PATHWAYS TO HEALTH SEEKING, TREATMENT AND OUTCOMES IN PERSONS WITH SEVERE OSTEOARTHRITIS OF KNEES IN SOUTH KERALA

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This dissertation is dedicated to my parents for their inspiration, encouragement, support and unconditional love.
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ABSTRACT

**Title:** Pathways to Health seeking, treatment and outcomes in persons with severe osteoarthritis of knee in south Kerala.

**Objective:** Primary objective was to explore various factors that influence pathways to health seeking, treatment and outcomes of severe osteoarthritis of knee. Secondary objective was to explore any gender differences that exist in these pathways.

**Methods:** A qualitative study was done in south Kerala among 13 men and 19 women with severe osteoarthritis or has undergone a Total Knee Replacement surgery (TKR). In-depth interview and appropriate scales were used for research. Analysis was done manually and with assistance from NVivo-10 (Free trial version)

**Results and Discussion:** In ageing societies, like in Kerala, osteoarthritis is a widely prevalent chronic condition causing serious disability and contributing significantly to Disability Adjusted Life Years (DALYs) lost. The present study focussed on health care seeking for osteoarthritis and found a pattern of care-giving that is untenable and unaffordable for a developing country setting. The tendency of allopathic physicians to manage early osteoarthritis with pain killers alone results in escalation of the level of severity where there is no option other than TKR. What is worse in the present study is that despite the heavy expenditure in care of osteoarthritis, outcomes are relatively modest, with pain relief being the chief gain. The study points out that if we do not have strategies to prevent or manage such chronic disease such as osteoarthritis in early stages, it will become a major burden of illness as population ages.

What is urgently needed is a public health perspective for the management of OA of the knee. Every effort should be made to prevent worsening of the condition through exercises, appropriate lifestyle adjustments and safe working conditions. Adequate information about the disease has to be made available to the public.
CHAPTER – 1

Introduction and review of literature
1.1. **Background**

Problems of the knee joint are one of the common chronic health conditions seen in older persons. It is associated with pain and disability affecting their quality of life. Osteoarthritis (OA) is the most commonly diagnosed condition of such knee joint problems. As the process of OA can start at any age, it gets worsened as a person gets older giving rise to more disabling symptoms at a later age. Hence, with the current trends in ageing and early onset of such diseases, this will be one of the leading causes for disability and loss of quality of life in India and globally.

Knee pain is not always OA; conditions causing pain in the knee could be such as fibromyalgia, which is the commonest in individuals 50-75 years old, rheumatoid arthritis, lupus, spinal diseases, ruptured meniscus, bacterial infection and crystal synovitis.\(^1\) Because OA is a common condition among older persons, there is a tendency to consider it as part of normal ageing.\(^2\)

1.2. **Burden of Osteoarthritis**

Globally, symptomatic OA affects 9.6% of men and 18% of women above the age of 60.\(^3\) According to studies in US, hip and knee OA ranked high in ‘years lived with disability’ (YLDs) and ‘disability adjusted life years’ (DALYs).\(^4\) Since OA is non-reversible, it progresses to more disabilities at older ages if care is not taken.

Studies have also shown that OA is a major cause of morbidity and disability with a significant economic burden on patients and health system.\(^5,6\) The failure to value opportunity costs associated with OA such as lost wages, cost of informal caregivers and income lost from disability or limitations on work underestimates the true burden.\(^5,7\) The situation is more important with developing countries when ageing along with morbidity due
to OA will be a burden in economic, social and psychological terms according to the available reports. In 2008, China and India were at the top two ranks in having the largest number of older persons. In the developed world, arthritis is the second most common reasons for missed work, only next to heart disease. Osteoarthritis, at its later stages is associated with pain and functional decline that would significantly reduce the quality of life and increase the risk of further mortality and morbidity. Since Prevalence and incidence of OA increases with age, extending life expectancy and rapid ageing population will increase the burden of the disease in developing countries like India where accesses to specific treatment modalities such as joint replacements are not readily available.

1.3. Rationale for the study

Osteoarthritis of the knee is identified internationally as a chronic disease significantly affecting the quality of life of persons. It also raises serious implications for the nation’s health and economy making it a significant public health concern. Better understanding of factors affecting the disease is essential for planning, financing and to suggest a framework for management of the disease. Life Style modifications and management of OA right from the onset, as for non communicable diseases, may improve quality of life as age advances. In-depth studies are needed to understand pathways to health seeking and outcomes of severe OA among both men and women. It is worth noting that women with knee problem usually did not seek any kind of treatment or are ignored. There are no studies in India comparing the utilisation of orthopaedic services among men and women.

As Prevalence and incidence of OA of knees increases with age, extension of life expectancy and rapid ageing population in developing countries (more so with Kerala state of India) will increase the burden of the disease.
1.4. Review of Literature

1.4.1. About Osteoarthritis

Osteoarthritis is characterized by degeneration of cartilage with secondary changes in the bone. There will be focal areas of loss of articular cartilage within the joint and associated hypertrophied bone and thickening of the capsule. Clinically, the disease is non-reversible and patients present with pain, limitation of movements, crepitus (a crunching sensation as the knee bends back and forth), swelling and inflammation. While primary OA can be localised to a joint or generalised, secondary OA can be due to injuries, Paget’s disease, obesity or an inflammatory arthritis. Hence investigations are required to confirm the diagnosis and causes at the earliest to plan treatment.

In India, OA is the second most common rheumatologic problem with a prevalence of 22% to 39%. The Community Oriented Program for Control of Rheumatic Disorders (COPCORD) publications provides prevalence of OA of the knee among adults in Pune. While Musculo-Skeletal pain was found more in the rural area than in urban, fewer numbers (3.9%) of rural adults had OA of knees as compared to urban (5.5%). However, when adjusted to the age-sex distribution to the standard India census population, prevalence in Rural was higher. Another cross-sectional study conducted in northern India (both rural and urban areas) reports a prevalence of OA of 30% among women above the age 60 years. The Kerala Ageing Survey in 2006 identified joint pains as the most reported morbidity with prevalence of 53.5% among women and 43% among men above 60 years of age.
1.4.2. Risk factors of OA of Knees

Generally, OA is considered as a disease of older persons as symptoms become significant at a later age along with disabilities. Even though a new onset of OA is frequent in older persons and in women, age is not found independently to affect disease occurrence or progression.\textsuperscript{19} It is suggested by some studies that 20-35% of the knee OA may be genetically determined.\textsuperscript{20,21} However, OA usually affects men below the age of 45 while more women above the age 55.\textsuperscript{3} There are also studies that show an inverse association of OA of the knee with osteoporosis.\textsuperscript{22,23} Studies have shown that obesity is a major issue that results in increased risk of developing OA.\textsuperscript{24-26} However, the Framingham offspring cohort study on the effect of recreational exercise program on OA, showed walking, jogging or other self-reported activities as neither decreasing nor increasing the risk for OA in obese persons.\textsuperscript{27} Other risk factors for OA include positive family history, diabetes mellitus, hysterectomy, age, previous trauma, activities and occupation requiring repeated and prolonged knee bends, squatting, nutrition and Muscle weakness.\textsuperscript{22,24,28-30} Prevalence of OA was found to be higher in illiterate women as well as in low socio-economic class in a study conducted among women in Delhi.\textsuperscript{31} There is also a significant interaction between mood, lower social strata, depression, etc. with the reporting of pain and hence the outcomes. Such psychological distresses are seen as a risk factor for presence or increased perception of pain in OA. Interruption of sleep and other co-morbidities in older persons will add to this vicious cycle.\textsuperscript{32}

1.4.3. Management options available for OA

Primary prevention of OA could be through weight reduction as well as prevention of injuries in day-today life, sports injury and occupational injury. Early detection of asymptomatic OA is quite difficult as there are no bio-markers available and radiologic
screening is not always feasible. There are no curative options for OA except for control of pain, preventing adverse effects of medications, improving functionality of the joint and improving health-related quality of life. It should be kept in mind that not all cases of arthritis are bound to progress, and hence non-surgical treatment may be enough. But as disease progresses to an advanced stage, conservative treatment, non-pharmacological and non-surgical treatment may not be cost effective. Therapeutic options for managing OA could be classified into non-pharmacological, pharmacological, intra-articular treatment and surgical; a list of available options is given in Annexure (A1).

1.4.4. Total Knee Replacement (TKR) Surgery

Total knee replacement is an effective surgical option for severely damaged knee joint when non-surgical interventions no longer provide significant symptom relief and functionality. In this surgery, the worn-out joint is replaced with artificial joint, which has metal and plastic components. Knee replacement has been proven to be an effective option for relief of pain and improving physical functions in most of the cases and hence an improved quality of life as compared to those waiting for surgery or under non-surgical management with a similar level of pathology. A study done in Greece found the overall improvement in functionality and quality of life as immediate and satisfactory. A systematic review of literature suggests several relations between age, sex and obesity exist with the outcome of surgery. They found despite several adverse relations between subgroups, all derived better outcome from TKR whereby urging surgeons not to restrict access to surgery based on certain patient characteristics. As far as age of the patient is concerned, outcome of surgery depends largely on functional status prior to procedure. But studies suggest that age does not affect the outcome adversely. A case of a 93-year-old man who underwent a successful TKR surgery is a positive sign as reported in a leading news paper in India.
survey in the US, even for those obese persons whose outcome of a surgery may be not as
good as for non obese persons, relief of pain and relative functional improvement was good
suggesting that obesity is not a contraindication for surgery.\textsuperscript{50}

Due to long waiting list in some developed countries, patients are denied surgery for the
reason that the person is not severely disabled.\textsuperscript{51} This along with ageist attitudes of the
providers leads to a delay in obtaining the right treatment. The net result would be a
relatively poor outcome in those delayed cases. Many a times, in developing countries like
India, TKR surgery is sought when there is severe damage of joint that the outcome of
surgery is also minimal. There were no studies so far that looked into factors that determined
availability, access and utilization of TKR surgery in India. A retrospective descriptive study
done in Government medical college, Trivandrum, Kerala, India shows that even clinical
improvement was observed only in 60\% of these operated cases while functional
improvement was seen only in 25\%. The failure to achieve a better outcome has been
attributed to factors external to the surgical procedure in the study.\textsuperscript{53} This contradictory
finding on outcome of TKR surgery from Kerala warrants more research into the reasons for
such failures while it is found to be a highly successful intervention in the developed world.

\textbf{1.4.5. Health seeking behaviour}

Major problems associated with OA of knee (OAK) are pain, relative inability to meet basic
activities of daily living, psychological problems and feeling of social exclusion.\textsuperscript{45} When
knee pain deteriorates, it is accompanied by an increase in perceived pain, night pain,
catastrophic thoughts, depressive symptoms and limitations in activities of daily living.\textsuperscript{2} In a
study done in UK to explore the healthcare utilization of persons with OA, it was found that
disability was comparatively more of an important determinant in seeking help than pain,
depression or anxiety. It also says that the factors determining help seeking from a general
physician is different from an alternative medicine practitioner. There can also be an urban and rural difference in such help seeking behaviour.\textsuperscript{54} Health seeking behavior is also influenced by level of literacy and social class. A study in Delhi, India among women showed that more than half of the illiterate women of low socio-economic class with knee problem did not seek any kind of treatment.\textsuperscript{31}

Patients tend to cope with the symptoms of OA by modulating the prescribed medicines according to the severity of pain, functional limitations and perceived side effects.\textsuperscript{55} Apart from the use of prescriptions and Over-The-Counter analgesia, a range of cognitive-behavioural-coping strategies such as praying and hoping, coping self-statements are used especially by older persons to cope with their symptoms of pain.\textsuperscript{2, 57} When denied treatment by doctors, such as persons with OAK may perceive that their condition has no viable treatment options, and this is also based on their previous negative encounters with health system.\textsuperscript{58} They also consider that they themselves are responsible for maintaining their health than other socio-cultural, economic and environmental interactions.\textsuperscript{59} Such behaviours are also a result of poor literacy about this chronic disease among persons suffering from OA.\textsuperscript{60} A study from UK finds persons suffering from chronic OA are good self-managers of their condition and could cope well with their conditions provided they get good support from health professionals, physiotherapists, efficient management during crisis and by imparting appropriate information.\textsuperscript{61}

Role of physicians and the health system influences health seeking. A study from the UK showed that patients who were referred for specialist care by the GPs were not the ones with the most pain and disabilities, but were with higher scores in the financial and economic profile. Referral was also for those patients with severe OA with swelling of the knee and those who perceived a more serious consequence for the disease condition.\textsuperscript{62} A qualitative
meta-analysis taking ten qualitative studies brings evidence to the role of a physician in decision making and shaping their expectations about OA.\textsuperscript{63} As far as TKR surgery is concerned, it is not just that pain and disability are the factors for health seeking. Poor uptake of OA patients in the UK for TKR is considered as a result of the perceptions of physicians as well as of the patients towards surgical procedure and their personal meanings for the disease.\textsuperscript{64} Clarification of patient’s misconceptions doesn’t occur because the provider’s perception of patient’s expectations, and their views vary significantly as per one of the studies done in Paris, France and also in the US.\textsuperscript{55, 56} Good communication between the healthcare provider and patients found essential to build trust and to make the right decision for treatment.\textsuperscript{65}

Research from the western world suggests that ageist attitudes prevail, and definitive treatment procedures are frequently rejected considering such conditions of pain and functional decline as part of normal ageing process.\textsuperscript{51, 58, 66} This general ageist attitude of the health system as well as of the public will result in overlooking the symptoms of OA as an age-related problem. This will lead to late referrals and subsequent poor outcome of otherwise beneficial treatment modalities.

\textit{1.4.6. Gender influencing outcome of OA of Knee}

As described in the earlier session, prevalence of OA and that of the knee is seen more among women globally. Community Oriented Program For Control Of Rheumatic Disorders (COPCORD) study conducted in rural India also finds proportionately more women suffering from OA.\textsuperscript{14} One of the studies done in Coimbatore, south India, infers that nearly half of the women above 60 years (46.8\%) suffer from joint pain for the past 6 months.\textsuperscript{67} It is worth studying how the disease, the processes associated with it and outcomes differentially affect women and what makes women other than biology prone for such a high incidence.
A meta-analysis of sex difference in incidence, prevalence and severity of OA showed evidence that both prevalence and incidence of the disease is more in women especially in the post-menopausal age and severity of the disease is also more as compared to men.\textsuperscript{68, 69}

A study done in USA, found that women complained of significantly worse pain and functional loss than men while their physical activity level remained the same and had fewer severe grade of OA.\textsuperscript{70} In other words, women with OA of the knee regardless of the severity of disease or functional loss had a negative feeling about their disease as compared to men.\textsuperscript{71}

The outcome of treatment for OA especially TKR surgery for women is not as satisfactory as for men according to many studies. A study from the US that looked into the health-related quality of life after knee replacement also found that women reports more pain and functional loss and consume more medicines as compared to men with comparable concomitant musculoskeletal problems.\textsuperscript{50} The out-of-pocket expenses incurred in care of OA by women was double that for men in the US.\textsuperscript{72} Yet another Study which systematically reviewed literature suggests that men seem to benefit more from the intervention than did women.\textsuperscript{47}

Some studies from the United States also has shown that physicians recommend or refer to a surgeon for TKR more to a male patient than a female patient.\textsuperscript{73-75}

Health seeking behaviours of women has been studied in the western world but to a lesser extent. One of the studies in the US shows that the utilization of primary and specialist care as well as emergency treatment for OA was more for women.\textsuperscript{73} However, women undergoing total knee replacement are mostly seeking treatment at a later stage of the disease with greater functional disability as compared to men to have a poor outcome.\textsuperscript{74} The reason for this delay could be complex and not fully known as per the authors. This could result in a gender bias resulting in more women with OA undergoing TKR at a later stage of the disease when functional recovery is poor.\textsuperscript{75-77}
CHAPTER – 2

Methodology
2.1. Objective of the study

1. To explore the various factors that influence pathways to health seeking, treatment options and treatment outcomes of severe osteoarthritis of knee.

2. To explore if there are any gender differences that exist in the pathways to health seeking, major treatment options such as a TKR surgery and outcomes.

2.2. Study design

Qualitative research methodology (patient perspective): In-depth interview was used to study the experiences of patients with severe OA of either or both the knee to explore how they see the disease condition, its impact on their lives, their experiences with health system and health seeking pattern in managing the condition. Osteoarthritis is not a life-threatening condition at any of its stages; but it significantly reduces the quality of life and tends to worsen as time pass by. Given these characteristics of the disease, several social determinants and health system factors play a significant role in the pathways, treatment and outcome of this disease. Such detailed information on the behaviours and factors that influence them could be captured only through a qualitative methodology.

Interview of the primary care giver of the person with OA was conducted. This has helped in supplementing the data collected from the subject. In-depth interview of key informants (health care providers) including orthopaedic surgeons was also conducted to obtain the provider perspectives and expert opinion. This has been used here for triangulation purpose.

2.3. Study setting

The study was done in the two southern districts of Kerala namely Thiruvananthapuram and Kollam. One major private hospital, one government hospital and a speciality hospital under Employees State Insurance Corporation with established and reputed orthopaedic
departments were selected for identifying study subjects with representation from different socio-economic and cultural backgrounds. The Government hospital was offering TKR surgery at a very low cost to the patient and has stopped now since a year for technical reasons. ESIC hospital is still conducting knee replacement surgeries without incurring any cost to their patients.

2.4. Sample selection

A purposive sample of men and women with severe OA from each of the three above-mentioned hospitals in Trivandrum and Kollam city were selected. The treating orthopaedic surgeons of these hospitals may refer patients for the study after obtaining an informed consent for the same and recruitment was done till saturation was observed. From the observations, it is found that predominantly women are affected by OA, and they form majority who went in for a surgical procedure. Hence both men and women were selected as gender is a variable of interest in how they experience living with OA. A major problem with purposive sampling is the source error as the persons identified from these hospitals may be having more serious problems, and their families may have greater education and financial resources. However, this was minimized by also selecting a government hospital and a hospital under an insurance scheme. As total knee replacement is considered generally as a last option, persons who have undergone the surgery and those persons who are advised surgery are taken as having severe OA in this study. A total of 32 persons with OA was interviewed as saturation was attained at this level.

A total of six care-givers, including both men and women; who were caring either a severe OA patient or the one who has undergone a surgery were interviewed. The information received from them was supplementing the information received from the patients. For
triangulation purpose, three leading orthopaedic surgeons from private as well as government hospitals were also interviewed.

2.4.1. Inclusion criteria:

Men and women above the age of 50 years, with severe OA diagnosed by an orthopaedic surgeon or those who have undergone a total knee replacement surgery between six months and 18 months prior to the interview.

2.4.2. Exclusion criteria:

Other debilitating co-morbidities that are significantly contributing to current health status and quality of life, those who are fully dependent and bed-bound, physically disabled, persons with Dementia or cognitive impairment, psychiatric Patients and persons below 50 years of age.

2.5. Data collection tools

A semi-structured and open-ended interview guideline for an in-depth interview for subjects with severe OA, those underwent a TKR surgery, care-giver of the subject and key informant was used (see annexure A2). Ability of persons with severe OA of the knee or post Total Knee Replacement (TKR) surgery to perform activities of daily living and the instrumental activities of daily living was assessed using appropriate scales such as the Katz ADL Score, Lawton-Brody IADL Scale (Annexure A3). Pain being the main symptom common to all will be assessed using a visual analogue scale (Annexure A4). The overall quality of life shall be also assessed using the WHO-QOL-Bref questionnaire (Annexure A5). Details of the scales that were used are mentioned below. These scales are intended to understand the present status of independency, symptom control and overall quality of life as outcomes of the disease.
2.5.1. *Katz ADL Score:*

Katz scale of independence in activities of daily living is an appropriate tool to assess the subject’s ability to perform the basic activities of daily living independently. It looks at the activities such as bathing, toileting, transferring, continence and feeding. This scale was developed to assess the daily self-care activities within an individual’s home or an indoor environment. The scoring is done as “Yes” or “No” for independence in each of the above mentioned six functions. "Yes " is considered a value of ‘1’ and a total score of ‘6’ indicate full functionality, ‘4’ as moderate impairment and ‘2’ or less as severe functional impairment. This instrument is in use globally and most effectively in older persons in a variety of settings for more than fifty years. Over these years, the instrument has shown its utility consistently throughout the literatures available. The scale has been in the public domain for a long time and do not require a permission for use.

2.5.2. *Lawton-Brody IADL Scale:*

This is an ideal tool for assessing Instrumental Activities of Daily Living developed by Lawton & Brody in 1969. There are eight domains of functions and behavior assessed using this instrument such as telephoning, shopping, food preparation, housekeeping, laundering, use of transportation, use of medicine and financial behavior; of which, functions such as food preparation, housekeeping and laundry are not scored for men usually. Respondents are scored according to their highest level of functioning in a given category that ranged from 0 (dependent) to 8 (independent) for women and 0 through 5 for men. This instrument is appropriate to assess the more complex living skills especially in older adults. The only limitation of the instrument could be that the self-report used here in the study could over report or under report the actual functional ability of the person as there is no demonstration of the task. The inability to perform certain tasks could be also due to certain other social
determinants other than gender. This tool is also in the public domain free to use. This will be done only for respondents who have scored more than 4 in Katz ADL scale.

2.5.3. Visual Analogue Scale for pain (VAS):

This is a simple tool with a depiction of a scale marked 0 to 10. Zero indicates no pain while 10 indicates worst pain that could be experienced. The visual scale may also have facial expressions on either extreme. This scale is widely used in clinical practice for assessing pain.

2.5.4. WHO-QOL-Bref Questionnaire:

The tool has been developed by World Health Organisation in 1991 in collaboration with a number of centres worldwide and widely field-tested, including south India. It takes into account of personal perceptions in the context of their cultural and value systems, their personal goals, standards and concerns. The tool has 26 items under broad domains such as physical, psychological, social relationships, and environment. WHOQOL-BREF is a shorter version of original instrument that is convenient for use. Permission for use of this sale was obtained prior to administering.

2.6. Data collection

The interviews as part of data collection were carried out from the 1st of July to 15th September by the principal investigator. The orthopaedic surgeon of the hospitals selected identified eligible patients from his clinic. He had informed the patient about the research work and introduced the primary investigator after getting an informed consent. Forty two such persons who fulfilled the inclusion criteria from the Government hospital, ESIC super specialty hospital and a private hospital with OA (both who have undergone total knee replacement and who are on medical management) were thus identified. All of them were contacted by the primary investigator over a telephone to confirm their willingness to
participate in the study and for the investigator to visit their homes for the interview after a minimum of two days. A telephone call was made again to confirm the visit on the day of the interview to give the person another opportunity to decide on participation in the study. Two of the 42 identified could not be reached over the phone, and two were reportedly not free for an interview during the times when the telephone calls were made. Every effort was taken to get adequate privacy during the interview. It was seen commonly that one of the relatives preferred to be present during the interview with the respondent. A lady assistant also accompanied the principal investigator during the house visits for interview. In all the cases, role of the assistant was to be present with the principal investigator and especially when the subject was a woman. The assistant was also trained to keep any other person in the house who was keen in the process engaged so that there was no interference or undue influence on the person being interviewed. This was in fact the most challenging part of conducting an interview in home setting. Requests were made to the care fivers for providing adequate privacy with the subject. In spite of all this, there were six situations where an environment for an in-depth interview could not be created. In these three cases, a casual discussion took place where information regarding the disease condition was provided and their queries regarding their health were answered. As a result, 32 subjects whose interviews were valid are included in this study.

A written informed consent was obtained prior to the interview in the presence of a caregiver / relative of the subject at home. As audio recording was essential to avoid missing important points made by the respondent, informed consent was obtained with special reference to the use of a voice recording device.

Primary caregivers of both men and women who have undergone a surgery and not undergone were interviewed as per the availability. Six such caregivers were identified and
interviewed after getting an informed consent. The three orthopaedic surgeons were
interviewed in their clinic setting after completing interviews of all the subjects and also the
preliminary data analysis. In-depth interview was conducted using an interview guideline
after obtaining an informed consent.

2.7. Data analysis

Data analysis was done in the following stages manually with assistance of NVivo-10 (Free
trial version)

Stage – 1: All the recorded interviews were transcribed verbatim in Malayalam also
incorporating the field notes. All the transcripts were verified and checked with the audio
record for discrepancies. All the verified transcripts were organised and compiled to start the
analysis.

Stage – 2: Codes were developed for the first set of field notes and observations inductively.
Personal reflections and comments were noted while coding the transcripts.

Stage – 3: After coding the entire transcripts through an inductive process, the codes were
organised into different hierarchical categories and thematic groups.

Stage – 4: Patterns, themes, common sequences in health seeking, differences between
subgroups and relations between different attributes were identified.

Stage – 5: Further analysis was done to find the linkages between these themes to develop
models of pathways of health seeking, treatments and outcome among the subjects studied.

2.8. Data storage

All the audio recordings are stored in a hard disk without any personal identifiers in safe
custody of the principal investigator. These records shall be retained only for a period of
three years after submission of this dissertation with limited access.
2.9. Ethical considerations

The study proposal and all the tools that will be used in the research were screened by the technical advisory committee and the institutional ethics committee of Sree Chitra Tirunal Institute of Medical Sciences and technology, Thiruvananthapuram. Those persons identified by their respective treating doctor and suggested to be enrolled in the study were called over phone to confirm their willingness to participate in the study. A Written informed consent was obtained from all individuals on meeting them for the interview. An information sheet typed in Malayalam as well as a copy of the consent form duly signed by the principal investigator was given to all those who were enrolled in the study. Similar pattern of obtaining consent was followed for the caregivers and medical practitioners who participated in the study.

All participants had their freedom to quit the study at any point of time. Principal investigator being a doctor with basic skills in the area gave them health advises, necessary information pertaining to their problems that are identified during the session on demand and answered to their queries / doubts regarding the disease or health status. Each study individual was given a unique identification at the outset. All data collection forms and soft copies pertaining to individuals shall be kept confidential without any identifiers in a removable hard disk and only the principal investigator and guide will be having access to it.

2.10. Plan for dissemination

The findings from the study will be presented in scientific meetings like conferences both as oral presentations and posters. The findings will be published in peer reviewed scientific journals. Salient findings and recommendations shall be incorporated in articles to be published in general and health magazines for awareness and health promotion for public. The findings shall also be published in periodicals that are accessed by policy makers.

***************
CHAPTER – 3

Results
3.1. Introduction

This chapter presents the results of analysis of experiences shared by 32 individuals who have gone through and lived with pain in the knee as a result of severe osteoarthritis for several years. We discuss here respondents’ history of severe osteoarthritis of the knee and their experiences with the health condition; their pathways to health seeking; sources and nature of treatments and treatment outcomes. Factors that influenced health-care seeking has been gleaned based on respondents’ accounts. Since osteoarthritis is more commonly found in women and that a total knee surgery is been done more on women, the analysis also included an exploration of how gender has its influence on the lived experience of severe osteoarthritis of the knee and pathways to health seeking.

3.2. Socio-demographic profile

This study enrolled 32 subjects; 13 (41%) men and 19 (59%) women above the age of 50 years from two southern districts of Kerala - Kollam and Trivandrum. Socio demographic characteristics of the subjects are given in a below (Table 3.1). All subjects were diagnosed as either having severe osteoarthritis (OA) of knee or having undergone a total knee replacement (TKR) surgery for severe osteoarthritis. Fourteen persons – five men and nine women – underwent total knee replacement surgery. The present age of the subjects ranged from 52 to 85 years (mean age 61 years) among women and 57 to 82 years (mean age 66 years) among men. There were 24 Hindus (10 men and 14 women), six Christians (one man and 5 women) and two Muslims. Five subjects belonged to Scheduled caste while 13 belong to other backward caste and the remaining 14 belonged to the general caste category. There were five widows, one widower and one unmarried woman in the sample. The remaining 25 were married and living with their spouse. Nineteen subjects lived in extended families while
11 subjects lived in nuclear families and two in a joint family. Most of the subjects (23) had studied up to secondary school, and there were three graduates, three postgraduates, two professionals and one skill trained person. Of the 19 women in the sample, seven had never worked outside their home, and seven women stopped working because of OA. Two women were still working on daily wages, and three had retired. Among men, eight have stopped working while three are still self employed, one person is on daily wage, and one has retired. There were 18 subjects (seven men and 11 women) above poverty line (APL) and 14 subjects (Six men and eight women) below the poverty line (BPL). At the time of interview, seven subjects (five men and two women) had their own source of finance while 13 subjects (three men and 10 women) had to depend on their family for financing health care. The remaining twelve had insurance that would cover medical expenses.

3.3. History of development of Osteoarthritis

3.3.1. Probable causes of OA in the subjects

Injury to knees is one of the reasons for osteoarthritis later in the life. Five subjects in this study (three men and two women) out of 32 reported injury in the past that could be attributable to developing osteoarthritis. Of the three men, problems started following sports injury in their young age (early 20s) for two men while the other man gave a history of a road traffic accident in the past. Injury of the knee in these three men progressed from their age of early 20s to the 60s. Injury to the knee 20 and 27 years back following fall inside the house marked a sequel of problems in the knee for the two women in the sample.

Insult to the knees may not be just out of a fall or accident; certain lifestyles and occupations also increase the risk of osteoarthritis. In this study, persons working in the coir and cashew industry for a long time gave history of pain in the knee while working. Being a skilled work in these industries, there is no option for them to be given an alternative task.
### Table 3.1 Socio demographic characteristics of study participants

<table>
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<tr>
<th>Attribute</th>
<th>Male (n)</th>
<th>%</th>
<th>Female (n)</th>
<th>%</th>
<th>Total (n)</th>
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<tr>
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<tr>
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<td>7</td>
<td>100.00%</td>
<td>7</td>
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<tr>
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<td>7</td>
<td>46.67%</td>
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</tr>
<tr>
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<td>25.00%</td>
<td>3</td>
<td>75.00%</td>
<td>4</td>
</tr>
</tbody>
</table>

......Contd
There were six men and eight women among the study subjects who were involved in activities that required sitting continuously for hours with bent knees, prolonged standing and lifting heavy weights in the coir and cashew industries and in other occupations such as nursing or manual labour. Apart from injuries and occupation, six women report having been overweight in the past and were asked to reduce their weight. Except for one woman who had a maid to help, other women did not have any help with household activities that led to lack of adequate rest in the event of an early arthritis.
3.3.2. First presentation of symptoms of osteoarthritis

Osteoarthritis in this study has presented at different ages starting from 27 years in women and 36 years in men until the late 70s. The mean age of onset of OA in women is 47 years and 55 years in men. The duration of OA also varied from two to 35 years among women (mean of 14 years) and from four to 28 years (mean of 11 years) among men.

Of the 32 subjects, 28 had pain in the knee at the onset of the disease while four subjects presented with either weakness or discomfort in the knee. However, the predominant symptom for all the subjects later was pain in the knee with limitation in activities to different extents.

3.3.3. Living with pain from severe osteoarthritis

Pain is a major symptom in the disease course of osteoarthritis. Pain is the first symptom of osteoarthritis in 28 out of 32 subjects and is the main symptom of osteoarthritis and trigger for seeking help in the beginning. All the subjects who have severe OA and have not undergone a TKR surgery give history of episodes of severe pain in the last two years. For those who have undergone a surgery, except two, pain was unbearable and present even at rest prior to surgery. This was also the reason for seeking surgery. All subjects give history of pain causing disturbed sleep or sometimes sleepless nights.

Living with pain and disability pose different issues for men and women even though several common issues are present. Performing activities of daily living becomes difficult during episodes of severe pain, which would require depending on others in the family or on friends. According to the respondents, episodes of severe pain limit many of their activities and it is at this time other family members come to know the severity.

Help with household activities was the major challenge for women of all ages in the study and was given priority by almost all the women that they tend to ignore the symptoms of OA.
at the onset while they suffer the pain. In many of the situations, they identify those activities that make pain worse and try to avoid it as far as possible, which requires rescheduling and reallocation of roles within the family.

Using the Indian type toilet was one of the biggest challenges that remained unaddressed for a long time till a stage when there were no other options left. Three women in the study group disclosed with great shame and hesitation that they were using the toilet in semi-standing position supporting themselves on both the walls with great difficulty. One lady disclosed that she had a chronic constipation just for this reason, and now she has a modified chair with a hole in the seat that can be placed over the closet that was made when her husband was convalescing from a hernia surgery.

Dependencies that arise from pain and other symptoms that become obvious in the public or in front of significant others are the major challenges for men. In this study, it was seen that they sought different methods as fast as possible to get rid of pain to prevent such dependency. Pain was what they could control through such measures, to some extent; but living with symptoms other than pain, such as weakness and instability of the joint that could not be managed with medications were considered by men as the major problem.

Six out of 13 men in the study group preferred not to go to social gatherings or social functions such as marriages. This was because of the chance that they may have to stand for a long time and also that there may not be a comfortable seat to sit. In such a situation, these men thought that they were losing their dignity if they had to request someone for providing a space to sit. In some of these situations, they may also have to climb steps, which were difficult without a support. Since these men did not wish to be seen as dependent and needing assistance in front of others, they felt it was better to avoid such situations. This had
significantly affected to their social life as per four out of these six men and was one of the main factors for undergoing a surgery.

Instability of the joint led to repeated falls for four men in the group. They reported that this resulted in severe fear of falls that was limiting their activities and self-confidence. One man who is still managing a small provision store says that he falls once almost every day while getting things from the rack and packing it for a customer. If such a fall happens outside on the roads or so, a help may not be gotten as per another man who was a manual laborer who narrated an incident when he fell down while returning from his work in the evening. He says that he had to be on the road side for a long time as the people thought he was drunk and nobody wanted to help him. Such situations reduced the confidence of many of these men to go out freely either for work or socializing.

As joint degeneration progresses, invariably deformity sets in to various extents and the most common is having a sideways bend. The biggest problem for one gentleman was that the deformity becomes prominent and visible on wearing a trouser. He stopped wearing a trouser ever since this problem aroused and wore only a “Mundu” (a wrap around clothing) until TKR surgery was done.

Respondents’ experiences of pain and the ways in which they managed it were also obtained from caregivers (four women and one man). Caregivers of three men and a woman say that unnecessary anger and irritability are the only sign of pain or discomfort that was seen externally. Men usually did not complain of pain, but their spouses understand from their gestures. “If I ask him more, then he will get angrier,” said the caregiver of one man. Three women caregivers interviewed feel that men are more affected with such a disease as it makes them difficult to go out for work or shopping. It is more difficult for both women as well as men if men are suffering from such a painful OA as per two of these caregivers.
However, all the caregivers except one believe that this disease is more limiting for women than men.

Care-giver stress is also an important part that needs attention. Even routine work at home during severe pain of a member at home is faced with much difficulty by women-caregivers. Even for minor needs the person will be dependent such as lifting a telephone which is not very far away, getting a newspaper, getting water for drinking, etc. This along with the usual household work becomes difficult to handle resulting in frequent burn-out. All the six caregivers interviewed were of the opinion that the whole family is affected when a member is in severe pain and there is no cure to it. All the women caregivers were of the opinion that caring a person with this type of pain is extremely difficult and require much patience. If men were caregivers, according to the women caregivers, they wouldn’t have this much of patience and will stop caring.

The specific case of one of the caregivers is worth mentioning in this context. She is the wife of a subject, and also suffers from severe OA of both the knees with severe pain and disability. However, she did not see a doctor so far. At the same time, even though the subject is diagnosed as having severe OA, the pain was not as severe as compared to his wife. This incidental finding also points to the difference in health seeking, living with OA and treatments between men and women even when both husband and wife are suffering from the same disease. In this case, she was using the medicines and oils that he was using as she considers her condition as almost similar to his. She had such severe pain since a long time that she was unable to use the Indian type of toilet but only when her husband started getting severe pain, a chair in their house was modified so that it can be kept over the closet. She says that she never sought or told her husband for a solution to her problem.
3.3.4. Management of pain

A majority of the subjects resorted to self-medication with over-the-counter analgesics and ayurvedic preparations without consulting a doctor in the initial days. Over-the-counter analgesics and previous prescriptions were found used more by men as and when required to tide over situations of severe pain as they were more mobile and could access shops routinely. Three out of four caregivers of men say that they used to get medications on their own whenever they had pain or other symptoms. It is seen that hot fomentation, massage with pain oils and balms are some of the self-care options used to tide over episodes of severe pain. Men usually get help from their spouses. Four men out of the five who were using ayurvedic oil for pain since the early days were helped by their wives for application and massaging. Women, on the other hand, were not receiving such help, and three women complained that there was no one at home who could help in such applications.

As the pain aggravated in the due course of the disease, all of them consulted either a general physician or a specialist for relief. As the disease progress, other symptoms such as locking of knee, deformity of the limb, limitation in movements also set-in, that require medical consultation. Many such problems also closely associated with pain become difficult to manage with home remedies or conventional medical management.

An example of how pain was managed over the course of the disease by one of the subjects in the study who underwent a TKR surgery is shown in a timeline below (Fig.3.1). Milestones in the health seeking pathway as well as different treatment taken in response to pain during the course of the disease are depicted here. It can be seen that there were times when multiple systems were sought in sequence as well as parallel for seeking pain relief.
Fig. 3.1 Example of a typical timeline of a subject over four phases with milestones and treatment taken at times of pain of varying intensity.
3.4. Understanding about osteoarthritis and its treatment

Most of the subjects appear to have formed their own impressions about the disease based on information and advice received from family, friends, acquaintances and health care providers. Some respondents tended to compare knee joint with a hinge joint of a machinery. Osteoarthritis was seen as the result of “wear and tear” of the joint, which is imagined and compared with a worn out hinge, and the “fluid” within the joint compared to a lubricant oil. In most instances, this idea was adopted through logical reasoning and information received from friends, literature and partially from treating doctors. About half (15) of the respondents believe that the disease is as a result of their lifestyles and occupation, while twelve subjects believed that OA is part of an ageing process, but that pain can be managed successfully with medications.

All subjects believed that the condition could be cured with medications and that the resurgence of pain is just because the treatment received so far was not optimal. None of the subjects were aware that the core of the treatment and prevention of further damage to the joint due to osteoarthritis is non pharmacological.

None of the subjects were aware about the actual procedure of TKR or the actual disease process. This includes patients who have undergone a TKR surgery. Except one respondent, all those who had undergone a TKR has some imagination about a “Plastic” or a “steel” artificial knee been placed in the place of the damaged knee. Eleven out of the 14 persons who underwent surgery believed that the main part of the surgery is to remove the patella and replace it by a steel patella. One respondent believed that an “egg shaped” steel body has been replaced after removing his patella. However, no one’s patella was found to be removed on examining the available reports and post-operative X-rays.
Of 14 subjects who were advised surgery, none were aware of the actual process but knew that a part of the knee will be removed and a steel spare-part will be substituted. Four have nevertheless decided to undergo it and are awaiting surgery. Five are not convinced with the opinion of the specialist and believe it to be a risky surgery with poor outcomes. “Even highly influential and resourceful persons such as our previous prime minister Shri Vajpayee is still not walking comfortably after a surgery. Then what would be our situation?” – said one of the women who did not want to get operated.

3.5. Pathways of health-care seeking

Based on health-care seeking of persons with osteoarthritis, four phases was identified. The time duration of each phase may vary from person to person depending upon other determinants described in the next section.

**Phase – 1 (From self-management to a specialist consultation)**

The first phase starts from the first onset of symptom (either pain or other symptoms such as weakness of the knee or mere discomfort) till the first consultation with an orthopaedic specialist.

**Phase – 2 (Receiving definitive diagnosis and treatment advice)**

Second phase, the cure seeking phase is the period between the first contact with a orthopaedic specialist to the formal diagnosis of osteoarthritis of knees or till information is received about the incurability of the disease or the need for knee replacement surgery.

**Phase - 3 (Shopping and bargaining phase)**

This phase starts with the disclosure by the treating doctor about the incurability of the disease and the essentiality of a replacement surgery. Even though shopping around from providers to providers is also present in some instances in the previous phase, such behaviour is the hallmark of this third phase. Patients seem to have felt a sense of desperation and in
some instances, denial of the incurability of the conditions. Consequently, there is a search for alternatives, and bargaining for the best possible outcome, some amount of functional improvement or reasonable pain relief. Eventually, incurability is accepted. Among those who are advised TKR surgery, some opt to accept the option, while others continue in this same phase of shopping for temporary relief sporadically.

**Phase – 4 (post operative phase)**

Those who undergo TKR surgery enter a fourth phase. This is the post TKR surgery phase starting from the immediate post operative period. This phase is important as unless the post operative period, both immediate and long term is managed well, the life of the prosthesis will be shortened.

### 3.5.1. Phase-1: From self-management to formal consultation

This phase may be further divided into two categories depending on the delays in seeking help from formal medical systems (Fig.3.2).

a) Those who contacted a primary physician in Modern medicine or Ayurveda within six months of onset of symptoms before reaching an orthopaedic specialist – hereafter termed as those with “no delay.”

b) Those who contacted a primary physician or a specialist after a delay of more than six months – hereafter termed as those with “delay”

#### a) Subjects with no delay in first contact

There were only 11 subjects (34%) out of the 32 who consulted a doctor within six months of starting of pain. Four out of the 11 had sudden excruciating pain that made them consult. All of them were treated symptomatically with analgesic tablets and ointments. Out of the 11 subjects, majorities (eight) were also on certain home remedies such as hot fomentation, pain balms or some ayurvedic oils available in the market.
Fig. 3.2 Pathways to formal medical consultations, reference to an orthopaedic surgeon and current TKR status

Legend

- All subjects
- No delay
- Delay in health seeking
- Primary physician
- Ortho reference by physician
- Self reference to ortho
- TKR done
- TKR not done
It is important to mention here that despite early contact with a primary physician; only two of the 11 were referred to an orthopaedic surgeon for further management by the primary doctor. The other nine were self referred to a specialist following information availed through other sources. The time taken for such a consultation ranged from six months to seven years with an average of 15 months. Six out of the 9 had gone through more than two systems of care and also to multiple providers till date or till the surgery was done. None of the eleven subjects were told or advised by any of the many consultants of preventive measures such as exercises to strengthen knee joint. Nor were they recommended lifestyle modifications.

b) Subjects who delayed first contact

There were 21 subjects (66%) who did not seek help immediately from a formal medical practitioner for pain in the knee. The duration of this delay depended mainly on the symptom relief and ranged from six months to around 12 years with a mean of 7.75 years. Four subjects out of the 21 had a significant delay in health seeking ranging from two years to 12 years. The remaining 17 had a delay ranging from six months to two years.

There were five subjects in this group who had a history of injury to the knee in the past. In all these cases, the pain that appeared in the previously injured knee later in life was attributed to the aftermath of the injury alone, and they therefore did not consider any active treatment as necessary. This misconception led to the delay in seeking help from a medical practitioner for pain among this group.

The person with the longest delay of 12 years before even a first contact with a formal provider is a woman. Pain started for this woman at a very young age and progressed slowly, and since the pain was not very severe and since it did not stop her from doing her household chores, she ignored it. She says that she did not feel that the pain was significant enough to
seek health advice as her mother also had similar conditions. The intermittent pain that she was going through was not given much care even by the family. As with this woman, family support and prompt treatment of initial symptoms was what lacked for most of the women in this group.

During the period of ‘delay’, all patients found some relief for their pain through certain home remedies such as balms, heat application or pain oils. Use of allopathic drugs obtained over the counter was adopted sequentially with ayurvedic preparations. Homoeopathy and other commercial products were also tried during this period by three persons. Pain was always a trigger while influences from friends and others, including information from advertisements were the base for each trial.

Following the delay, five out of the 21 were self referred to an orthopedic as the first contact while the remaining 16 consulted a primary physician. Out of the 16, only three were promptly referred to an orthopedic by the treating physician. Rest of the 13 subjects were later self-referred to a specialist during their shopping for different providers.

None of the 21 subjects recollect any of the providers giving them an advice on preventive care for the knee or any lifestyle modification during the early stages of the disease. Orthopaedic surgeons were advising exercise; however, did not demonstrate the same, and none of the subjects were aware of the right way of doing the exercise nor were they doing it.

There were almost equal numbers of men and women who had a delay. Ten out of 13 men (77%) and 11 out of 19 women (58%) were the ones in this group. In both Above Poverty-Line and Below-Poverty Line groups, two thirds delayed their first formal consultation. Three-fourths of those who had to find a source of finance for this treatment from their own or from family income had a delay in seeking help as compared to half of those who had insurance cover. Looking at the educational background of the subjects, seven (88%) out of
the nine subjects who had graduation, post-graduation, professional or skilled training showed a delay in first contact. There were 14 out of 23 subjects (61%) with either primary or secondary education who had a delay; it means that in this study sample, relatively more subjects with higher education had a delay in first contact.

3.5.2. Phase-2: Receiving definitive diagnosis and treatment advice

In this study, only five persons in all were referred by the primary physician to meet an orthopaedic surgeon and the remaining 27 reached a specialist on their own choice as the symptoms persisted, and they experienced considerable difficulty in performing activities of daily living. A diagnosis of osteoarthritis was made by the orthopedic following an evaluation, including an X-ray. The diagnosis of osteoarthritis was conveyed by the doctor in all cases and wherever the condition was severe, an option of TKR surgery was told. Except for four persons, all were advised surgery at some point of time during the course of their illness. Only six out of the 32 subjects recollect that some information on the disease process was discussed by with them by a doctor out of the many they had met during this period, while nine reported that a doctor had discussed with them the risk of consuming analgesics for long duration of time and that a surgery could be anticipated.

Four out of the six caregivers who were interviewed complained that the doctors were not very helpful and seldom had the time to listen to the caregivers. The care-givers were not given an opportunity to ask their doubts about the disease. The doctors were very busy and were just prescribing medicines. The women care-givers reported that doctors tended to discuss progress of the disease and the procedures with the male relatives and friends and not the wives of the male patient. “Unless I get to know what is to be done, how I will plan things at home or arrange what is needed” asked one woman who is taking care of a man with OA.
On the other hand, the doctors interviewed were of the opinion that patients consulted them only in a crisis situation of severe pain, and the only option at that time is to prescribe analgesics within the busy OPD schedule. It needs to be mentioned here that the doctors did not say that they advised patients to return later for discussing a plan for further management.

3.5.3. Phase-3: Shopping and bargaining phase

While 28 of 32 respondents were advised TKR surgery, only seven of them accepted the option of surgery as soon as the doctor conveyed it as the only best option available. Of the remaining 21, seven others came around to the decision to have surgery sometime later. Of the 14 who have not had surgery as yet, four are awaiting surgery while the remaining are either undecided or yet to be convinced of the desirability of the surgery.

All those who were advised a TKR surgery were given no other option, irrespective of their social or financial background. Those with insurance or reimbursement were asked to avail it as early as possible and others were asked to arrange for necessary funds to get operated at the earliest. It is also worth noting that TKR surgery has been advised as the only option for a woman with other severe other co-morbidities like Chronic Obstructive Lung Disease and obesity without trying out any of the conservative methods such as physiotherapy or exercises. Moreover, this lady in her 60s is unmarried with no other support financially or from the family.

The seven who opted for surgery right away had also not delayed their first contact with a formal provider. Five out of this seven were covered with ESI scheme, and the other two were with good financial and family support. (ESIH was providing TKR surgeries freely during this period).

In vast majority, there seems to be a tendency for denial of the fact that osteoarthritis is incurable or rather irreversible at this late stage of disease that the only option left is a
surgery. Such patients enter the phase of shopping around for remedies and bargaining for the best possible outcome within the non-surgical options available. Intention of seeking help is to regain at least some of the essential functional capacity and a pain free state. Alternate modes of treatment options are experimented with. Expensive unscientific treatment options were tried by four of the subjects who were influenced by friends or commercial advertisements. Fifteen out of 32 consulted more than one orthopaedic surgeon for pain. According to the respondents and their care-givers, one reason for consulting multiple specialists was, that although they were told about the diagnosis, they felt the lack of information about achievable targets and about the disease process, and reasons for the inadequate symptom relief that they were experiencing.

In search for either cure or better symptom control without going for a surgical process, many of the subjects resorted to multiple medical systems, including non-conventional methods (Table 3.2 and 3.3). Among systems, other than modern medicine, 28 out of 32 subjects had Ayurvedic treatments. Ayurvedic pain oils and decoctions were found used throughout the the disease. The general thought that modern medicines are chemicals was reported as a reason for also resorting to other systems such as Ayurveda, homoeopathy, Sidha, Unani or ‘Nadi chikilsa’, magnet therapy and certain nutritional supplements. Other treatment methods tried were certain nutritional supplements, tablets been marketed through multi-level marketing schemes and marketed commercial advertisements promising a full cure. Ayurveda, since considered safe by most of the subjects was used extensively.
Arranging for someone to take over the household work and also provide support for the patients for a few months during the post-operative period became an imperative, especially for women. Seven of the nine women who had undergone surgery reported this. This was one of the major reasons for the delay in undergoing a surgery. No such external reasons for delay were observed among men.

Among the 12 of the 14 who were advised surgery but did not undergo the surgery, the time elapsed since the advice of TKR surgery ranges from six months to three years, while in two cases it is nine and 12 years. There seems to be some indication that being women and not having insurance or adequate means has contributed to the delay.

### Table 3.2: Number of healthcare systems consulted during the course of disease

<table>
<thead>
<tr>
<th>No. of systems consulted</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TKR done</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td><strong>TKR not done</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>6</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>5</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2</td>
<td>13</td>
<td>9</td>
<td>8</td>
</tr>
</tbody>
</table>

### Table 3.3: Number of healthcare providers consulted during the course of disease

<table>
<thead>
<tr>
<th>No. of providers consulted</th>
<th>1 to 5</th>
<th>6 to 10</th>
<th>11 to 15</th>
<th>Above 16</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TKR done</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td><strong>TKR not done</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>10</td>
<td>15</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>
3.5.4. Phase-4: Post TKR surgery

Patients reported having minimal contact with the health-care system post-TKR surgery. Follow-up after surgery was not done in the initial three months, and patients reported that they were not encouraged to have regular follow-up with the operating surgeon. Eight out of 14 were informed by the hospital after the first review that there was no further need to review with the doctor who last treated / operated on them or to even return to the same hospital. They were free to seek help from any doctor in case of any need. Six months to two years had elapsed after surgery at the time of this study, and none of the patients had developed any significant symptoms that required referral.

TKR being a major surgery, all the subjects who underwent surgery had the expectation of discomfort and pain in the immediate post operative period and were prepared to face it. Except that one man who had a post-operative wound infection, the immediate post operative period was medically un-eventful; however, all the respondents commented that the initial two to three weeks after surgery was quite difficult with severe pain and even physiotherapy was painful. This initial post operative period with increased pain lasted for up to three months for five of the subjects while none were informed about the immediate post operative period and about what to expect and the timelines.

One of the recurrent themes in the narratives of those who had undergone the TKR surgery was the general lack of information on self-care and management of the operated knee following the surgery. For example, no one was aware of the extent of recovery that could be expected practically in the short as well as the long term. Patients could not recollect any advice given on do’s & don’ts following surgery, especially in activities that need full flexion of the knees such as squatting, sitting down on the floor, etc. Four of the post TKR subjects
were still hopeful and trying to do such activities while others were scared to try as they found it not so easy.

All the respondents reported that doctors had informed them about exercises that had to be continued after discharge from the hospital. But they did not understand that such exercises were part of the treatment regimen and that it that continued exercising was absolutely essential to preserve the prosthesis in good condition.

The physiotherapist is found to be a significant person in the immediate post OP period in all the 14 cases. Much of the information about the surgery and care during the post-operative period was given by this physiotherapist who started visiting them in the immediate post operative period in the hospital. Advice on continuing physiotherapy even at home for a few months was advised by all the physiotherapists; but only two women had such a visiting physiotherapist at home while others tried repeating the exercises taught by the physiotherapist. Only 12 of 14 did any exercises at all, and none had continued it beyond six months following surgery. Interestingly, one of the women who got operated for her left knee was doing the prescribed exercise only for that knee even though she had moderate to severe OA of the other knee also. Compliance with the advices to exercises also depends on the satisfaction with treatment. One man who underwent replacement surgery only out of compulsion from family and not convinced, reported his condition worse than that it was before surgery and did not comply to the advices to do regular exercises.

3.6. Treatment outcomes

Outcomes were measured using different scales and self-reported measures. Status of symptoms, including pain, present quality of life and present functional capabilities were considered to measure outcomes.
Relief from pain was a major outcome for all the subjects who underwent a replacement surgery. All the subjects except for one person have adequate pain relief following surgery even though there was pain of a different nature in the initial months post operatively. For those who also had a deformity of the joint, it got nearly fully corrected following surgery. This was an unexpected beneficial outcome for six of the subjects who had it and got corrected. Intensity of pain was measured during the study using a visual analogue scoring. All those who underwent surgery except for one person (pain score of 5 to 6 out of 10), gave a pain score of ‘0’ (no pain). There were no episodes of severe pain in the last one month. Out of the 18 subjects who are still on conservative management, five had severe pain (score of 9 to 10 out of 10) on the date of interview and who were on medications. Twelve out of the 18 subjects reported to have episodes of pain almost every day. Seven subjects report the episodes of pain they undergo daily as beyond that could be expressed. “It cannot be scored out of 10 .... Sometimes I get pain, which is 20 out of 10” – says one woman who is in her late 60s.

All the subjects in the study were asked to rate their present quality of life ranging from ‘excellent’ to ‘very bad’ (Table 3.4). The self rated quality of life following TKR Surgery was reported generally as “good” to “very good” as compared to what it was before among the women and “very good” to “Excellent” for men. Only one man who underwent a surgery without getting convinced rated his quality of life as very bad. Among those who did not undergo a surgery, self-reported quality of life ranged from ‘good’ to ‘bad’ among men while it ranged between ‘good and very bad’ with majority being ‘bad’ and ‘very bad’ for women. Overall quality of life was assessed using the WHOQOL-bref questionnaire where quality of life was measured in four different domains such as physical, psychological, social and environmental apart from overall quality of life. Results show that there is an overall better
quality of life for those who have undergone a total knee replacement surgery. Looking at the individual domains, there is no much difference in the psychological, environmental and social domains among subjects who have undergone a surgery or not (Table 3.5).

Table 3.4: Self reported present quality of life

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Very good</th>
<th>Good</th>
<th>Bad</th>
<th>Very bad</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TKR Done</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>TKR Not done</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TKR Done</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>TKR Not done</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>5</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>3</td>
<td>7</td>
<td>7</td>
<td>11</td>
<td>4</td>
<td>32</td>
</tr>
</tbody>
</table>

Table 3.5: WHOQOL- bref Score in four domains by sex and TKR status

<table>
<thead>
<tr>
<th>WHOQOL Domains</th>
<th>Sex</th>
<th>TKR done</th>
<th>TKR not done</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical</td>
<td>Male</td>
<td>80.4</td>
<td>64.38</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>83</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td><strong>Overall</strong></td>
<td><strong>81.7</strong></td>
<td><strong>58.19</strong></td>
</tr>
<tr>
<td>2. Psychological</td>
<td>Male</td>
<td>51.2</td>
<td>49.25</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>43.25</td>
<td>41.3</td>
</tr>
<tr>
<td></td>
<td><strong>Overall</strong></td>
<td><strong>47.2</strong></td>
<td><strong>45.28</strong></td>
</tr>
<tr>
<td>3. Social behavior</td>
<td>Male</td>
<td>51.4</td>
<td>49.25</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>39.13</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td><strong>Overall</strong></td>
<td><strong>45.26</strong></td>
<td><strong>39.63</strong></td>
</tr>
<tr>
<td>4. Environmental</td>
<td>Male</td>
<td>66.4</td>
<td>62.625</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>62.63</td>
<td>59.5</td>
</tr>
<tr>
<td></td>
<td><strong>Overall</strong></td>
<td><strong>64.51</strong></td>
<td><strong>61.063</strong></td>
</tr>
</tbody>
</table>

WHOQOL score (Total)

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>62.35</th>
<th>56.375</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
<td>57</td>
<td>45.7</td>
</tr>
<tr>
<td></td>
<td><strong>Overall</strong></td>
<td><strong>59.68</strong></td>
<td><strong>51.04</strong></td>
</tr>
</tbody>
</table>
Improvement in functional ability is another expected outcome of treatment of severe osteoarthritis. Outcomes in terms of functional capacity were studied using standard scales such as the Katz Basic Activities of Daily Living (ADL) scale, the Lawton-Brody Instrumental activities of Daily Living (IADL) scale. All the subjects had a full score in ADL scale at the time of interview while all of them reported of having the experience of being dependent on one or more such activities of daily living in the past. In this study, men generally have a better Instrumental Activity of Daily Living (IADL) Score at the time of surgery (Fig. 3.3).

Among those subjects who did not undergo a surgery too, men are more functional as per the IADL score irrespective of the severity of pain (Fig. 3.4). Score is found less for women as activities such as cooking, washing clothes and other household activities quite difficult to be done and these were the expected activities that women had to do. Except for one man who underwent a TKR who used to wash his own clothes, no other male subjects were involved in these activities at home. Much of the work done by men as part of their activities of daily living did not essentially require prolonged standing, bending of knees or such repetitive movements.

Out of all the subjects who underwent a TKR surgery, 12 found the surgery beneficial given their present status while one person was dissatisfied of the improvement, and another person is fully satisfied as his expectations were met. Expectations from the surgery apart from pain relief for women were to regain the capability to do some of the household activities while it was pain relief and mobility for men. Kneeling down during prayers or while in church was the biggest expectation for a lady who realized later that it should not be even tried again in this life to protect malfunctioning of the implant. During the long course of the disease, most of the subjects and their families were adjusted to the incapability and certain roles with
household activities were readjusted. In such cases, the expectation of recovery in terms of functionality as compared to pain relief was low, which could be the reason for good perceived quality of life in spite of the persisting incapability.

**Fig. 3.3** Comparison of performance with IADLs before and after a TKR surgery among men and women (using percentage of expected IADL score)

**Fig. 3.4** Comparison of performance with IADLs among men and women who have not undergone a TKR surgery (using percentage of expected IADL score)
3.7. Factors influencing health-care seeking pathways

Health-care seeking pathways for the knee pain are influenced by information and perceptions about knee pain, attitude of others and self towards pain and the barriers to help-seeking if there is any such as financial, family support and gender apart from the severity of symptoms. The various factors influencing health seeking pathways during different phases is summarized in the concept map below (Fig. 3.5). These determinants of decision making to seek help at the first onset of symptoms also influence subsequent patterns of health-care seeking including consulting multiple providers, multiple systems and self-medication during the course of the disease process.

3.7.1 Knowledge and perceptions

While the first symptom of osteoarthritis could be knee discomfort or weakness, pain is generally the first symptom which is the trigger to help seeking. During the early stages of the disease, majority of the persons with knee pain decided not to seek help from a doctor. They instead resorted to self-medication with OTC analgesics and home remedies. Such a delay in consulting a doctor was mainly due to information gap and misunderstandings. Consulting a modern medicine practitioner for most of the subjects is just one of the options for getting quick relief to severe pain. For all those who have consulted a doctor, after a delay or not, none received any further information from the health care providers. It was actually their previous experiences with treatment, logical reasoning, lessons learned from the experiences of others and commercial advertisements that shaped their decisions regarding where to seek help from. There was also the fear of complications on long term medications, while other systems such as Ayurveda and home remedies were considered safe.
Fig. 3.5 Concept map of pathways to health seeking and factors influencing them in the subjects with severe osteoarthritis of knees

Factors influencing Pathways
- Past Experiences
- Advices Received
- Information
- Logical reasoning
- Perceptions
- Financial reasons
- Family Support
- Expectations
- Gender

Attitudes of self & others

Knowledge Information Perception

Symptom

PHASE - 1

Influence

PHASE - 2

Severities of symptoms & barriers to help-seeking (Financial, Health system, family, gender etc)

PHASE - 3

Multiple Systems and providers

Deterioration

Improvement

PHASE - 4

POST TKR status

* Numbers in small circles denote the total number of subjects who has undergone that path
3.7.2. **Attitude of self and others**

Attitudes of the subject, family and friends or the providers influenced their health seeking behavior significantly. Decisions to choose a particular path leading to self-neglect were found mostly in women. This was obviously being guided by certain situations such as family in at least some of the cases. A lady in her late 60s with severe osteoarthritis and pain decided not to get operated and was carrying out all the household work even while in pain. The reason initially told by her was a fear for surgery and her belief that such a surgery is unsuccessful. Later during the interview it was apparent that the major reason for her neglect towards herself was the recently diagnosed oral cancer of her husband. Insecurity in leaving her daughters alone with their father who is always drunk was the reason for neglect in another woman. Lack of adequate finance or support were the reasons for such negative attitude towards the disease condition for most of the others who neglected their disease.

Attitudes of primary caregivers also influence the pathways chosen. In one extreme, a retired teacher was so supportive of his wife whom he takes proactive steps to get her the best of treatment and timely medications. She got operated without much delay and was well supported so far. On the other extreme was a son of a widow who did not bother even to pay attention to his mother who was staying alone. He considers knee pain as part of ageing and believes that pain medications are all that are needed. As per majority of women, knee pain was generally not considered as a disease process and was trivialized by the family members.

Attitudes of providers were reported to be mixed where subjects appreciated doctors who were empathetic to their painful situation and listening to their complaints. Doctors are seen to be taking a paternalistic attitude towards their patients by not providing them options to take a decision. There were several instances according to subjects where doctors were
reluctant to spend time to listen to their main complaints or even examine while they prescribe medications as if prejudiced. Most of them feel that they did not get enough opportunity to convince the doctor about the real pain they are going through as the OPD was crowded. Doctors were reportedly getting angry at them when more questions are asked or when they find at least some of their advices are not complied to. Interview with healthcare providers also revealed that there is a general trend to consider osteoarthritis is related to ageing, and TKR is the only ultimate option.

3.7.3. **Severity of symptoms**

Severity of symptoms is often the only trigger for health seeking for most of the subjects. Even though pain was a trigger for help seeking, problems with mobility associated with osteoarthritis limited the health seeking of most women with disability as they needed support from family or friends. Among the study subjects, the perceived severities of symptoms in terms of pain were not as grave as with women and this was the reason why many of the men had a delay while women went shopping with multiple providers as symptom relief was inadequate.

3.7.4. **Financial Barriers to seeking health-care**

Because osteoarthritis is a long term disease, the cost incurred for treatment of this condition is a definite barrier. Financial issues were highlighted by eight of the subjects and were the reason for delays and neglects of pain and other symptoms during the course of the disease. It was seen that the only option given to those who were having severe osteoarthritis was a TKR surgery that was highly expensive. Financial barriers were compounded by other social factors such as gender and support from family; detailed elsewhere. Those persons in the APL category with good financial resources were found having better quality of life and health seeking behavior as compared to those in the BPL category or not covered with
insurance. Financial constraints as well as resources not being at disposal makes the person vulnerable to delays and inadequate treatments.

3.8. Gender differences

Osteoarthritis is seen to affect both men and women but incidence and progression to sever OA is seen more in women everywhere in the world as per the literature. Apart from the high prevalence of osteoarthritis among women, several gender issues are found associated with this condition.

Obesity is a proven risk to osteoarthritis in both sexes while among the study subjects, majority of the women were reportedly having over weight. Putting on weight was considered desirable for women during their younger ages according to a woman presently in her late 60s, and it is evident from the discussion with the subjects that women during their young age or as children did not have enough exercise or games that could provide adequate strength to the joints.

Gender based division of roles in the household traditionally has left women alone to do most of the jobs that require prolonged standing, bending and repeated movements with stress such as cooking, laundry, housekeeping and so on. Most of the instances, the work extends daylong giving no opportunity for a rest as per many of the women. Technical advances and mechanization have brought down the strain of doing some of the house hold work such as grinding, laundry, storage and cleaning. This has brought down the burden of work that was potentially hazardous. Several misunderstandings persist regarding the aetiology of the condition while some are deeply gendered. There are still some men, especially caregivers who believe that the decreased work load of women, especially in the house is the cause for ill health among women. This not only affects validation o pain, but also influences promptness with which they may be taken to a healthcare provider.
Women also prioritize their household activities over health care seeking. For example, a mother of three sons had to wait for years till two of her sons got married until she could effectively take care of her health. “They will get up in the morning and get prepared to go for their job .... both sons and my husband never helped me in cooking or laundry ..... I used to do everything after getting up early in the morning ..... and also I had to go for work in a cashew factory ....”. She could now go for regular doctor visits and had undergone a TKR surgery covered by insurance only because there was another woman in the house to share the roles.

Gender norms related to appropriate female behavior made women ashamed of talking about some problems affecting their everyday life. For example, essential daily activities such as toileting were also compromised in many women. “I used to be scared of going to a toilet .... and I was always constipated. I couldn't squat down and used to still maintain a semi-sitting position or even had to support the floor to come up from that position. I used to cry, and nobody knew ... I found it awkward and ashamed to discuss this matter with others at this age of mine .....” said a woman who was in her mid 60s.

It is also seen among women in the study that the perception of pain measured by the self rated severity of pain is more than that in men. Despite this, they appear to be continuing with the household tasks. This was also true of the self rated quality of life that was poor in women. On measuring the quality of life using a standard WHOQOL-bref questionnaire too, men had a better quality of life in all the four domains (Refer Table 3.5). Women generally were more dependent because of a functional decline as compared to men. Since the functions generally done by women required prolonged standing, repeated bending and strain on the knee joint, a functional decline was more pronounced among them as compared to men who could take a rest while work.
In the study, it was seen that when men are with osteoarthritis and in severe pain, caregivers usually try to understand from their gestures, body language, irritability and other behavior. Support in such cases is provided without a formal demand while the pain and symptoms which women go through often get un-noticed. Tolerating pain as much as possible by women was considered as a norm according to 16 out of the 19 women in the study group. Issues of men living with osteoarthritis were different from that of women which has been discussed in an earlier section. However, it is worth reiterating that the major concern of men in living with disability from osteoarthritis is the mental hurt arising from being seen as ‘physically dependent’ in public that would affect their social positions and roles. For women, the concerns were guilt of not able to contribute or fulfil her roles in household activities. When men were concerned about the deformities of the knee joint that were adversely affecting their external appearance and gait, women were not found to be that much concerned.

Healthcare providers somehow do not identify the gender issues associated with this chronic disease and view it from a biologic and medical point of view as evident from the interviews. Decisions, opinion and advices given are without considering these gender issues. Women are often kept away from decision making and planning care by healthcare providers according to most of the women in the study. Disease condition and care plan was discussed with either their spouses or to a male member accompanying them. This holds true many times even when the patient is a man accompanied by his wife.
3.9. *Health care providers’ perspectives*

Three Orthopedicians, one each from the three hospitals from where the sample was obtained were interviewed. TKR surgery is performed regularly in the private hospital while surgery is not done now in the district hospital studied. Lack of infrastructure in the hospital is the main reason for not conducting this surgery now at the district hospital. The third hospital, a referral hospital of ESI Corporation conducts surgery only when there is adequate manpower. All the three hospitals have a heavy rush of patients with busy out-patient department.

Orthopedicians were asked about the aetiology of osteoarthritis among the patients they commonly come across and whether there is any association with age of the person. Two out of the three doctors believe that OA is part of the ageing process as ageing bone is vulnerable for more degeneration in the background of history of injury. According to them, certain occupation that requires continuous movement and hyper flexion of the knees will predispose to OA and its progression. Even though there are international guidelines for management of knee osteoarthritis, there are no practical guidelines in India for the management of a patient with osteoarthritis and prevention of its progression opined by one of the doctors.

Doctors working in the government sector because they see such patients more often, recognize lifestyle and work pattern at home and workplace as contributing to worsening of arthritis. Even with such an understanding, they are of the opinion that no further modification in lifestyle and work is practically possible.

According to the doctors, orthopedic department in the government hospital deals mainly with trauma and fractures. Patients with joint pains do visit the OPD in large numbers, but they visit only when there is severe pain requiring analgesics.

According to the providers, a typical patient (whether male or female) is with history of longstanding pain, who has tried several types of treatment including modern medicine and
other alternative medicines and someone who does not comply with the advices given to them. They reported that patients go from one doctor to another and do not understand that there is no cure for OA. All the three doctors believed that there is no cure for OA, and the only solution is a TKR, and that has to be done in an extreme situation.

When probed further, two of the doctors agreed that there is some role for exercises and lifestyle modifications. However, such advice was not given regularly to patients with early stages of osteoarthritis. Main reason for this was the lack of time. All three doctors had a busy OP schedule which gives only minimal time to take care of each person. Given the variety of conditions that are presented in the OPD, OA of knees is not of high priority as pain relief is what the expectation is from the patient’s side.

The doctors reported that patients discontinue the medicines prescribed to them after the initial pain has subsided and continue taking it again when there is pain. The three doctors expressed their helplessness when they are faced with patients coming OA; they believe that there is actually nothing more to be done and hence analgesics are prescribed. Whenever there is a patient with very severe OA is seen, the option of TKR is told. TKR surgery according to the doctors interviewed is a good surgery as it gives good pain relief and some degree of deformity correction. The three doctors were not able to comment on the extent of functional improvement patients would get from doing this expensive surgery apart from pain relief. Poverty was identified by doctors treating OA as a factor impeding treatment, because TKR surgery is quite expensive in the absence of insurance or reimbursement.

When asked about sex and gender-related differences, the providers observed that OA is seen more with women, and the reason is considered by the doctors interviewed as partly because of biology. In their view, the higher prevalence of obesity, general gait abnormality and the structure of the female pelvis could be the reason for OA being more prevalent among
women. All the three doctors agree to the fact that OA is found more in women and progression to severe OA is more rapid in women. The three doctors did not have a clear reference to a probable cause for this feminization of OA but would attribute to some biology of women that make them vulnerable. No gender difference is identified by the providers other than the increased prevalence and the increased need for TKR in women while most of the men having OA are with a history of injury to knees.

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CHAPTER – 4

Discussion, conclusions and recommendations
4.1. Introduction

The main objective of this qualitative study was to study the pathways to health seeking among persons with severe osteoarthritis and to understand the various factors that influence these pathways. Since this condition was found more prevalent among women, gender and sex differences affecting the pathways were also studied.

With the advent of better healthcare and technologies, life expectancy has been increasing both in India as well as in Kerala. Nearly 13% of Kerala population are above the age of 60 in Kerala with increasing prevalence of non communicable diseases and chronic non-life-threatening such as osteoarthritis. All these diseases cannot be attributed to ageing as life-course plays an important role. Appropriate management of conditions such as osteoarthritis becomes extremely important for healthy and active aging with good quality of life for older people. This is the context for this qualitative study that identifies several complexly interrelated physical, social, cultural, and economic and gender issues that are of significant public health relevance.

Osteoarthritis is a chronic disease that potentially compromises the quality of lives of people affected. Millions of quality years are lost due to osteoarthritis according to one of the studies done in the United States.78 which could be also true for our setting with the reported low quality of life of subjects in the study. This is also a disease that progresses to a stage where the only option is an expensive surgical correction if not managed earlier adequately. As of now, osteoarthritis is considered as a non-life-threatening condition of trivial wear and tear requiring just analgesics.
4.2. Life course and osteoarthritis

Factors early in the life are associated with increased risk of chronic diseases in adults.79 Osteoarthritis is a degenerative disease of the knee joint that may arise in a previously injured knee, overweight, weakness of muscles and nutritional factors. One of the studies that evaluated an association between knee osteoarthritis and certain occupation, sports and lifelong daily activities bring out the risk of osteoarthritis in such occupations requiring repeated movements of the knee, squatting down and among housewives.79 The present study also brings out experiences of subjects who had severe symptoms of osteoarthritis while at work and had to discontinue the work when bearing the pain while working was no longer possible. Housewives who had such severe pain did not have any of such option to stop working until some other woman in the house took that responsibility. In most of the subjects in the study, lifestyles and occupation seem to have played its role such as with coir and cashew industry workers and head-load workers. This would suggest the relevance of viewing osteoarthritis with a life-course approach.

4.3. Presentation, Pain and other symptoms

Osteoarthritis may present either as pain, joint stiffness, weakness or deformity where pain is the most common presentation. Even though pain and disability are considered the major issues, a study from the UK found that disability was comparatively more of an important determinant in seeking help than pain, depression or anxiety.54 However, in this study, pain was the major presenting symptom for all followed by disability. The reason could be that those with osteoarthritis and disability were continuing with their activities as far as possible till severe pain set in. Other symptoms included locking of the knee, weakness and joint deformity. All these symptoms occurred at different times and the severity of these were the triggers to go for a doctor's consultation. According to treating doctors, the usual presentation
of osteoarthritis is with one of the symptoms in a severe stage after trying other medicines or methods where symptom relief is the only demand.

4.4. Factors influencing Pathways to health seeking

Pathways to health seeking of the subjects in the study has been summarised in four phases along a continuum starting from a phase of self-management to the post TKR phase. There were four major factors identified as having as an influence in the pathways to health seeking that are detailed below. However, the two inter-related factors - knowledge about osteoarthritis and health system related factors were found to be most influential.

4.4.1. Knowledge about osteoarthritis

Knowledge about the disease influence the decisions that are made and hence the pathways. Self-management and choice of health provider / system are also influenced by their knowledge and available information. Self management that was sought by all the subjects in this study for varying durations were based only on information from sources such as magazines, advertisements or from friends which were not authentic. No efforts were found to be taken by treating doctors to help their patients manage their pain and coping with disability while letting the joint heal and prevent further damage. Understandings of persons regarding replacement of knee are also incorrect. None of those who underwent a surgery or those who were advised surgery was aware of the actual process. Furthermore, all the post TKR subjects were unaware of the ways the operated knee needs to be taken care of. Without knowing the ‘do’s and don’ts’, post TKR subjects were engaged in activities that would potentially damage the implant or decrease its life. This is a serious situation where those who are currently benefited from the surgery may be left with disability and no further options when the knee implant malfunctions at a later age.
4.4.2. Attitudes of self and others

Attitudes of family members or primary caregivers are significant determinants in health seeking as well as the choice of providers. Negative attitudes and trivializing the disease is seen among some of the family members while subjects themselves did not give it much priority until episodes of pain was significant. When pain significantly affected household activities, issues related to OA was given due importance by care-givers of most women. Neglect of pain by women was also found as part of coping with poor family support and prevailing socio-economic circumstances. Studies from the UK and US shows ageist attitudes of doctors towards delivery of care for OA of knees.\textsuperscript{51, 58, 66} However, there were no such attitudes observed among modern medicine practitioners in this study according to the subjects. At the same time, OA is still considered a disease of old age by other systems according to the subjects. Since many of the subjects had pain since long time, they do not believe OA as part of ageing. Attitudes of providers are detailed in the following section.

4.4.3. Financial barriers

Financial barriers to health seeking are seen throughout the study when the person has to depend on others or family on a long run and unable to continue work or engage in income generating work. TKR surgery which has been advised for severe osteoarthritis remains unaffordable for most of the people, unless there is an insurance coverage.

4.4.4. Health system factors

Health systems have not given osteoarthritis the priority that it deserves although quality of life of several individuals is at stake, and they are in pain and agony. The general propensity of healthcare providers is to be interested in taking care of curable condition, which is evident from experiences of patients. Most of the study subjects were complaining that doctors were not empathetic or did not spend enough time to examine them or listen to their
problems. The trend seen in general practice is to treat with analgesics alone and this is against the internationally accepted guidelines and best practices, for example, the NICE guidelines of NHS (UK), the EULAR guidelines, guidelines of American association of orthopaedic surgeons and the National guideline clearing house of the US.\(^{80-83}\) It is a well-established fact that patient education on the disease process, treatment and prognosis is very important given the chronic nature of the disease. Exercises to strengthen the muscles of the leg and that support the knee joint is established to be beneficial and is considered as part of standard treatment. Education, advice, adequate information, exercises and weight loss are considered as the “core treatment” for managing osteoarthritis.\(^80\) One of the community-based intervention studies in Australia looked into how ‘Self management programs’ can be effective in the management of osteoarthritis by bringing in long term behavioural changes in persons with the disease. Exercises and disease coping strategies were promoted so as to improve quality of life, general health and relief from pain. This self-management program was guided and supervised by professionals. There are also programs in other developed countries that tried supervised self-management regimes and found beneficial.\(^40\) Health education for lay public regarding such chronic disabling conditions are totally lacking while public gather wrong information about health that can prove detrimental. Lack of adherence to advice by doctors could be partially due to this ignorance.

A total knee replacement is considered as the ultimate option for severe osteoarthritis only when the cost of this expensive procedure could be met with. What we see in the present study is that the problem is at first managed incorrectly even by trained general physicians and allowed to proceed to a level of severity requiring a total knee replacement. Then patients are given no other option but TKR, irrespective of whether or not the patient will be able to accept this option. Lack of social support and high cost of surgery are not the concern
of the orthopaedic surgeon. Those who do not accept surgery are left to their own devices, and suffer a poor quality of life and serious disability.

4.5. Factors affecting Treatment outcomes

Outcomes of treatment depend on the promptness of treatment and the stage at which a treatment is taken. According to studies conducted in the developed countries, TKR surgery carries a high post operative benefit in terms of health-related quality of life, functional recovery and pain relief.\textsuperscript{44-46} For subjects in this study who underwent a TKR surgery, it was evident that those who were better off functionally prior to surgery were the ones who gained the most out of the surgery. The major outcome for the surgery was relief from chronic pain and there was no much recovery in functional capacity. It is worth highlighting here that, contrary to the literature from the developed world as in the above literature, all that an expensive TKR surgery could do was pain relief. This observation almost matches the finding of yet another study done at Medical College Thiruvananthapuram where 60% of the post TKR patients had a good clinical outcome while only 25% had good functional outcome. Scores of WHOQOL suggested that there was an improvement in physical domain of quality of life while no difference in the psychological and social domains of quality of life was observed between subjects who underwent a surgery or not. The reason could be the delay in undergoing a surgical correction when other psychological and social issues have already set in as part of prolonged pain and disability.

Support from family and source of finance are other factors that affect the outcomes. Disability associated with pain in osteoarthritis would make the subjects dependent on someone to go for a doctor's consultation. When this support is poor, there is a delay and neglect followed by irrational self-medication resulting in further deterioration. Such persons with inadequate family or financial support are never identified by the health providers as
vulnerable for further deterioration. Educating the patient, that is considered as one of the core management for osteoarthritis internationally would be beneficial, especially for such persons.

4.6. Gender and outcome

Globally, prevalence of osteoarthritis is more in women compared to men of all ages, and similar finding is obtained from the Community Oriented Program For Control Of Rheumatic Disorders (COPCORD) study conducted in rural India.\textsuperscript{14} All the three specialists interviewed in the study are also of the opinion from their daily practice that majority of patients with osteoarthritis are women and majority of patients who undergo a TKR surgery are also women.

One of the studies in the west found that there was a delay for unknown reasons in health seeking for women which was supposed to be a reason for poor outcomes in women.\textsuperscript{74-77} This study found several reasons for delay such as financial and dependency on others for taking them to a provider. Household responsibilities were another concern for women in this study that caused a delay as men of the household would not take over because of notions related to gender norms and roles. So she had to find someone else to take up those responsibilities before she could take leave.

A study done in USA found women complaining worse pain and functional loss than men while their physical activity level was the same for both.\textsuperscript{70,71} Women in this study also were found to be reporting worse pain and functional impairment as compared to men; but this study also other reasons such as inability to stop everyday household tasks, lack of validation of pain by family members and financial dependency. Lifestyles of women, especially housewives with life-long activities that require prolonged standing, bending of knees or sitting down may make them vulnerable for osteoarthritis. As is the case for all, for women
also pain is a trigger for help seeking; however, women in this study were generally seen to have given more priority to their household responsibilities by neglecting many of the significant symptoms and getting into a vicious cycle of inadequate symptom relief leading to further ineffective consultations. It is also necessary to explore more about the experiences of pain in detail and its relation to biology as well as gender. Women also face embarrassing moments and feel ashamed to discuss certain matters like difficulty in toileting or self-care as they feel it inappropriate for female behavior. Probably, this could be a reason why women had more providers and had tried multiple systems. Even during consultations, they were not made a party to the decision making, and all explanations and advices were given by the doctor to the person who has accompanied her. Similar was the case when the caregiver is a woman; doctors preferred to discuss prognosis or treatment either with the patient himself or with another male member in the family.

A study done by systematic review of literature observed that the outcome of treatment procedures for men is better than the outcomes of women. And another study observed that generally those women undergoing a TKR surgery are the ones who have reported also late.

In the present satudy too, the treatment outcomes for men are better than women while duration of osteoarthritis is more in women as compared to men. It was observed in the study that the current functional capabilities of women were lower than men. If functional status prior to surgery determines the expected outcome, men would have a better outcome than women.

Men with osteoarthritis were at an advantage compared to women as they were able to find help with daily activity. However, it was unavailable for women as majority of their daily activity were parts of the household activities where men did not usually get involved.
4.7. Cost to society and individual

Healthcare utilization for osteoarthritis is high and accounts for a high number of physician and specialist consultations, hospitalizations, cost of medicines and expense of surgery. The health care needs related to osteoarthritis are enormous given the high prevalence of the condition. It is observed from this study that osteoarthritis management in our setting does not follow any standard treatment guideline or give importance to preventive aspects. As a result, the cost for symptomatic treatment as well as the need for an expensive TKR surgery remains high. Government expenditure on this long-standing condition in our country has not been measured and hence under estimated. Insurance schemes, both private as well as government ends up paying heavily for the treatment when no preventive aspects or standard conservative methods of management were tried to prevent such costs. Not only is it a heavy cost burden for the society, but family and individual spending is also high as per the respondents. Reported individual expenses in the study are also very high. They include cost of medicines, consultations, hospitalisations, surgery or trying other alternative methods for symptom control. Expenditure on OA treatment affects the financial condition of entire family. Indirect costs to individual such as loss of income, quality of life, pain and disabilities are identified in this study. Lack of availability of effective treatment options resulted in excess spending and shopping around in the absence of appropriate information. The unscientific practices of health system as far as life-altering disease like osteoarthritis is concerned, is resulting in an unfair use of available scarce resources. This could prove to be detrimental for a developing country like ours.
4.8. Strengths of the study

This is one of the very few studies that has viewed this chronic disabling condition from a public health perspective which is of importance in the current demographic context of Kerala State. The study could examine health seeking behavior of people with osteoarthritis in depth in different contexts bringing out those subtle factors affecting treatment outcomes and quality of life that would not have been possible in a quantitative study. Interview with care-givers helped in validating the history provided by the subjects and also in supplementing the information provided them. Orthopaedic surgeons were also interviewed after the preliminary analysis of interviews with subjects, and care-givers were over. This has helped in a triangulation of the findings and observations making it more valid. Gender differences in health seeking and outcomes have been also inquired in detail in this study and have brought out certain important and valid observations.

4.9. Limitations of the study

There are also certain limitations for this study. Subjects were selected from hospitals where there is a full-fledged orthopaedic department and only those who visited such a facility were interviewed. It is possible that the picture would have been different for a different study setting. Hence the knowledge generated from the findings, and observations could not be generalised to other people or other setting. Principal investigator being a doctor by profession and been known to their currently treating doctor was a limitation to a small extent. There is a chance that subjects have not completely revealed their experiences with their doctor, hospital or health system if at all there were any for this reason. Hence more research is required to identify the complex interlinks of various factors that are associated with pathways to health seeking, treatment and outcomes of osteoarthritis.
4.10. Conclusions

In ageing societies, OA is a widely prevalent chronic condition causing serious disability and contributing significantly to Disability Adjusted Life Years (DALYs) lost. Consequently, the burden of OA in Kerala is likely to be considerable, although public health studies on this are limited. The present study focused on health care seeking for OA and found a pattern of caregiving that is untenable and unaffordable for a developing country setting. The study found that no promotive or preventive care is offered at all by the treating physicians and specialists. The tendency of allopathic physicians is to manage early OA with painkillers and allow the condition to escalate to a level of severity where there is no option other than TKR. This poses a heavy drain of health system and individual resources. What is worse in the present study is that despite the heavy expenditure, the outcomes are relatively modest, with pain relief being the chief gain. The study points out that if we do not have strategies to prevent or manage such chronic disease in early stages, diseases such as osteoarthritis will become a major burden of illness as population ages.

What is urgently needed is a public health perspective for the management of OA of the knee. TKR should be the solution for the worst-case scenario after all other established treatments have been tried and failed. Every effort should be made to prevent worsening of the condition through exercises, appropriate lifestyle adjustments and safe working conditions that are mindful of negative consequence of repetitive movements. Adequate information to the public and implementation of a standard treatment strategy is the responsibility of a humane health system to improve the health status and quality of life of many.
4.11. Recommendations

1. Osteoarthritis being non-life-threatening, even though it is a significantly disabling disease, adequate attention has not been given. Policies and strategies with a public health perspective are needed for managing osteoarthritis of the knees.

2. Standard treatment protocols, and best practices need to be developed and implemented by incorporating standard and evidence based international guidelines.

3. Strategies for prevention or progression of the disease should be given importance at any stage of the disease, especially in the early stages.

4. Healthcare providers should identify correctable problems based on a standard protocol for early intervention and with the help of physiotherapist, occupational therapist, dietician or a psychologist, a solution may be found. A life-course approach has to be incorporated in planning care and worsening of present condition should be prevented through targeted exercises, appropriate lifestyle adjustments and safe working conditions.

5. Supervised self-management programs should be tried appropriately. Educating the patients and their family would empower them to prevent certain preventable events and seek appropriate help at the right time.

6. Availability of surgical management of osteoarthritis should be ensured and made affordable for those who are in need.

7. Management of osteoarthritis should be evidence based, and non-medical managements as per the protocol should be tried. TKR should be the solution for the worst-case scenario after all other established treatments have been tried and failed.

8. More research needs to be undertaken to understand how the pathology of osteoarthritis is different in women and the gender factors that affect the outcome.
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Annexure

(A1 to A6)
## Table - 1.1: Available Management Options for Osteoarthritis of Knee

<table>
<thead>
<tr>
<th>Pharmacological management</th>
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<tbody>
<tr>
<td>1  Paracetamol/Acetaminophen</td>
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<tr>
<td>2  Non-steroidal anti-inflammatory drugs</td>
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<tr>
<td>3  Opioid analgesics</td>
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<tr>
<td>4  SYSADOA (Symptomatic Slow Acting Drugs for OA)</td>
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<tr>
<td>5  Topical Non-steroidal anti-inflammatory drugs</td>
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<td>6  Topical capsaicin</td>
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<tr>
<th>Surgical management</th>
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<tbody>
<tr>
<td>1  Arthroscopy, Chondroplasty</td>
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<tr>
<td>2  Osteotomy</td>
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<tr>
<td>3  Osteochondral Autograft (or allograft) transplant (OATS procedure)</td>
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<tr>
<td>4  Unicompartmental Knee Replacement</td>
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<td>5  Total Knee Replacement</td>
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<tr>
<th>Intra-articular treatment</th>
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<tbody>
<tr>
<td>1  Corticosteroids</td>
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<tr>
<td>2  Hyaluronans</td>
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<td>3  Tidal irrigation</td>
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<tr>
<th>Non-pharmacological management</th>
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<tbody>
<tr>
<td>1  Self Management program</td>
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<td>2  Education (patient and spouse or family)</td>
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<td>3  Social support</td>
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<td>4  Weight reduction</td>
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<tr>
<td>5  Physiotherapy</td>
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<tr>
<td>6  Occupational therapy</td>
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<td>7  Orthotic devises</td>
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<td>8  Exercise</td>
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<td>9  Bracing</td>
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<td>10 Pulsed Electromagnetic field therapy</td>
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<td>11 Laser</td>
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<td>12 Ultrasound</td>
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<tr>
<td>13 Transcutaneous electrical nerve stimulation (TENS)</td>
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<tr>
<td>14 Acupuncture</td>
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<tr>
<td>15 Supplements such as glucosamine sulfate and chondroitin sulfate</td>
</tr>
</tbody>
</table>
Annexure A2
RESPONDENT INFORMATION CUM INFORMED CONSENT FORM

Pathways to health seeking, treatment and outcomes in persons with osteoarthritis of knee in Southern Kerala, India.
Achutha Menon Centre for Health Science Studies,
Sree Chitra Tirunal Institute for Medical Sciences & Technology,
Thiruvananthapuram, Kerala, India. PIN-695011

“Namaskaram”- my name is Dr. Praveen G Pai and presently I am a student of public health at Achutha Menon Center, Sree Chitra Tirunal Institute for Medical Sciences & Technology, Thiruvananthapuram. I am sure Dr. ……….. (Your treating doctor) must have given you a brief description of what I am doing. As part of my training, I am conducting this survey among persons with osteoarthritis of knee in Thiruvananthapuram to know the various problems associated with living with the disease, health seeking patterns and managing the disease. I am also looking into any form of support you are getting from family, society and health system.

There will be no direct benefits to you for participating in this interview. You may chose to answer all or some of the questions that I put to you. Everything you will say will remain private and confidential

The approximate time I will take is about 45 minutes to 1 hour. If you agree to participate in the interview please indicate your agreement. Your name will not be used in any report but your ideas and experiences will be of great help to plan interventions among persons with osteoarthritis and to prevent progression of the disease leading to severe osteoarthritis. However you are free to quit the interview at any point of time if you feel so.
Annexure A2

Informed Consent

I have read/ been read out the information in the information sheet above. The nature of the study and my involvement has been explained and all my questions have been answered. I understand that you will also be asking me details about my personal understanding of the disease and views and regarding support from family and society. I understand that I will be asked about the previous treatment histories and records. I also understand that you wish to record our conversations and that any information collected from me will be used for the study purpose only. By signing this consent form, I am giving you permission to record our conversation and use the same for the study purpose only with the understanding that my identification details will be kept confidential.

By signing this consent form, I indicate that I understand what will be expected from me and that I am willing to participate in this study. I know that I can withdraw at any time. I have been informed who should be contacted if the need arises

☐ Yes, I am agreeing to the interview
  Signature/Left thumb impression …………………………

  Or

☐ The respondent is not willing to sign or give thumb impression (verbal consent)

Signature of the witness……………………………………
Name and address of the witness:
……………………………………………………………………

……………………………………………………………………

If you are not willing to participate, then thank you for your time.
Name of the respondent:……………………………………
  Address:…………………………………………………………

……………………………………………………………………

Date:  /0 /2012

If you have any further queries, you are free to contact the following people
Principal investigator: Dr. Praveen G Pai (Mob no: 08129060055) or Guide & co-investigator, Dr.T. K. Sundari Ravindran, Professor (Ph. No- 0471- 2524233)
Member secretary of the Institute Ethics Committee at Sree Chitra Tirunal Institute, Dr. Anoop Thekkuveettil(Ph. 0471-2520256/257)
Pathways to health seeking, treatment and outcomes in persons with osteoarthritis of knee in Southern Kerala, India.

Achutha Menon Centre for Health Science Studies,
Sree Chitra Tirunal Institute for Medical Sciences & Technology,
Thiruvananthapuram, Kerala, India. PIN-695011

Dr. Praveen G Pai, who is a student of public health at Achutha Menon Center, Sree Chitra Tirunal Institute for Medical Sciences & Technology, Thiruvananthapuram is conducting a study among persons with osteoarthritis of knee in Thiruvananthapuram to know the various problems associated with living with the disease, health seeking patterns and managing the disease. There will be no direct benefits to you for participating in this interview. Everything you will say will remain private and confidential. If you agree to participate in the interview please indicate your agreement. Your name will not be used in any report but your ideas and experiences will be of great help to plan interventions among persons with osteoarthritis and to prevent progression of the disease leading to severe osteoarthritis. However you are free to quit the interview at any point of time if you feel so. Dr. Praveen shall provide you with more information about the study. By signing this consent form, I indicate that I am willing to share my contact details including residential address and phone numbers.

☐ Yes, I am agreeing for the reference

Signature/Left thumb impression ………………………
Name and Address: ………………………………………
………………………………………….

Signature of the treating doctor…………………………. ........
Name and address ………………………………………………………..
……………………………………………………………………………………………

Date: …………………..
### KATZ BASIC ACTIVITIES OF DAILY LIVING (ADL) SCALE

<table>
<thead>
<tr>
<th>Independent</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bathing (sponge bath, tub bath, or shower) Receives either no assistance or assistance in bathing only one part of body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Dressing - Gets clothes and dresses without any assistance except for tying shoes.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Toileting - Goes to toilet room, uses toilet, arranges clothes, and returns without any assistance (may use cane or walker for support and may use bedpan/urinal at night.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Transferring - Moves in and out of bed and chair without assistance (may use can or walker).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Continence - Controls bowel and bladder completely by self (without occasional &quot;accidents&quot;).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Feeding - Feeds self without assistance (except for help with cutting meat or buttering bread).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### LAWTON - BRODY INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)

<table>
<thead>
<tr>
<th>A. Ability to Use Telephone</th>
<th>E. Laundry</th>
<th>F. Mode of Transportation</th>
<th>G. Responsibility for Own Medications</th>
<th>H. Ability to Handle Finances</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Operates telephone on own initiative-looks up and dials numbers, etc.</td>
<td>1. Does personal laundry completely</td>
<td>1. Travels independently on public transportation or drives own car</td>
<td>1. Is responsible for taking medication in correct dosages at correct time</td>
<td>1. Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income</td>
</tr>
<tr>
<td>2. Dials a few well-known numbers</td>
<td>2. Launders small items-rinses stockings, etc.</td>
<td>2. Arranges own travel via taxi, but does not otherwise use public transportation</td>
<td>2. Takes responsibility if medication is prepared in advance in separate dosage</td>
<td>2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.</td>
</tr>
<tr>
<td>3. Answers telephone but does not dial</td>
<td>3. All laundry must be done by others</td>
<td>3. Travels on public transportation when accompanied by another</td>
<td>3. Is not capable of dispensing own medication</td>
<td>3. Incapable of handling money</td>
</tr>
<tr>
<td>4. Does not use telephone at all</td>
<td>0</td>
<td>4. Travel limited to taxi or automobile with assistance of another</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>B. Shopping</td>
<td>1</td>
<td>5. Does not travel at all</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1. Takes care of all shopping needs independently</td>
<td>1</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2. Shops independently for small purchases</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3. Needs to be accompanied on any shopping trip</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Completely unable to shop</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>C. Food Preparation</td>
<td>1</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1. Plans, prepares and serves adequate meals independently</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>2. Prepares adequate meals if supplied with ingredients</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3. Heats, serves and prepares meals, or prepares meals, or prepares meals but does not maintain adequate diet</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Needs to have meals prepared and served</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>D. Housekeeping</td>
<td>1</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1. Maintains house alone or with occasional assistance (e.g. &quot;heavy work domestic help&quot;)</td>
<td>1</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>2. Performs light daily tasks such as dish washing, bed making</td>
<td>0</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>3. Performs light daily tasks but cannot maintain acceptable level of cleanliness</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4. Needs help with all home maintenance tasks</td>
<td>1</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>5. Does not participate in any housekeeping tasks</td>
<td>0</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Visual Analogue Scale for pain

No pain

Worst pain ever

0 1 2 3 4 5 6 7 8 9 10
WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How would you rate your quality of life?</td>
<td>Very poor, Poor, Neither poor nor good, Good, Very good</td>
</tr>
<tr>
<td>2. How satisfied are you with your health?</td>
<td>Very dissatisfied, Dissatisfied, Neither satisfied nor dissatisfied, Satisfied, Very satisfied</td>
</tr>
<tr>
<td>3. To what extent do you feel that physical pain prevents you from doing what you need to do?</td>
<td>Not at all, A little, A moderate amount, Very much, An extreme amount</td>
</tr>
<tr>
<td>4. How much do you need any medical treatment to function in your daily life?</td>
<td>Not at all, A little, A moderate amount, Very much, An extreme amount</td>
</tr>
<tr>
<td>5. How much do you enjoy life?</td>
<td>Not at all, A little, A moderate amount, Very much, Extremely</td>
</tr>
<tr>
<td>6. To what extent do you feel your life to be meaningful?</td>
<td>Not at all, A little, A moderate amount, Very much, Extremely</td>
</tr>
<tr>
<td>7. How well are you able to concentrate?</td>
<td>Not at all, A little, A moderate amount, Very much, Extremely</td>
</tr>
<tr>
<td>8. How safe do you feel in your daily life?</td>
<td>Not at all, A little, A moderate amount, Very much, Extremely</td>
</tr>
<tr>
<td>9. How healthy is your physical environment?</td>
<td>Not at all, A little, A moderate amount, Very much, Extremely</td>
</tr>
</tbody>
</table>
The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Moderately</th>
<th>Mostly</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.</td>
<td>Do you have enough energy for everyday life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11.</td>
<td>Are you able to accept your bodily appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12.</td>
<td>Have you enough money to meet your needs?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13.</td>
<td>How available to you is the information that you need in your day-to-day life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14.</td>
<td>To what extent do you have the opportunity for leisure activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.</td>
<td>How well are you able to get around?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>16.</td>
<td>How satisfied are you with your sleep?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17.</td>
<td>How satisfied are you with your ability to perform your daily living activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18.</td>
<td>How satisfied are you with your capacity for work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19.</td>
<td>How satisfied are you with yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
20. How satisfied are you with your personal relationships?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

21. How satisfied are you with your sex life?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

22. How satisfied are you with the support you get from your friends?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

23. How satisfied are you with the conditions of your living place?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

24. How satisfied are you with your access to health services?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

25. How satisfied are you with your transport?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
</table>

The following question refers to how often you have felt or experienced certain things in the last four weeks.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Seldom</th>
<th>Quite often</th>
<th>Very often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

**Do you have any comments about the assessment?**

________________________________________________________________________

[The following table should be completed after the interview is finished]

<table>
<thead>
<tr>
<th></th>
<th>Equations for computing domain scores</th>
<th>Raw score</th>
<th>Transformed scores*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>4-20</td>
<td>0-100</td>
</tr>
<tr>
<td>27.</td>
<td><strong>Domain 1</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □ + □ + □ + □ + □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.</td>
<td><strong>Domain 2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □ + □ + □ + □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29.</td>
<td><strong>Domain 3</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Q20 + Q21 + Q22</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td><strong>Domain 4</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25</td>
<td>a. =</td>
<td>b:</td>
</tr>
<tr>
<td></td>
<td>□ + □ + □ + □ + □ + □ + □ + □ + □</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* See Procedures Manual, pages 13-15
In-depth Interview guidelines

(For persons with severe osteoarthritis of knee, advised but not undergone surgery)

**Topic**: Pathways to health seeking, treatment and outcomes in persons with osteoarthritis of knee in Southern Kerala, India.

**SOCIO-DEMOGRAPHIC FACTORS**

- Age in completed years:
- Sex:
- Religion:
- Caste:
- Location / Address:
  - Terrain, how easy / difficult to access hospital/ doctor/ treatment
- Marital Status: Married / unmarried / widow / widower / separated
- Type of family: Nuclear / joint / Extended
- Education status:
  - Primary / Secondary / Graduate / Post graduate / professional / skilled training.
- Employment: Currently employed (Self employed, daily wages, salaried), Currently not employed (Never employed, stopped working, retired)
- Nature of work at home and during employment:
  - Relevant to osteoarthritis of knee such as repeated bending, squatting, prolonged standing, climbing.
- Monthly income: Self and Family (In Rupees & Source)
- Source of financial support for treatment – Self / Family / insurance / Reimbursement.

**HISTORY OF OSTEOARTHRITIS**

Q: I understand that you are suffering from a variety of problems related to your knee osteoarthritis. Can you tell me about how and when it started?

**Probe:**
- Was there any history of injury to knee in the past?
- First appearance of symptoms of crackling sound in knee and or pain
Q: After the appearance of the symptoms of pain (or what the person says), how did it progress over the years?

Probe:
- What did you do in the immediate period after symptoms appeared? (over the counter medications, home remedies, consultation with a health care provider, other)
- Was there a period when you overlooked these symptoms? What were the reasons?
- Did you discuss your condition with others? Who? What were their responses?

Q: When was it first diagnosed by a doctor as osteoarthritis? What were the investigations carried out to arrive at the diagnosis??

Q: How can you explain what has happened inside your knees (understanding about the disease) resulting in this situation? How and from where did you get this information?

Probe
- What were the understandings before and how it was different from what it is now?
- How much information you have received from your treating doctor and did you feel you were informed adequately
- Do you know anyone with similar condition and have their experiences influence you?

Q: During this long course of illness, what were the different sources of health care used?

Probe:
- When was the first consultation with any health care provider for this knee problem? What were the reasons prompting the first consultation? How long after appearance of crackling sound in knee or pain?
- Ayurvedic treatment, nature therapy, other?
- How do these different treatments differ in your opinion? What do you find good in each and that which is bad?

Q: What were the advices given by doctors at different times?

Q: Apart from osteoarthritis, what are the other problems you are having for which you are on regular medications?

List with duration: (Diabetes/ Hypertension/heart disease/ cancer/ renal / liver disease etc) Check prescriptions or the current medications to know of other co-morbidities.

what was the priority given for OAK earlier and at present and why?
SEVERITY OF SYMPTOMS

Q: At present, what are the main symptoms of the knee that are bothering you?
Q: What were the main symptoms earlier that were felt as an urgent need to seek help?
Q: I understand pain could be worst symptom. Can you explain your pain and its severity?
  • What makes it worse and what reduces it? How do you manage pain?
  • Does this pain affect your sleep? If yes, how bad are those nights?
  • Whom do you contact when pain is severe? (Doctor/self medication?)
• What do you usually do when pain (or the symptoms) persist or get aggravated?
Q: How do you rate your quality of life at present (Excellent/ very good/good/bad/very bad).
  Probe: How different is it from before? Was it more bad or good anytime before and why was it so? (Explore further based on the answer)
Q: How much satisfied are you with the current treatment and state? (Excellent/ very good/good/bad/very bad). (Explore further based on the response)
Q: What according to you are the major limiting problems of living with osteoarthritis?
Q: Being a woman/man, what were the challenges you had to face in living with knee osteoarthritis symptoms?
  Probe: Challenges in doing household work, carrying out responsibilities of the role in family, self care, expectations/support received from others
Q: Have you ever thought that if this long-standing condition was for a man/woman, the whole situation could have been different? What difference would you think of?

HEALTH SYSTEM FACTORS

Q: What are your experiences with health care providers (Not just modern medicine) in getting help with control of symptoms and getting information and advice?

Probe
  • Whom do you visit for your knee problem in case of an emergency?
  • How much satisfied are you with the support from health providers?
Q: When you were first advised for a surgery as an option? At what stage and situation you were given such an advice?
Q: What are the reasons for not doing the surgery
  Probe: fears of surgery, misconceptions, financial reasons, support of family, related to period of rest at home etc.
ANNEXURE – A6

Q: What is your understanding about such a Total knee replacement surgery?
   
   Probe: the procedure, complications, expected outcome and timelines etc.

Q: There is a general belief that OA is due to ageing. What are your experiences in this regard from the treating doctors / health system?
   
   Probe:
   • Did treating doctor ever tell that the disease is part of ageing?
   • If so, in what premise was that comment made?
   • Do you think you would have got a better treatment if you were of a lesser age?
   • Do you think there are better treatment options for osteoarthritis which you are not able to access? If yes what are they and why you are not able to access?

SUPPORT AVAILABLE

Q: Who is your primary care giver at home and who decides treatment options or give reliable opinion on such decisions?

Q: What were the sources of finance in managing treatment for the disease? What were the difficulties if there were any?

   Probe

Whether financial difficulties resulted in postponement of any treatment options?

How did financial conditions influence decisions regarding management?

Q: During difficult times due to symptoms of OAK, what were your experiences with support from family and friends?

   Probe

   • Do you think family / friends understand the depth of your problems? Are they empathetic to you?
   • Whom do you depend when you are in low mood / worried with pain or other problems?

EXPECTATIONS AND PERCEPTIONS

Q: At this point of time, after a long course of illness and experiences, what are your expectations?
ANNEXURE – A6

Probe:
- Expectation of short term and long term goals for current treatment option?
- Why do you think some options failed in the past?

Q: With the current treatments you are undergoing, do you think the disease is fully curable?

Q: Many people say OAK is related to life styles. Do you think life style may have been a factor in your developing the condition? If yes, what aspects? If no, what else could be the reasons?

Q: What are your expectations and what are the realities with support from doctors, family, friends etc when a treatment / management option is chosen

PHYSICAL STATUS
- Which of the following activities you are able to do on your own?
  - Use Katz Activity of daily living score (Also probe into coping strategies with each dependency)
  - Instrumental activity of daily living score
    - How much of the dependency if present is due to knee problem
    - Probe for support from family or friends in getting assistance
    - Self rating of level of dependency and satisfaction with support
- Visual Analogue pain scale if the respondent has pain
- Lawton IADL Scoring if respondent score above 4 in Katz IADL Scale

MENTAL STATUS and QOL
- WHO QOL- Bref version

CONCLUSION
Q: For the benefit of others who are suffering from this disease, what in your opinion, from your experience could improve lives and how can this suffering be prevented?

Q: Thank you for all your inputs. Do you have any more queries regarding this in which I could help?
ANNEXURE – A6

In-depth Interview guidelines
(For persons with severe OAK who underwent surgery)

Topic: Pathways to health seeking, treatment and outcomes in persons with osteoarthritis of knee in Southern Kerala, India.

ID No:------------------------

SOCIO-DEMOGRAPHIC FACTORS

- Age in completed years:
- Sex:
- Religion:
- Caste:
- Location / Address:
  Terrain, how easy / difficult to access hospital/ doctor/ treatment
- Marital Status: Married / unmarried/ widow/ widower/ separated
- Type of family: Nuclear / joint / Extended
- Education status:
  Primary / Secondary/ Graduate/ Post graduate/ professional / skilled training.
- Employment : Currently employed (Self employed, daily wages, salaried), Currently not employed (Never employed, stopped working, retired)
- Nature of work at home and during employment:
  Relevant to osteoarthritis of knee such as repeated bending, squatting, prolonged standing, climbing.
- Monthly income: Self and Family (In Rupees & Source)
- Source of financial support for treatment – Self / Family / insurance/ Reimbursement.
- Date of surgery
HISTORY OF OSTEOARTHRITIS

Q: I understand that you are suffering from a variety of problems related to your knee osteoarthritis. Can you tell me about how and when it started?

Probes:
- Was there any history of injury to knee in the past?
- First appearance of symptoms of crackling sound in knee and or pain

Q: After the appearance of the symptoms of pain (or what the person says), how did it progress over the years?

Probes:
- What did you do in the immediate period after symptoms appeared? (over the counter medications, home remedies, consultation with a health care provider, other)
- Was there a period when you overlooked these symptoms? What were the reasons?
- Did you discuss your condition with others? Who? What were their responses?

Q: When was it first diagnosed by a doctor as osteoarthritis? What were the investigations carried out to arrive at the diagnosis??

Q: How can you explain what has happened inside your knees (understanding about the disease) resulting in this situation? How and from where did you get this information?

Probes:
- What were the understandings before and how it was different from what it is now?
- How much information you have received from your treating doctor and did you feel you were informed adequately
- Do you know anyone with similar condition and have their experiences influence you?

Q: How do you feel now after undergoing a surgery?

Probes:
- How long back did doctor advice a surgery for the first time? What was the main reason for deciding on undergoing a surgery now?
- Was there a delay in deciding? Why?
- What was the actual factor that pushed you in undergoing the surgery?
- What are the experiences during decision making, surgery, convalescent period etc.
ANNEXURE – A6

• Do you think it was a wise decision to do the surgery?
• Will you recommend surgery for those having severe OA?

Q: How much change do you appreciate after undergoing the surgery? What were the expectations when you decided to undergo the surgery and what were the realities?

Q: During this long course of illness, what were the different sources of health care used by you?

Probe:
• When was the first consultation with any health care provider for this knee problem? What were the reasons prompting the first consultation? How long after appearance of crackling sound in knee or pain?
• Ayurvedic treatment, nature therapy, other?
• How do these different treatments differ in your opinion? What do you find good in each and that which is bad?

Q: What were the advices given by doctors at different times?

Q: Apart from osteoarthritis, what are the other problems you are having for which you are on regular medications?

• List with duration: (Diabetes/ Hypertension/heart disease/ cancer/ renal / liver disease etc) Check prescriptions or the current medications to know of other co-morbidities.
• what was the priority given for OAK earlier and at present and why?

SEVERITY OF SYMPTOMS

Q: At present, what are the main symptoms of the knee that are bothering you?

Q: What were the main symptoms earlier that were felt as an urgent need to seek help?

Q: I understand pain could be a worst symptom. Can you explain your pain? How severe it is at times?

• What makes it worse and what reduces it? How do you manage pain?
• Does this pain affect your sleep? If yes, how bad are those nights?
• Whom do you contact when pain is severe? (Doctor/self medication?)

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Q: How do you rate your quality of life at present (Excellent/ very good/good/bad/very bad).
   Probe: How different is it from before? Was it more bad or good anytime before and why
   was it so? (Explore further based on the answer)
Q: How much satisfied are you with the current treatment and state? (Excellent/ very good/good/bad/very bad). (Explore further based on the response)
Q: What according to you are the major limiting problems of living with osteoarthritis?
Q: Being a woman/man, what were the challenges you had to face in living with knee osteoarthritis symptoms?
   Probe: Challenges in doing household work, carrying out responsibilities of the role in
   family, self care, expectations/support received from others
Q: Have you ever thought that if this long-standing condition was for a man/woman, the
   whole situation could have been different? What difference would you think of?

HEALTH SYSTEM FACTORS

Q: What are your experiences with health care providers (Not just modern medicine) in
   getting help with control of symptoms and getting information and advice?
   Probe
   • Whom do you visit for your knee problem in case of an emergency?
   • How much satisfied are you with the support from health providers?
Q: When you were first advised for a surgery as an option? At what stage and situation you
   were given such an advice?
Q: What are the reasons for not doing the surgery then?
   Probe: fears of surgery, misconceptions, financial reasons, support of family, related to
   period of rest at home etc.
Q: What was your understanding about Total knee replacement surgery before and has it
   changed after the surgery?
   Probe: the procedure, complications, expected outcome and timelines etc.

Q: There is a general belief that OA is due to ageing. What are your experiences in this
   regard from the treating doctors / health system?
ANNEXURE – A6

Probe:
- Did treating doctor ever tell that the disease is part of ageing?
- If so, in what premise was that comment made?
- Do you think you would have got a better treatment if you were of a lesser age?
- Do you think there are better treatment options for osteoarthritis which you are not able to access? If yes what are they and why you are not able to access?

SUPPORT AVAILABLE
Q: Who is your primary care giver at home and who decides treatment options or give reliable opinion on such decisions?
Q: What were the sources of finance in managing treatment for the disease? What were the difficulties if there were any?

Probe
Whether financial difficulties resulted in postponement of any treatment options?
How did financial conditions influence decisions regarding management?
Q: During difficult times due to symptoms of OAK, what were your experiences with support from family and friends?

Probe
- Do you think family / friends understand the depth of your problems? Are they empathetic to you?
- How were the days immediately after the surgery and what difference you find now?
- Whom do you depend while in low mood / worried with pain or other problems?

EXPECTATIONS AND PERCEPTIONS
Q: At this point of time, after a long course off illness and experiences, what are your expectations?

Probe:
- Expectation of short term and long term goals for current treatment option?
- Why do you think some options failed in the past?
Q: With the surgery and current treatments you are undergoing, Do you think the disease will be fully curable?
Q: Many people say OAK is related to life styles. Do you think life style may have been a factor in your developing the condition? If yes, what aspects? If no, what else could be the reasons?

Q: What are your expectations and what are the realities with support from doctors, family, friends etc when a treatment / management option is chosen

**PHYSICAL STATUS**

- Which of the following activities you are able to do on your own? What difference you find as compared to what it was before the surgery?
  - Use Katz Activity of daily living score (Also probe into coping strategies with each dependency)
  - Instrumental activity of daily living score
    - How much of the dependency if present is due to knee problem
    - Probe for support from family or friends in getting assistance
    - Self rating of level of dependency and satisfaction with support
- Visual Analogue pain scale in case the respondant complains of pain
- Lawton IADL Scoring if respondent score above 4 in Katz IADL Scale

**MENTAL STATUS**

- WHO QOL- Bref version

**CONCLUSION**

Q: For the benefit of others who are suffering from this disease, what in your opinion, from your experience could improve lives and how can this suffering be prevented?

Q: Thank you for all your inputs. Do you have any more queries regarding this in which I could help?
In-depth Interview guidelines
(For caregivers of persons with severe osteoarthritis of knee or those undergone surgery)

Topic: Pathways to health seeking, treatment and outcomes in persons with osteoarthritis of knee in Southern Kerala, India.

ID No:------------------------
(This is to supplement the information gathered from the person with OAK who has been already interviewed)

SOCIO-DEMOGRAPHIC FACTORS
- ID NO of the person with OAK who has been interviewed:
- Relationship with the person for whom care is given:
- Education status:
  - Primary / Secondary/ Graduate/ Post graduate/ professional / skilled training.
- Employment: Currently employed (Self employed, daily wages, salaried), Currently not employed (Never employed, stopped working, retired)

HISTORY OF OSTEOARTHRITIS
- How did the disease start and when
- How did it progress over the years? What are the different treatments taken so far?
- What used to be done whenever there is pain – going to hospital/ doctor / self medication?
- Do you think the symptoms were often ignored? explain?
- Do you consult different doctors for different symptoms of knee? why do you think you had to do that?
- Q: What according to you are the major limiting problems of living with osteoarthritis?

EXPERIENCE WITH HEALTHCARE PROVIDERS
- How helpful are the doctors when approached for symptoms of OAK? Are you been discussed with in planning treatment?
ANNEXURE – A6

- What are your experiences with health care providers (Not just modern medicine) in getting help with control of symptoms and getting information and advice?
- How much satisfied are you with the support from health providers?
- When you were first advised for a surgery as an option? At what stage and situation you were given such an advice?
- What are the reasons for not doing the surgery
  (Probe for fears of surgery, misconceptions, financial reasons, support of family, related to period of rest at home etc.)
- Were you ever told that osteoarthritis is due to ageing? What do you believe? What makes you believe it or not?

CARING A PERSON WITH OAK

- What kind of caring do you do?
- Osteoarthritis is a disabling disease which progress over years. What are your experiences in caring for a person with the disease? What are the challenges faced?
- How does pain or symptoms of OAK affect you or your family as a whole?
- What do you think about the symptoms of OAK? (Explore)
- What in your opinion would have improved your condition/ quality of life while living with osteoarthritis?
- How does the support you receive as a care-giver (from doctors, family, friends and society) vary depending on the kinds of challenges you have faced, for example, physical problems, psychological stresses, emotional problem or daily routines?
- (For women respondents)
  - Being a woman, did you have to face any challenge in caring for a person with knee symptoms?
- What are the advantages / disadvantages you felt during caring for a person with this long

Information & knowledge about OAK

- What is the source of information about the disease and various treatment options?
- Do you know anyone with similar condition and have their experiences influence you?
- What is your current understanding on what is wrong with the knee?
ANNEXURE – A6

- How do you think these treatments are going to improve the current situation?
- Do you think the disease is fully curable with current medication / treatment?
- I understand that knee surgery was advised. What is your understanding about such a Total knee replacement surgery - the procedure, complications, expected outcome and timelines etc?
- Do you think the information you have is adequate? if no, then why do you think so and in what area you think more information is needed?

PHYSICAL & MENTAL STATUS

- How much of the regular work and activities are the person able to do? what sort of support does you provide and what do you think they need?
- How does the increasing dependency affect the family?
- What is the current mental status of the person? Has it any relation with the disease now or earlier?
- Do you think the person gets mentally upset or depressed when the symptoms are more or due to the disease (Explore)
- How the disease has affected the social life of the person, interaction with others? (Explore)
- Thank you for all your inputs. Do you have any more queries regarding this in which I could help?
Key Informant interview (Healthcare provider) - Guideline

Topic: Pathways to health seeking, treatment and outcomes in persons with osteoarthritis of knee in Southern Kerala, India.

ID No: Location and Time:

Years of experience in osteoarthritis care:

Qualifications:

Nature of specialisation:

Challenges of OAK

- Can you give me a picture in general of a typical patient with osteoarthritis, both male and female?
- Dealing with the osteoarthritis patients has many challenges. What you have felt are the biggest challenges you have faced while dealing with such patients? (respond and reflect for elaboration)
- What are the suggestions/solutions for overcoming the challenge?
- In dealing with these kinds of challenges, what have you found helpful?
- How does OA of knees relate to ageing? How much does this influence the treatment and expectations?

Treatment related

- How much time will you spend with the osteoarthritis patient at one time?
- What in your opinion are the health seeking patterns of patients with osteoarthritis especially relating to compliance with treatment?
- Do they go to different doctors for the same symptom and also to different systems? if so, then what could be the reasons for that?
- To what level are patients with such a chronic disease compliant to the treatment offered by doctors?
ANNEXURE – A6

- What are the probable reasons for non adherence to treatment advised?
- How expensive in terms of finances and other resources is OAK on a long term?
- In your opinion, what are the major reasons why more women are undergoing surgical treatment for osteoarthritis? At what stage do they usually get operated and what are the outcomes as compared to men?
- What is your opinion regarding prevention of progression of osteoarthritis at an early age rather than treatment in older ages?

**Regarding Information and knowledge of patients/ caregivers**

- How much information do you give the patient or the caregiver regarding the disease? do you think it as adequate? if not, then what are the reasons for the inadequacy and how it can be improved?
- Are there any general behavioral patterns of patients with OAK and especially when it is long-standing
- Generally, how informed are the patients with OAK about their disease condition?
- How much information in your opinion do patients have and whether more information and support would have been needed for effective management?