in 2000 because of old age.”

Gursharon, age 53, came to Canada sponsored by her father in 1996 at age 36. She is a very independent woman who ran a boutique in India and had experienced no knee problems until she came to Canada. She started having knee pain in her forties and had her first knee surgery in 2002 and the second in 2005. “Problem started when I came to Canada due to the work (standing close to eight hours) at Armstrong cheese factory.

Worked at airport as a cashier, standing job. Thought problem was because of weight, started to exercise, maybe because of weather. Body couldn't balance the temperature."

Satinder, age 73, has two sons and two daughters. Coming to Canada in 1991, she was sponsored by one of her daughters. In India she did farm work and housework. She had her first knee surgery in 2011 and her second knee was replaced in August, 2012. "Knee problem started 15 years ago when in Canada."

Ajmer, sponsored by her daughter, came to Canada in October, 2010. In India she was a housewife who not only looked after her one son and two daughters, but also helped her husband in his dairy business. Her knee surgery took place in March, 2013. "I could not work outside of the home because of my knee problem. My pain in my knees got worse when I came to Canada because of the cold weather."

It should be noted that all of the participants, named or given pseudonyms, gave permission for the above information to be released.

After the necessary form signing, we used the following guiding questions to help participants explore their post-surgical experiences:

- How did you feel on your first day back home after surgery?
- What experiences did you share with others after your surgery?
- What did you learn from other people who had the same experiences?
- Reflect on your story.

We interviewed each of the participants in his or her own home, and all interviews were taped, with careful notes taken. The setting allowed each narrator to be comfortable with the process, thus allowing the emergence of rich, complex stories. Both the experiences and reflections on the experiences emerged as we listened carefully to our interviewees.

REFLECT Focus Group

We held the REFLECT section of the research in the home of one of our participants, once more providing an intimate relaxed milieu for the emergence of ideas. At this meeting we presented our analysis of the SET focus group and the information we had gained from the ten narrative interviews. We used the following guiding question to ensure our analysis and findings were an accurate, true reflection of experiences:

- How do these findings fit with your experiences after surgery?
- How might these findings be used to help patients with OA who are scheduled for, have had surgery?
- What other observations and thoughts do you have?
- What future research can you suggest?


Once more, we asked our questions in Punjabi, Hindi, and Urdu, translating the responses into English for inclusion in our process notes, although tape recording the conversation in the participants' first languages as they spoke. We received confirmation that our findings were accurate reflections of participants' experiences, beliefs, thoughts and feelings.

Data Analysis

Narrative Analysis. We used the following form (Table 1) to record all of our data with respect to the emerging scripts, ensuring that we kept a record of the participants' names with their respective quotes. This meant we had a clear audit trail strengthening the credibility and trustworthiness of the research (Lincoln & Guba, 1986).

Narrative Script Form. The narrative analysis followed the process outlined in Grey Matters (2010) and used information from both the set/reflect focus groups and the nine narrative interviews.

Table 1
Narrative Analysis Format

Title
Plot <i>(Triggers; strategies)</i>
Outcomes/Consequences/Lessons <i>(PER Researchers' summary)</i>

<p>Storyteller's reaction to telling the story/what they learned:</p> <p>Your reaction to the story, what you learned:</p>

We followed the following steps:

1. The first step was to identify the story units and ideas from each of the narrative interviews. This was done using the story analysis format. This provided a reference to the quotes and ideas for each participant. From this point we began to look for stories that were shared by other participants.
2. The search for common stories yielded 14 general story areas. These were identified by beginning with one story element (e.g. a quote that suggested an antecedent, plot action or a consequence). With each story fragment we looked through the other stories to collect similar ideas that could relate to the same story. These general story ideas were entered on the story analysis format. We,

- the researchers and the instructors, spent time combining story elements and experimenting with potential stories.
3. From this analysis process, we identified seven general storylines and used the short form process to identify the common scripts. This included finishing the following three sentences:
 - a. "When ..." (the antecedent)
 - b. "I ..." (the action within the plot)
 - c. "Then ..." (the consequence)

We have chosen to use narrative scripts to analyze and present the information. Such scripts, in general, are the recognizable patterns that repeat in many similar stories; a script makes the particular story relate to other similar stories. In other words, script is a common pattern that can explain many stories recounted by different storytellers, or the same storyteller. Bruner (1990) explained scripts as the "canonical events" which introduce the meaning or frame of a story. Labov and Waletzky (1967) defined scripts as the referential core of personal narratives.

We also used "phenomenological reduction" (Patton, 1990, p. 408) which involves looking at each interview in great detail, breaking each interview into pieces of information finding distinct elements or categories that make up the experience of the phenomenon thus coding the data (Patton).

We believe that, as a result of shared experience on a multitude of levels explained above, we were able to use patient engagement research, narrative interviewing and analysis, as well as phenomenological reduction of the data, to explore our participants' post-surgical experience at a depth and richness unobtainable by any other means.

Articulating Experience

Following the methodology outlined above in the Engagement Methods section, we identified seven general story lines, or scripts. Each of the scripts is presented along with a background produced by us, as researchers engaged with the Southeast Asian community. We were able to use our contacts and experience within the community to

attempt to provide additional information giving some context for the scripts to assist health care providers who are unfamiliar with the strengths and challenges of patients within the Southeast Asian Community. Quotations are drawn from the data gathered from the narrative interviews and focus groups, as described in the Data Analysis section, and are embedded in the text to support the scripts we have identified in the data.

1. Oh! Canada: *When I came to Canada I got arthritis. I couldn't help my family and I was homebound.*

This first script emerging from the data shows us that those immigrants from Southeast Asia experience difficulty in adapting to the more severe climate in Canada particularly the winters in Calgary. They have enjoyed a mild climate in their home of origin and the change encountered here in this county has a profound effect on older immigrant, affecting their physical and mental health. Eight out of nine participants told us that the change in weather from their country of origin when coming to Canada either caused their joint pain or was responsible for a definite worsening of any joint pain they had noticed "back home." "The knee pain started because of the weather change from India to Canada," Satinder told us, while Nashan said, "I believe that because it is cold in Canada my knees may have worsened because it is much warmer in India." Parkash and Kartar were in no doubt that their OA was climate change related when they variously stated, "the pain in my knee started after coming to Canada" (Parkash), and "I had no knee pain when I was in India" (Kartar). The Canadian winters also affected Ajmer whose "pain in the knees got worse when I came to Canada because of the cold weather."

Kalash, who also told us that she thought her OA was weather related, "I think that my condition was caused because of the weather here in Canada," went on to address a second issue around weather when she added, "I was unable to go out and work. I was much more active back in India with all the farm work." This is echoed by most of the participants. Gursharon related, "I had no problem with the knee back when I was in India. It started when I came to Canada due to the type of work I was doing where I had to stand for eight hours and I don't think my body could balance the temperature change."

Coming to Canada meant not only increased joint pain, but also profound changes in lifestyle and activity levels. The severity of Canadian winters, as shown by Kalash (“I could not go out as much and did not work”), is allied to a change in roles within the family: “I was busy with housework and taking care of the grandkids” (Satinder). In addition, this change in roles meant oftentimes that these participants experienced long periods of isolation. As we will see below in more detail, family became a sole resource for support. Nashan told us, “I don’t have a lot of close friends because I spend most of my kids.”

Harsh weather-related isolation, as well as physical disability, caused many participants to become depressed. Kartar told us, “when coming to Canada I felt alone because I was living in an open space and now I had to stay indoors.” This theme is picked up by Darshan: “Most of the time I would be alone after coming to Canada. Back in India you are much more social where friends are constantly visiting ... I felt like a prisoner here in Canada.” The familiar pattern of life in India, where those who stayed home when children and spouses went off to school or work would run errands and drop in on friends, was lost. Gone too was the familiarity with a whole village and all the people like deliverymen and the local shop owners. In its place is the reality Darshan expressed, “I stayed indoors because I didn’t know a lot of people here and I didn’t understand the white community.”

One of the key stressors evident in the Oh! Canada script is the severe change in climate. Antonovsky (1985) believes that such stressors cause physical and emotional harm to a person’s general wellbeing. He posits that we need to utilize General Resistance Resources (GRR) to combat the stressors in our lives. Although many programs are available in Calgary to help immigrants settle and integrate into a very different world, these programs are not always available or accessible to those who are working or who are isolated within their homes. Elderly immigrants are also generally more reluctant to engage in these programs on their own either because of fear of revealing their lack of discomfort or for practical reasons such as lack of transportation. If there were greater

accessibility to learning how to adapt to the climate, particularly to winter, together with other older immigrants, there might be some alleviation of this stress.

2. Family Re-Formation: *When I was back home, I lived as part of an extended family and older people were looked after. When I came to Canada, I was expected to take care of my family because childcare is expensive here and family needs to get ahead.*

This compelling script outlines the huge changes in family composition and role older immigrants face when coming to Canada. Back home families did not just consist of parents and children, but also included paternal aunts, uncles, cousins and grandparents all living under one roof. The head of such families are the elders, usually the grandparents, who are in charge of making important family decisions such as who would marry whom, settling family disputes, and budgeting family expenses. Nashan and his wife found it particularly difficult four years ago when they moved out of their son's house to live alone. They expressed an experience of having a sense of feeling abandoned and neglected by their son and his family who no longer wanted them to live with them as "they caused a lot of work." Nashan told of having "to be with my wife all the time, which made me housebound and inactive ... which caused my knees to be in pain. Since my wife's illness I have not been able to look after my health much as I have been too busy taking care of her."

In India grandparents like Nashan and Parkash, as the heads of the family, are taken care of by their sons and daughters who ensure all their needs are met; they are at the top of the family hierarchy. Like the majority of older immigrants from Southeast Asia, our participants were sponsored by one of their children and are expected to take over house care and look after their grandchildren while the parents both work. This constitutes a major role shift and change in the hierarchy of care. Family support remains central to Southeast Asian families but the nature of support shifts.

All of our participants have osteoarthritis and have had at least one joint replacement surgery. Family played an integral role, both negative and positive, during the surgical experience. A repetitive element in the script is the part family played in the timing of

surgery, “even though many seniors need surgery many of them have to work around the family’s schedule” (Parkash). Many participants put off having necessary surgery: “I was usually busy with the housework” (Parkash), and “the discomfort with the knee continued to increase but I never paid much attention to it because I was busy with the housework and taking care of the grandkids” (Krishna). There was a reluctance to become a burden on the family by not fulfilling the necessary childcare role: “it becomes difficult to schedule surgery since I take care of my two grandkids and my daughter-in-law works ... if I didn’t have to take care of the kids then I would have had my surgery earlier” (Kalash). This belief is echoed by Satinder who told us “if I had my knee surgery five years ago, I would be in a better state now.” Participants also had to time surgery when it was convenient for all the family members. Darshan told us that she had to wait for her daughter-in-law to “co-ordinate their work schedule around my surgery,” while Kartar said, “I was scheduled for surgery but had to go to India for my son’s wedding and when I returned I got a new surgery date.”

A second negative element in the script with relation to role shift within the family occurs because of a language barrier. While this barrier does exist in their day-to-day life, many older immigrants who have little English and are put in a stressful situation such as visiting a surgeon or being in hospital after surgery, find it very difficult to either understand or communicate their needs. They rely mostly on their sons to act as interpreters: “my son and daughter would go to all of my appointments with me to interpret the information. I’m not sure exactly what information I was given prior to surgery because I don’t understand English. My son got all the information four days before surgery;” “my son went with me two or three days prior to the surgery to get more information” (Kartar). This need for translation puts patients in an extremely dependent position in relation to their children with respect to their healthcare. They may not always get all their questions answered, and are only aware of what their children choose to tell them. This can increase the anxiety level around the surgery.

Despite the difficulties outlined above, the data shows that these participants experience extensive support from their families before, during and after their joint replacement

surgery. Satinder says, “without the support of my family I would never have got the surgery done ... I overcame my fear of surgery because of the support of my family ... I always had someone at home after surgery to help me.” This is echoed by multiple voices. “The daughter whom I live with always made sure all my needs were met,” “all of my children were with during all four surgeries” (Kalash), and “living together with family was very beneficial after surgery because someone was always there to help me” (Ajmar). Sons, daughters, grandchildren and husbands showed family solidarity by helping out and taking time off work: “my husband took time off work after my surgery to help me” (Darshan) and, “after surgery my daughter-in-law used her vacation time to take care of me” (Kartar). “One of my daughters who would be available would always go with me to my appointments” (Parkash), and “when I got home my family would made me walk after surgery” (Darshan). While the role reversal may have got in the way of having surgery, once the surgery was scheduled and performed, family became central to the care and recovery process.

Key stressors revealed in this script include role-reversal issues, financial challenges and dependency on younger family members. These stressors are difficult to change since most elder immigrants have no personal financial support, and learning English to the point of being able to comprehend medical language is unlikely to happen because of their lack of interaction with the world beyond their families.

3. *Friendless: When I came to Canada, I left behind all my friends. Now I live a closed family life.*

Isolation is the topic of the third script. “I felt trapped when coming here and missed back home because I could go out a lot more and visit friends and families” (Ajmer). There is a sense of being imprisoned or marooned on a desert island with no contact to the outer world, “here in Canada I felt alone. I don’t have a lot of friends. I felt like a prisoner in Canada” (Darshan). This sense of being unsupported by friends outside the home, as noted in the literature review, is detrimental to a speedy recovery from surgery.

While it is difficult, given the barriers already noted for older immigrants, some do develop some level of relationship with people, usually acquaintances through temples and mosques. Satinder and Kartar “talked to peers from the temple and they would share their surgery experiences”; “peers at the temple would tell me how to sit after surgery. They were useful.” These do not tend to be like the close relationships they had developed over time in their homeland, although they do become a source for knowledge and encouragement about the upcoming surgery. Ajmer tells us that “talking to my friends made a big difference because it gave me hope before and after surgery... I also talked to a family friend who had knee surgery for both her knees and she told me what to do and what not to do. She gave me the confidence to go through with the surgery.”

Nashan also appears to have been fortunate to find a friend, although it is notable that the friend is from the same place as Nashan had lived in India. “I went to visit a friend who was from the same village as me to see how he was doing after his surgery. I asked him how he was feeling and he told me that he was much better and advised me that one should get surgery because it was worth it in the long run.” Gursharon found friends outside the usual places as she “would talk to people from my swimming class to get more information on what to do to alleviate the knee pain, such as exercise.” Others, like Krishna, were not able to form any relationships outside of close family, “I don’t go outside of the home or to the temple so my interaction with peers is limited.” Parkash, too, stated “I did not speak to any peers before my surgery because I did not go out a lot except when I was working.”

There is little doubt that the participants’ circle of friends and their connectedness with the world outside their homes shrank significantly when they left India for Canada. The key stressor affecting wellbeing and recovery from surgery is the physical and emotional isolation described by these participants. Many seem to be trying to overcome the seclusion they experience, but they are working against significant obstructions in their quest.

4. No English?! *When I am with my family in Canada my spouse / son / daughter speaks on my behalf and tells me what I need to know.*

This script, which tells of the effects the inability to communicate effectively in English has on the participants, is alluded to in nearly every narrative. There are direct medical ramifications for recovery when the participants lack of knowledge of English. As we discussed with the role reversal within the family participants are dependent on family as translators. "My son or daughter would go with me to my appointments to translate the information" (Ajmer). This means that the patient is not in control of either the information that is received or the decisions to be made from that information.

This is completely different from their situation in their homeland where they are perceived as competent adults capable of consulting with health professionals and making their own decisions. Now, as Kalash says "I'm not sure exactly what information I was given prior to the surgery because I don't understand English but my son got all the information four days before the surgery." This lack of knowledge and the ability to make one's own decisions about one's care is very frightening for patients already in the anxiety-provoking situation of facing joint replacement surgery. It is as if they are put into a childlike position where the adults, their own children, are making all the decisions; lack of English has stripped these patients of whatever autonomy they might have had. Kartar expressed this as "I'm not sure exactly what information I was given prior to surgery because I don't understand English ... my son got all of the information four days before surgery." Darshan recounts a similar experience: "my son went with me two to three days prior to surgery to get more information."

Only two participants on the day of their surgery were provided with interpreters. Satinder had a telephone interpreter "I went to hospital on the day of my surgery with my son but there was an interpreter on the phone who translated everything I was told," while Nashan had an interpreter "present to provide service in Punjabi."

Not only did our participants go into hospital not really knowing what to expect, they faced the daunting task of trying to get their needs met by staff who, with the best will in

the world, were not always sure of what the patients wanted. Kartar encountered such problems and says “for my next surgery I would like someone at the hospital to speak Punjabi ... during my last surgery I had an incident where I couldn’t go to the bathroom and I couldn’t explain it to the nurse.” Kalash and her family tried to get around this difficulty as her “son made me a list of items which I may need in Punjabi and next to that the word was written in English.” Strategies such as this may be helpful, but they don’t cover every eventuality. Most of the participants wanted to leave hospital as soon as possible: “I would have stayed longer at the hospital but I did not understand the staff and my daughter-in-law could not always be there so I decided it would be best if I went home” (Kartar). It is possible that some patients may be released earlier than might be usual because of the distress they experience being in an alien environment which they cannot understand and one in which they cannot make themselves understood.

Not being in control of their own healthcare decisions and being isolated in a world they cannot understand unless there is a family member present are two significant stressors which affect the success of the surgery. Acting as interpreters also puts family members under stress time wise, and possibly with having intimate knowledge of their parents they might rather not access. One wonders why two participants were provided with interpreters; is this something case managers could arrange for all non-English speaking patients? There is also a need for printed information to be available in the patients’ first language.

5. *What Services?! When I am offered services after my surgery I turn it down because I have support from my family and feel uneasy to take advantage of free services.*

This story tells us why most Southeast Asian patients chose not to use post-surgery services. Firstly, as noted in a previous section, family support and taking care of family is a major belief and indeed one of the supporting pillars of this society. “I was offered services after the surgery but I refused because of family support” (Satinder). Kalash, too, refused offered services: “I was asked if I had help at home and I told them that my daughter-in-law would be home along with my daughter who lives nearby to take care of me, therefore I didn’t think I needed additional support.” There is also an indication that

patients feel uneasy around using or taking advantage of the healthcare system and there is little doubt that patients are more comfortable having family to help them.

One of the differences between healthcare provision in Canada and that in India may also be responsible for the refusal of services. In India most patients pay directly for care at all levels so our participants would shy away from incurring any extra expense for their families. Gursharon commented that, “doctors in India are very good if you can afford them” and Kalash noted “I had seven sessions of exercise after my surgery and after that it would have cost me but I decided that seven was enough for my recovery.” Money and the beliefs around not being a burden to their families plays a part in refusing services as does their homeland experience. In India you have to find your own surgeon, pay for all medications used in the hospital and depend on your family for post surgical care. “There are many hospitals in India which offer good service but one needs money to access it” (Darshan).

However, many of the participants had no idea of any post surgical services, while others had incomplete knowledge. “No-one advised me prior to surgery about services that are available after surgery” and, “I never knew there were services offered after surgery which I could access,” said Darshan and Kartar. Knowledge of services appears to come from friends who have had surgery and as we noted above these participants were fairly isolated and did not speak or read English. Darshan expressed this well, “what we have seen is patients who have family did not feel the need to accept services after surgery.” The only experience of support came from a tight knit community that revolved around family support. Kalash was told about services when a worker came to her home. However, she tells us “the worker who came to my home would speak English and my daughter-in-law would translate but if she wasn’t there I would have refused services.” Without the sanction of family Kalash would not have accepted the available post-surgery assistance.

The major stressors here may be the traditional belief that service costs money and isolation from mainstream knowledge. While these beliefs and situation can be changed, it might be useful if healthcare providers were more open about available services.

6. The After Effect: *When I got my surgery I thought everything would be okay. I had no idea what I was in for.*

Surprise around the post-surgery experience is the theme here. The majority of our participants had no idea of the level of pain they would have to endure after their surgery. Ajmer reflects the thoughts of others when she says, "When the doctor came the next day to check on my knee I was in so much pain I thought I was going to die." No one seemed to have warned these patients that the first few days after surgery would be extremely painful and that they would have to make sure that their pain medications were given on time.

These surprises were usually the result of misinformation. As we noted above, everything is filtered through a family member who may not fully understand, or may be reluctant to frighten or upset their parent by warning them about the pain or the possibility that the surgery might not be successful. Kalash related "I continue to experience pain throughout my body and doctors don't really tell me how I can overcome the pain. The pain ... has overtaken my life. Prior to my surgeries I was active and outgoing and would go to the temple to visit with friends but now I am stuck at home." Darshan, who was persuaded to have surgery after watching a video, told us, "after watching the surgery video, I knew the surgery had to be done so I went with the flow. I felt helpless during the first surgery and regretted my decision to do the surgery because of the pain." Whatever video she had seen had not prepared her for the physical and emotional reality of undergoing joint replacement surgery.

None of our participants appeared to understand that there were risks of complication in all surgeries, and that the older one was, the greater the risk. Gursharon, who has undergone three knee surgeries, experienced various complications. "After my first knee surgery I was in the hospital for ten days because my blood pressure was fluctuating and I had pneumonia after two of my surgeries. I also had shortage of blood during the second surgery and was in the hospital for three weeks." Nashan had complications when he got home: "After my first knee surgery I got an infection and had to go to the ER where I had a reaction to a certain medication which caused a skin rash ... it has been over a year now

and my skin problem has not gone away and continues to bother me.” Problems can also occur when patients believe they have not been properly informed about the surgical procedure. This may happen, as noted above, because much is lost in translation or, as sometimes happens in surgery, the surgeon decides to change the procedure depending on what he or she finds when the patient is “opened up.” Not being told about this possibility can adversely affect a patient and cause setbacks in recovery. Gursharon had such an experience when she “was not told by the specialist that they had performed a partial knee replacement until after. I was shocked to learn that partial surgery was done and was very upset not being able to understand the surgical procedure clearly which caused resentment towards the healthcare system.” Her recovery was delayed because of this lack of information or understanding.

The stressors in this script come from not being fully or accurately informed about possible pain and surgical complications. A question arising here is how consent forms are managed and who signs them. Not having their expectations met for a fairly speedy, relatively pain-free, and uneventful recovery can adversely affect both recovery and the patients’ perceptions of the healthcare system. “Back home” these patients would have had a much better understanding of the post-surgical experience.

7. Point of No Return: *When I had pain in my joints I tried to deal with it by taking medications, but then I could not tolerate the pain anymore and had surgery.*

The final script tells us how and why the participants tried to avoid surgery as long as possible. Once more, there are elements that echo the findings in the narratives. The new role in the family, as outlined above, makes it difficult for these patients to put themselves first. Kartar explains, “if I didn’t have to look after the kids then I would have had surgery earlier.” They know they are there to look after grandchildren and they are all too aware that someone will have to look after them during their post surgical recovery. “My daughter-in-law took off two weeks after my surgery to look after me,” recounts Kartar as she explains why it took so long for her to agree to surgery. Even though their physicians recommend surgery, most waited “in pain for years before [they] got surgery” (Parkash). They usually try the temporary fix of pain medications as Parkash did: “the use of

medications is another common way to avoid pain and surgery.” Eventually some reach the end of the road. Nashan recounts, “I asked the specialist if there were any other medications I could take to alleviate the pain, but he said no, and that surgery is required for both knees.” Putting off surgery can have a detrimental effect on a successful outcome as Satinder knows to her cost, “if I had my knee surgery five years ago, then maybe I would have been in a better state than I am now.”

The stressors in this script are fear of being a burden and not fulfilling the family expectations in their new country. It is difficult to see how these can be alleviated. It is possible that counselling could alleviate some of this stress; however, many elder immigrants are unfamiliar with such support and may be very reluctant to share intimate and personal knowledge with a stranger.

Conclusion

While each of these scripts is a major story line in its own right, the scripts are inextricably intertwined. They paint a vivid picture of the differences between life in India and life in Canada and point to the courage of the participants. These patients are not only facing surgery and some level of disability because of their OA, they are doing it having been uprooted from their traditional familiar lifestyle. They have lost their position in the family and are faced with unfamiliar and harsh weather conditions. How confusing and frightening must it be to deal with pain and surgery not really understanding what healthcare professionals are telling them and without supportive friendships to keep them going? While most of the participants are happy with the eventual results of their surgery, how much easier could it have been if the healthcare system fully practiced the cultural competence outlined in the literature review?

The Journey

Rooh's Journey

When I became part of this project, I did not know what my commitment level would be, how involved I would become with the community, and I did wonder if my partners

would be as willing as I to invest their time and effort. At the beginning of the project I was acting *temporarily* as a single parent, and I was working a full time job in addition to preparing for my Medical Council of Canada Licensing exams. Fortunately, this turned out to be a great experience. Not only I was teamed with a great partner who was as enthusiastic about the project as I was, she also had strong community ties and relationship.

I learned that it is not about us! Patients will let us know what issues should be addressed and how we can work with them to address them in a positive and constructive way. They are tired of being seen from a roadside approach; they know they have assets, they bring experiences, skills and knowledge to the table and our research work should include them.

Finding a research project already in progress that we can contribute in is one way to get needed exposure. In my case, I was able to become involved in this project from the beginning and was provided with a further opportunity to participate in the Cardiovascular Health and Stroke Strategic Clinical Network (CVS SCN) as a patient engagement research consultant.

When I entered the PER study process, it did not help much with my understanding of how to bring this research idea to fruition. As I was introduced to other experienced faculty that acted as my advisors and mentors, it did not take me long to understand and implement those into our research study. Learning and implementing a different style of writing is a challenge at every age, let alone my age, having been trained to write academically, and to begin writing as a conversationalist writer. There were times when I was alone and reading my typed notes out loud (which at time did not make sense to me) and my house mate (Brenda) hearing me, came up and lent me her ears, input and generous feedback to put me back on track.

The greatest benefit from this experience was the ability to pick the brain of my advisors and mentor, who explained to me the steps they took to develop a research idea and see it through. By getting my name out there and helping with research, I now have

experienced faculty from different departments offering to help me with any questions I have in my own research endeavors.

“Remember you are not the only one who feels lost, we all have gone through this,” are the words of a very wise advisor, and “you have lots to offer,” are words from a very kind mentor. In the world of academia and research, I will not let feeling of being lost and what to offer stop me from becoming more involved.

Rashika’s Journey

When I was informed of the opportunity to get involved with Patient Engagement Research I was excited and nervous to start this new journey. Even though I was late to the program I was quickly brought on board with the help of Nancy Marlett and Svetlana Shklarov. My journey with PER all started during a time when I was re-thinking what direction I wanted my education to go and what career it would result in. During this time I decided to meet Nancy, who has been my professor for many of my graduate courses to get some guidance. The first thing she asked me was, “Rashika, where do you see yourself after you complete your Masters?” I sat there for a couple of minutes trying to formulate some type of educated response. All I said was that I would like to work with my community in terms of educating parents about their children's disability. As soon as I said that Nancy quickly pulled out her book *Grey Matters* and started telling me all about PER and what a good fit it would be for me to learn a new form of research and become engaged with my community.

I must admit that during the first half of PER I was quite lost in terms of the research style because I had never done or even learned about this new form of research. Having a background in Biological Sciences I was always use to doing research in the lab and following the scientific method. This new form of research I found much more interesting and it was surprising to see the vast number of the techniques being used. I was shown how effective qualitative research can be if you use the right methods. Initially I had a hard time grasping many of the PER methods such as focus groups and narrative interviews. However, I put on a brave face and buckled down because I did not want to let

my professor down, with whose help I had been recruited to the program. The big “a-ha” moment came when we started the actual research and it became more hands on. After the first practice focus group is when I realized the impact this type of research can have on patients and their families. At this point I stepped up my game and submerged myself in the research.

It was a delight working with Rooh on our research because she is also passionate about working within her own community and making a difference. She made me realize that in order to achieve something you must take charge and go after it, otherwise it will never happen. Since my involvement with PER I have discovered a whole new ME! Prior to this I would be hesitant to take on the role of a leader. This was the case during the narrative interviews because I thought that I lacked the skills to do the interviews. I would take the back seat and make Rooh do all of the talking. It wasn't until the third or fourth interview when I decided to step up and conduct the interviews. I realized that by sitting there and not talking was not going to get me far in building my interview skills. I told myself that the only way I would become a better interviewer was if I actually did the interview! I feel that PER has made me a well-rounded researcher where I am able to use both qualitative and quantitative research techniques. It has given me the skills to become a better researcher and has made me more engaged with others and myself. I now have the confidence to utilize the skills that I have learned to pursue a career as a Patient Engagement Researcher!

I would like to thank Nancy, Svetlana and Mary for all of their guidance throughout this journey. Without their help I would not have had such a memorable and life-altering journey!

A Mentor's (Mary's) Experience of the Reflect Focus Group

The last stage of the Set Collect Reflect method is a Focus Group session intended to provide an opportunity for the participants of the Set Focus Group to hear what researchers have drawn out during the Collect phase. In this study of OA post-surgery Southeast Asian and Punjabi-speaking patients this session took place in the home of one

of the participants. The surroundings were comfortable: three large sofas on three sides of the living room with a coffee table between the sofas. I was pleased to be able to be with these women even though I could not understand Punjabi.

During this session I heard English words, phrases and sentences peppering the Punjabi speech. I was surprised that this seemed such a natural part of their communication with each other. I began to write each English word and phrase down filling three pages of a notebook. Some of the words and phrases were related to particular disciplines or contexts; for example: family support, language problem, dependency, independence, lifestyle difference, peer support, peer-to-peer support, social network, social worker, social status.

As I listened to the reflective conversation unfold I recognized that one by one the two researchers were presenting what we have come to call scripts evoked by the narrative interviews done during the Collect research phase. When the script for Oh! Canada emerged with the quotation, "I came to Canada and I got arthritis" the women laughed heartily and I laughed with them. Some of them turned to me in surprise and said, "You understand?" I nodded and said, "Yes."

Discussion after the session brought a new awareness that though these patients are not necessarily fluent in English they have learned some words and phrases that have meaning for them. Words such as "arthroscopy" that are specific to a conversation about medical diagnosis and surgical procedures are a fearful mystery as they can be for many English-speaking patients. Concepts such as peer support and social network are also new and also mysterious and hold little meaning in their experience.

These patients have trusted bonds with families and friends but these bonds are also walls of dependency. In the midst of contractions of trust and dependency these patients struggle to comprehend what is happening to them after surgery and also struggle to manage their new post-surgical lives. For many of these patients the post-surgery experience is filled with fear and hope, confusion and yet more change which is at times almost incomprehensible and unmanageable.

Mary's Experience as a Mentor

My engagement with the participants in this research project was limited because I do not speak Punjabi or Hindi but work with immigrant women and gerontology courses has provided some prior knowledge. A dramatic enactment of the isolation of elder immigrant women presented at a gerontology symposium in Calgary revealed that isolation because of health challenges to elders can be debilitating.

Engagement with the two researchers became fairly intense as the proposal was constructed and the research begun and completed. Early in our engagement I came to understand my role as mentor would be most effective by being a willing learner. Not only did I learn *with* the researchers about the challenges of doing research in the southeast Asian community, but also I learned during our many meetings *from* them: Rooh provided me with lessons on how to cook butter chicken and Rashika told me about wedding customs in her community as she prepared for her marriage.

I came to know Rooh and Rashika as women vitally engaged in their families and communities and work. I observed them engaging with participants with respect, sensitivity and care at all times. OA post-surgery experiences among southeast Asian immigrants are filled with deeply intimate details and are not easy to bring to light. Language differences can act as barriers to understanding. While the researchers are fluent in English their participants were not always able to communicate in English. Rooh and Rashika were constantly moving back and forth across two languages, translating the meanings of unfamiliar words and interpreting the responses of participants. Their engagement with participants was a lively exchange interlaced with a kind of linguistic music composed of both English and Punjabi speech.

Prior experience from in my days as a young undergraduate participating in a World University Service of Canada a bi-lateral seminar in Pakistan in 1963 gave me a basis for connecting with Rooh and Rashika. I returned home knowing that we in North America are largely ignorant of the rich diversity of other cultures. Engagement with these researchers

has shown that there is much to learn about the immigrant experience of settling and integrating into Canadian culture particularly when there are health challenges.

Recently I came across an eye-opening comment by Amir Hussain: "Minority people have to know about the majority in order to survive, but the majority does not have to learn about the minority" (2006, p. 10). Engagement with Rooh and Rashika and the wondrously rich and complex experiences of their participants shows that there is much to learn from health research with immigrants if we but open our ears and eyes and provide the space and time for patient voices to be heard. The past fifteen months of engagement in research with immigrants as patients has brought to light for me the possibilities for a deeper understanding of care as it relates to the post-surgery experience of OA patients within the Southeast Asian community.

Further Research

This study was carried out to inform the Bone and Joint Strategic Clinical Network (BJSCN) about the experience of Southeast Asian immigrants who undergo joint replacement surgery and will be sent to the BJSCN Core Committee. Other interested parties such as all the partners and sponsors in the study, Strategic Clinical Network (SCN) and Operational Clinical Network (OCN) project managers, Alberta Health Services staff in the Patient Engagement Department, and several interested parties at the University of Calgary will be sent copies.

As with most qualitative research, this study asks more questions than it answers. It should be seen as an initiator in further research. Such research might include OA related topics such as: early diagnosis and treatment of OA among immigrants; the experience of waiting for surgery among older immigrants; the older patient's experience of language barriers; isolation as a factor in recovery after joint replacement surgery among older immigrants; the need for peer support for older OA patients within an immigrant community; pressure on families of older immigrant patients after surgery; complications for older OA immigrant patients when surgery is delayed. This list is not comprehensive

but mere a small example of areas of study that could benefit service delivery within older immigrant populations.

In addition to OA related studies, this example of patient engagement research can be used to point the way to improved patient input in all areas of healthcare. In-depth research of the lived experience of patients, no matter the disease, can only result in well-informed healthcare professionals. Patient satisfaction forms, no matter how detailed, cannot convey the depth and breadth of information patient engagement researchers uncover. Only peer-to-peer research with patients talking to patients can reach into the reality of living with a disease.

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