

A SITUATIONAL ANALYSIS OF ARTHRITIS IN CHANKOM

**THE PROBLEM OF ARTHRITIS IN THE MAYAN MUNICIPALITY OF
CHANKOM, MEXICO: A SITUATIONAL ANALYSIS FOR DEVELOPING A
COMMUNITY-BASED REHABILITATION PROGRAM**

By ADALBERTO LOYOLA-SANCHEZ, MD, MSc

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the
Requirements for the Degree Doctor of Philosophy

McMaster University © Copyright by Adalberto Loyola-Sánchez, April 2015

DOCTOR OF PHILOSOPHY (2015)

McMaster University

(Rehabilitation Science)

Hamilton, Ontario

TITLE: The problem of arthritis in the Mayan municipality of Chankom, Mexico: A situational analysis for developing a community-based rehabilitation program.

AUTHOR: Adalberto Loyola-Sánchez, M.D. (Universidad Nacional Autónoma de México), M.Sc. (McMaster University)

SUPERVISOR: Julie Richardson, B.Sc (PT), M.Sc., Ph.D.

NUMBER OF PAGES: xxii, 215

LAY ABSTRACT

There is a need to develop rehabilitation interventions aimed at reducing the onset and disabling effects of arthritis in poor areas of Mexico. This thesis reports findings from the initial implementation of a research project designed to decrease disability of people living with arthritis in Chankom, a poor rural Mayan community located in Southeast Mexico. These findings show that arthritis is common in Chankom and it is related to having problems performing usual activities, which reduce people's quality of life. People living with arthritis in Chankom need culturally appropriate healthcare services; however, they don't obtain these due to different barriers associated with their indigenous background. Consequently, it is necessary to design health policies and interventions to decrease the disabling effects of arthritis in Chankom. The findings of this thesis will help creating a rehabilitation program that increases access to appropriate healthcare, improving function and quality of life of Chankom's inhabitants.

ABSTRACT

Disability and arthritis in Mexico are important public health problems. There is a need to develop rehabilitation interventions aimed at reducing the prevalence and disabling effects of arthritis in low socioeconomic communities in this country. This thesis reports findings from the initial execution of a mixed-methods participatory research program. This program was designed to develop, implement and evaluate a community-based rehabilitation program to decrease disability of people living with arthritis in the municipality of Chankom, a low-income rural Mayan community located in Southeast Mexico.

Epidemiologic results showed a high prevalence of arthritis in Chankom associated with low levels of wealth and high body mass index. In addition, arthritis was associated with a higher prevalence of disability in this municipality. Further results showed that people who live with osteoarthritis in Chankom perform standardized and real-life activities with significant levels of disability. This disability was associated with levels of wealth, pain, muscle strength, self-efficacy, and physical activity. Ethnographic results showed that: a) arthritis reduces the health-related quality of life of people in Chankom through a process of disablement, b) people living with arthritis need access to culturally sensitive healthcare, and c) there are availability, attainability and acceptability barriers to accessing culturally sensitive health services in this municipality, which result from power imbalance between indigenous and non-indigenous people.

The work presented in this thesis is the extensive examination of the problems associated with arthritis in Chankom, using quantitative and qualitative methods. Our findings

justify the need to develop health policies and interventions to prevent and decrease the disabling effects of arthritis in this marginalized community. Moreover, these findings will support the creation of a culturally sensitive, community-based rehabilitation program, as a multi-level strategy to promote social development and improve health-related quality of life of people living with arthritis in the municipality of Chankom.

ACKNOWLEDGEMENTS

This thesis is the result of intensive work performed by many people.

I would like to start thanking my supervisor, Dr. Julie Richardson, for her extraordinary support and guidance during my PhD training. Julie, your vision about rehabilitation and your passion to expand this field to the primary level of care inspired and helped me find my vocation. Our endless and honest conversations allowed me reflect and question my ideas and actions, keeping me grounded and focused to finish this academic adventure. Most importantly, thank you for believing in me and supporting me to explore and pursue my research interests, you are a great mentor.

I also like to thank Dr. Ingris Peláez-Ballestas for her invaluable support during the completion of my doctoral thesis work. Ingris, your encouragement and constructive feedback always helped me to move forward. Thank you for sharing your vast research knowledge and for teaching me the importance to do research with moral values.

I would also like to thank the rest of my supervisory committee Dr. John Lavis, Dr. Michael Wilson and Dr. Seanne Wilkins, for their great support during my doctoral training. John, thank you for your guidance, your accurate advice is very much appreciated. Mike thank you for always providing very practical suggestions. Seanne, thank you for your kindness and words of wisdom, they helped me overcome adversity in turbulent times.

Conducting a large epidemiologic study in parallel with an ethnographic study required the hard work of many people. Thanks to: the municipal authorities of Chankom for opening the door to us to conduct research in their community; the team of local

interviewers in Chankom for all your hard work applying door to door surveys, specially to Mr. Diego Yeh Cen and Mr. Carlos Castillo Kuyoc for your Mayan-Spanish interpreter services and for helping me understand better the Mayan culture; the team of general physicians (Cindy and Abdi) for your intensive labour assessing people at their homes; Anthropologists Joan Matamoros Sanín, Gabriela Cruz and Daniela Flores for your enthusiastic collaboration and for helping me understand the value of your discipline; Dr. José Alvarez Nemegyei for your valuable academic contributions and personal support during my stay in Yucatán; Lic. Jonathan Escalante Góngora for your keenness to collaborate and for providing rehabilitation services to the people of Chankom; Dr. Hazel García Morales and Dr. Arturo Velazco Gutiérrez for your willingness to help the most in need, providing clinical specialized medical services to the people of Chankom; Psychologist Guillermo Pérez for transcribing the extensive qualitative data collected for this thesis; and Research assistants Maria Lizbeth Escudero and Beatriz Quintero for helping capturing and maintaining the quantitative database.

To my friends, colleagues, faculty and staff members in the School of Rehabilitation Science: thank you for your support. In particular, thanks to Paul Stratford, who was always available when I got caught in statistical problems, Norma MacIntyre for her good humour and assertive advice, and Liz Dzaman for keeping the administrative aspects of my PhD training under control. I also thank Christine Jackiw, counsellor of McMaster Student Wellness Centre, for her emotional support during my many ups and downs during this academic journey. Finally, I want to thank Liza Thong for always helping me organize my committee meetings.

I am extremely honoured and grateful for the funding support received throughout my doctoral training including: The Mexican “Consejo Nacional de Ciencia y Tecnología (CONACYT)” doctoral scholarship for studying abroad (#209621); CIHR-Doctoral Vanier Canada Scholarship (#268078); and McMaster University-School of Rehabilitation Science. CONACYT (grant #162154) and the International League against Rheumatism (ILAR) funded the projects of this thesis.

To my beautiful and brilliant wife, Gaby: thank you for always being there for me. Your love, kindness and tenacity helped me to accomplish what I considered to be the most difficult academic adventure I have lived so far and I would not have made it without you. To my son, Mateo: thanks for coming into my life; you are a precious light that motivates me to do my best everyday. Finally, I would like to thank the rest of my family, specially my Dad, Titi, Rubén, Jani and my Mom for all their support during these years, for motivating me to become a better individual and most importantly for always believing in me. Many thanks!

This dissertation is dedicated to the people of Chankom. I hope this work contributes to raise awareness on the health inequities and social injustice present in this community and motivates the creation of better health services.

PREFACE

This thesis is structured as a “sandwich thesis”, which includes four individual manuscripts as prepared for peer-reviewed publication.

Adalberto Loyola-Sánchez lead the conception, design, data acquisition, analysis and drafting of all manuscripts and was in charge of submitting them to peer-reviewed journals for their publication.

For the first manuscript titled “*Developing Community-Based Rehabilitation Programs for Musculoskeletal Diseases in Low-Income Areas of Mexico: The Community-Based Rehabilitation for Low-Income Communities Living With Rheumatic Diseases (CONCORD) Protocol*” Julie Richardson, Ingris Peláez-Ballestas, John N. Lavis, Michael G. Wilson, Jacqueline Rodríguez-Amado, José Alvarez-Nemegyei, Rebeca T. Martínez-Villareal, Dora J. Onofre-Rodríguez, Raquel Benavides-Torres contributed ideas for the conceptualization and design of the protocol.

For the second manuscript titled “*The impact of Arthritis on the physical function of a rural Maya-Yucateco community and factors associated with its prevalence: a cross sectional, community-based study*” Julie Richardson and Ingris Peláez-Ballestas contributed to the conception, design, analysis and drafting of the manuscript. José Alvarez-Nemegyei, John N. Lavis, Michael G. Wilson and Seanne Wilkins contributed to the design and drafting of this manuscript. All authors read and approved the final version of the manuscript.

For the third manuscript titled “*Physical function assessment of a rural Mayan population living with osteoarthritis: a cross-sectional, community-based study*” Julie Richardson

and Ingris Peláez-Ballestas contributed to the conception, design, analysis and drafting of the manuscript. José Alvarez-Nemegyei, John N. Lavis, Michael G. Wilson and Seanne Wilkins contributed to the design and drafting of this manuscript. All authors read and approved the final version of the manuscript.

For the fourth manuscript titled “*Barriers to accessing the culturally sensitive healthcare that could decrease the disabling effects of arthritis in a rural Mayan community: A qualitative inquiry.*” Ingris Peláez-Ballestas contributed to the conception, design, data acquisition, analysis and drafting of this manuscript. Julie Richardson and Seanne Wilkins contributed to the conception, design, analysis and drafting of this manuscript. John N. Lavis, Michael G. Wilson and José Alvarez-Nemegyei contributed to the conception, design and drafting of this manuscript. All authors read and approved the final version of the manuscript.

TABLE OF CONTENTS

LAY ABSTRACT	iii
ABSTRACT	iv
ACKNOWLEDGEMENTS	vi
PREFACE	ix
TABLE OF CONTENTS	xi
LIST OF FIGURES	xviii
LIST OF TABLES	xx
LIST OF ABBREVIATIONS	xxi
CHAPTER ONE	1
1.1 DISABILITY AND ARTHRITIS IN UNDERSERVED, LOW- SOCIOECONOMIC AREAS	1
1.2 COMMUNITY-BASED REHABILITATION PROGRAMS AS INTERVENTIONS TO REDUCE ARTHRITIS PREVALENCE AND DISABLING EFFECTS IN MEXICAN LOW SOCIOECONOMIC AREAS	2
1.3 CHANKOM: A LOW SOCIOECONOMIC LEVEL COMMUNITY IN MEXICO	5
1.4 TOWARDS THE DEVELOPMENT OF A CULTURALLY SENSITIVE COMMUNITY-BASED REHABILITATION PROGRAM IN CHANKOM	8
1.5 THESIS STRUCTURE	10
CHAPTER TWO	20
PREFACE TO CHAPTER TWO	21

2.1 ABSTRACT	22
2.2 INTRODUCTION	24
2.2.1 MUSCULOSKELETAL DISEASES AND DISABILITY	24
2.2.2 REHABILITATION INTERVENTIONS	25
2.2.3 COMMUNITY-BASED REHABILITATION AND COMMUNITY BASED PARTICIPATORY RESEARCH	26
2.2.4 MAIN INTENTION AND OBJECTIVE	29
2.2.5 THEORETICAL APPROACH	30
2.3 METHODS	30
2.3.1 RESEARCH STRATEGY AND METHODOLOGY OVERVIEW	30
2.3.2 STAGE ONE: SITUATION ANALYSIS	31
2.3.2.1 OBJECTIVES	31
2.3.2.2 EPIDEMIOLOGIC STUDY	32
2.3.2.3 ETHNOGRAPHIC STUDY	35
2.3.3 STAGE TWO: PROGRAM DEVELOPMENT	38
2.3.3.1 OBJECTIVES	38
2.3.3.2 COMMUNITY ORGANIZATION AND PARTNERSHIP FORMATION	38
2.3.3.3 EVIDENCE ASSESSMENT, MERGING AND SUMMARY	40
2.3.3.4 STAKEHOLDER DIALOGUE	41

2.3.4 STAGE THREE: PROGRAM IMPLEMENTATION	43
2.3.5 STAGE FOUR: PROGRAM EVALUATION	45
2.4 RESULTS	48
2.5 DISCUSSION	49
2.5.1 AN ALTERNATIVE APPROACH	49
2.5.2 DIFFERENCES BETWEEN COMMUNITIES	52
2.5.3 CONCLUSIONS	54
2.6 ACKNOWLEDGEMENTS	54
2.7 REFERENCES	54
CHAPTER THREE	69
PREFACE TO CHAPTER THREE	70
3.1 ABSTRACT	71
3.2 INTRODUCTION	73
3.3 MATERIALS AND METHODS	74
3.3.1 STUDY DESIGN	74
3.3.2 SETTING	75
3.3.3 PARTICIPANTS	75
3.3.4 MEASUREMENTS	76
3.3.4.1 CONFOUNDERS	76
3.3.4.2 PHYSICAL FUNCTION	76
3.3.4.3 MODIFIABLE RISK FACTORS	77
3.3.5 STATISTICAL ANALYSES	78

3.4 RESULTS	79
3.5 DISCUSSION	81
3.5.1 PRINCIPAL FINDINGS	81
3.5.2 STRENGTHS AND LIMITATIONS	85
3.5.3 IMPLICATIONS FOR PRACTICE AND POLICY	86
3.5.4 IMPLICATIONS FOR RESEARCH	87
3.5.5 CONCLUSIONS	87
3.6 ACKNOWLEDGEMENTS	88
3.7 REFERENCES	88
CHAPTER FOUR	100
PREFACE TO CHAPTER FOUR	101
4.1 ABSTRACT	102
4.2 INTRODUCTION	105
4.3 METHODS	106
4.3.1 STUDY DESIGN	106
4.3.2 SETTING	107
4.3.3 PARTICIPANTS	107
4.3.4 PHYSICAL FUNCTION EVALUATIONS	108
4.3.4.1 HYPOTHETICAL FUNCTIONING	108
4.3.4.2 EXPERIMENTAL FUNCTIONING	108
4.3.4.3 ENACTED FUNCTIONING	109

4.3.5 EXPLORATION OF KNOWN RISK FACTORS FOR OA	
PROGRESSION	109
4.3.5.1 SOCIAL FACTORS	109
4.3.5.2 PHYSICAL FACTORS	110
4.3.5.3 PSYCHOLOGICAL FACTORS	111
4.3.5.4 BEHAVIORAL FACTORS	111
4.3.6 STATISTICAL ANALYSES	111
4.3.7 ETHICS APPROVAL	112
4.4 RESULTS	112
4.4.1 PHYSICAL FUNCTION ASSESSMENT	113
4.4.2 KNOWN MODIFIABLE FACTORS FOR OA PROGRESSION	113
4.4.3 ASSOCIATIONS BETWEEN MODIFIABLE FACTORS FOR	
OA PROGRESSION AND PHYSICAL FUNCTION	114
4.5 DISCUSSION	115
4.5.1 PRINCIPAL FINDINGS	115
4.5.2 STRENGTHS AND LIMITATIONS	116
4.5.3 IMPLICATIONS FOR PRACTICE AND POLICY	117
4.5.4 IMPLICATIONS FOR RESEARCH	117
4.5.5 CONCLUSIONS	118
4.6 ACKNOWLEDGEMENTS	118
4.7 REFERENCES	118

CHAPTER FIVE	131
PREFACE TO CHAPTER FIVE	132
5.1 ABSTRACT	133
5.2 INTRODUCTION	134
5.3 METHODOLOGY	135
5.3.1 SETTING	135
5.3.2 STUDY DESIGN	136
5.3.3 ANALYSIS	137
5.3.3.1 RIGOR	138
5.4 RESULTS	140
5.4.1 LIVING WITH ARTHRITIS	140
5.4.2 SEEKING “GOOD MEDICAL CARE”	140
5.4.2.1 HEALTH PROVIDER CHARACTERISTICS	141
5.4.2.2 LOCAL HEALTH SERVICES’ CHARACTERISTICS	141
5.4.3 ACCESING HEALTHCARE	141
5.5 DISCUSSION	142
5.5.1 STRENGTHS AND LIMITATIONS	146
5.5.2 IMPLICATIONS FOR POLICY	147
5.5.3 IMPLICATIONS FOR PRACTICE	149
5.6 ACKNOWLEDGEMENTS	150
5.7 REFERENCES	150

CHAPTER SIX	163
6.1 MAIN CONTRIBUTIONS	163
6.2 LESSONS LEARNED	165
6.3 FUTURE ACTIONS	168
REFERENCES	171
APPENDIX A	175
APPENDIX B	187
APPENDIX C	191
APPENDIX D	202

LIST OF FIGURES

Figure 1.1: CONCORD project progress to date and thesis contributions	12
Figure 1.2: Chankom Municipality	13
Figure 1.3: Photograph of the road connecting Xcocail with Ticimul and Xcopteil	14
Figure 1.4: Photograph of a man from Xcopteil cleaning and preparing the land for sowing	15
Figure 1.5: Photograph of a woman from Ticimul washing clothes	16
Figure 1.6: Photograph of Yucatan’s Chaya (<i>Cnidoscolus chayamansa</i>), a type of spinach that is commonly used as a topical home remedy for joint pain. It provokes a burning sensation in the skin, which is associated with a therapeutic heating effect.	17
Figure 1.7: Photograph of a Mayan H-Men (witchdoctor) doing a “Kesh” ceremony or change ceremony for a child	18
Figure 1.8: Healthcare services available for the people of Chankom within the Mexican Health system.	19
Figure 2.1: The “Community-Based Rehabilitation for Low Income Communities Living with Rheumatic Diseases (CONCORD)” protocol	31
Figure 3.1: Study stages and participants’ flowchart	95
Figure 4.1: Study stages and participants’ flowchart	127
Figure 5.1: Process of defining community needs concerning the problem of musculoskeletal diseases in Chankom	160
Figure 5.2: The disablement process of arthritis in Chankom and its impact on the health-related quality of life	161

Figure 5.3: Barriers for accessing culturally-sensitive healthcare for people living with arthritis in Chankom and their causes

162

LIST OF TABLES

Table 3.1: Participants' general characteristics.	96
Table 3.2: Frequency of regular repetitive movements performance during principal occupation.	97
Table 3.3: Prevalence odds ratios for the associations between selected risk factors and arthritis, OA and RA.	98
Table 3.4: Adjusted prevalence odds ratios for the associations between selected risk factors and hand OA and hip or knee OA in women and men.	99
Table 4.1: Descriptive estimates for the physical function assessment.	128
Table 4.2: Descriptive estimates for known factors associated with osteoarthritis progression.	129
Table 4.3: Regression models' estimates.	130
Table 5.1: Quotations for the main theme: Living with arthritis.	156
Table 5.2: Quotations for the main theme: Seeking "good medical care".	157
Table 5.3: Quotations for the main theme: Accessing healthcare.	158

LIST OF ABBREVIATIONS

6MWT- 6-minute walk test

ACR- American College of Rheumatology

BMI- Body Mass Index

CBPR- Community-based Participatory Research

CBPR- Community-based Rehabilitation Program

CBR- Community-based Rehabilitation

CI- Confidence Interval

community-UHC-Nuevo León- Community served by the University Health Center of Nuevo León, Monterrey, México

CONACYT- Consejo Nacional de Ciencia y Tecnología

COPCORD Community Oriented Program for the Control of Rheumatic Diseases

csCBR- Culturally sensitive Community-based Rehabilitation

FDT- Functional Dexterity Test

GLADERPO- Grupo Latinoamericano para el Estudio de Enfermedades Reumáticas en Poblaciones de Origen

HAQ-DI- Health Assessment Questionnaire Disability Index

ICC- Intra-class Correlation Coefficient

ICF- International Classification of Functioning, Disability and Health

ILAR- International League Against Rheumatism

IMSS- Instituto Mexicano del Seguro Social

IMSS- Prospera- Health program provided by IMSS and Prospera

ISSSTE- Instituto de Salud y Seguridad Social para los Trabajadores del Estado

LogR- Logistic Regression

LR- Linear Regression

MSK- Musculoskeletal diseases

OA- Osteoarthritis

OLR- Ordinal Logistic Regression

PEMEX- Petróleos Mexicanos

pLRT- partial Likelihood Ratio Test

QoL- Quality of Life

RA- Rheumatoid Arthritis

RAPA1 - Rapid Assessment of Physical Activity part one

RCT- Randomized Controlled Trial

ROM- Range of movement

SD- Standard Deviation

SEDENA- Secretaría de la Defensa Nacional

UHC-Nuevo León- University Health Center of Nuevo León, Monterrey, México

WHO- World Health Organization

WHODAS 2.0- World Health Organization Disability Assessment Schedule version 2

CHAPTER ONE

INTRODUCTION TO THE THESIS

1.1 Disability and arthritis in underserved, low-socioeconomic areas

The International Classification for Functioning, Disability and Health, proposed by the World Health Organization in 2001, defines disability as an “umbrella term for impairments, activity limitations and participation restrictions” that results from the interaction between an individual’s health condition and that individual’s context (1). According to the 2011 World Report on Disability, 16% of the world’s population live with disability, making it a “universal experience with economic and social costs to individuals, families, communities and nations” (2). Consequently, disability is considered a public health issue.

Disability in low and middle-income countries has not been sufficiently explored (2). However, there is some evidence that disability is more prevalent among rural and less wealthy populations of low and middle-income countries (2). In addition, the severity of disability is inversely associated with people’s socioeconomic level (3).

Musculoskeletal diseases are among the most prevalent diseases in the world (4) and are considered among the 10 most common health conditions associated with disability worldwide (2). Furthermore, arthritis is one of the most common musculoskeletal diseases and refers to different pathologies of the joints, including

osteoarthritis and rheumatoid arthritis (5). Arthritis produces mobility limitations and is one of the leading causes of disability worldwide (6). The prevalence of arthritis and its disabling effects are higher in people from lower socioeconomic strata (7).

There are almost six million people living with disability in Mexico, most of them with mobility limitations (8). In addition, arthritis is the most prevalent musculoskeletal disease in this country (9). Consequently, it may be inferred that arthritis is a significant contributor to disability in Mexico. Moreover, the prevalence of arthritis in Mexico has been associated with social inequities (10) and with negative economic impact among people living in poverty (11).

In summary, disability and arthritis are important public health problems in Mexico. Moreover, it is expected that the prevalence and disabling effects of arthritis are higher in areas with low socioeconomic status. Therefore, there is a need to design interventions that aim to reduce the prevalence and disabling effects of arthritis in people living in low socioeconomic areas of Mexico.

1.2 Community-based rehabilitation programs as interventions to reduce arthritis prevalence and disabling effects in Mexican low socioeconomic areas

A possible intervention to decrease the prevalence and disabling effects of arthritis is to develop rehabilitation programs. Rehabilitation refers to “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment” (12). The World

Report on Disability shows that lack of access to timely rehabilitation services has detrimental effects on the functioning and quality of life of individuals, especially for those living in poverty (12).

Rehabilitation programs and services can function in a wide range of settings, from the hospital to the community. The World Report on Disability recommends the creation of rehabilitation programs at the community level, as a way to “overcome economic, cultural, and geographical barriers to access rehabilitation services” (12). Developing community-based rehabilitation programs may be an efficient strategy to decrease the disabling effects of chronic diseases in low socioeconomic areas, where lack of access to rehabilitation services is a fundamental concern.

Only 1.7% of the people who live with musculoskeletal diseases in Mexico have received rehabilitation services (9). It has been proposed that creating community rehabilitation services could address the lack of access to rehabilitation services in Mexico (8). Since the disabling effects of musculoskeletal diseases are higher in people living in low socioeconomic conditions, there is an urgent need to develop community-based rehabilitation programs in low socioeconomic areas of Mexico.

During my doctoral training I initiated a collaboration with Mexican and Canadian researchers from different disciplines (i.e. rehabilitation science, health policy, rheumatology, anthropology) to create a research program for the development, implementation and evaluation of community-based rehabilitation programs directed at decreasing the disabling effects of musculoskeletal diseases in two low socioeconomic communities of Mexico (see Figure 1). We named this research program the

“CONCORD project”, alluding to the noun used for describing a state in which people agree with each other and coexist in a peaceful way. The CONCORD project aims to develop community-based rehabilitation programs that are culturally sensitive, within a framework of scientific research. “Culturally sensitive” refers to programs that consider the cultural knowledge of the community where they will be implemented. Consequently, the CONCORD project responds to two of the main gaps documented in the development of community-based rehabilitation programs worldwide: a) the lack of cultural sensitivity (13) and b) the lack of rigorous research (14).

The CONCORD project is based on the use of quantitative and qualitative research methodology within a participatory research strategy. This project is structured as a cycle of four consecutive stages (see Figure 1): a) a situation analysis stage to understand the problems of musculoskeletal diseases within the target community, through the parallel execution of epidemiology and ethnography studies; b) a program development stage to define the components of the community-based rehabilitation program through the execution of three predominately qualitative activities; c) a program implementation stage to implement the developed community-based rehabilitation program through predominantly quantitative methods; and d) a program evaluation stage to evaluate and understand each component of the implemented community-based rehabilitation program using mixed methodology. The execution of these stages follows the principles of the community-based participatory research strategy defined by Israel et al (15). The work for my doctoral thesis comes from the complete execution of the situation analysis stage and the beginning of the program development stage of the

CONCORD project in Chankom, a rural indigenous Mexican municipality (see Figure 1).

This work addresses the problem of an absence of services for persons experiencing the disabling effects of arthritis within Mayan communities.

1.3 Chankom: a low socioeconomic level community in Mexico

One of the two low socioeconomic communities chosen to develop the CONCORD project was the rural municipality of Chankom, located within the State of Yucatán in Southeast Mexico (see Figure 2). Yucatan is the third most affected State by disability, with a prevalence of 11% (16). Chankom municipality has 4,464 habitants, all of them from the Maya-Yucateco ethnicity, and is considered to be a “highly socially underdeveloped municipality” by the Mexican government (17). Chankom’s inhabitants are distributed in 11 main rural settlements or *commissariats* (see Figure 2) connected by poorly maintained roads (see Figure 3).

According to our ethnographic findings, most men in Chankom work in agriculture or the “milpa”, as they called it, using ancient agricultural techniques that pose great physical demands on their bodies (see Figure 4 in which a man is seen clearing the land for planting using only a machete). Most women in Chankom work in household activities, which are also very physically demanding (see Figure 5 in which a woman is seen washing clothes by hand without running water). During the last 20 years there has been a transformation in the community’s work activities due to young people migrating to the tourist development areas in the State of Quintana-Roo (e.g. Cancún). This

situation has left older persons working alone in the community in their agricultural or household activities and not with the help of their children, which would previously have been the cultural norm.

When the people of Chankom have a health problem they typically attempt to solve the problem themselves, using home remedies and/or self-medication. Home remedies come from Mayan traditional knowledge and involve the use of plants or animal products (see Figure 6). People of the community usually encourage the use of self-medication by recommending that others use drugs that have helped them in the past, which were either prescribed to them by a physician or recommended by another neighbour. This self-medication is possible because in Mexico many drugs, including drugs such as steroids, can be obtained over the counter.

If the health problem is not resolved, they either visit a traditional health provider, such as an H-Men or witchdoctor (see Figure 7 in which a witchdoctor is seen performing a ceremony to cure a baby boy, who was affected by an evil wind, praying to all known catholic saints in the area to remove the evil from his body), or a health professional. This decision depends on their interpretation about the origin of their health problems. For instance, a problem perceived as caused by an evil wind warrants consultation with a witchdoctor, whereas a problem perceived as caused by body changes that can be “fixed” by western medicine warrants visiting a physician. In the case of musculoskeletal diseases the people of Chankom usually seek the services of health professionals.

The health services available to the people of Chankom belong either to the public or to the private sectors of the Mexican health system (see Figure 8). Ninety-seven

percent of Chankom's habitants are enrolled in the public health insurance program or "Seguro Popular". This program was created to fulfill the healthcare needs of Mexican self-employed workers and is funded by three parts: federal government, Yucatan's government and users (see Figure 8). People living in Chankom municipality are not required to pay for this insurance, due to their poverty and marginalized status. Some of Chankom's commissariats also receive healthcare services from a program called "IMSS-Prospera", which is directly funded by the Yucatan section of the Mexican Institute of Social Security (IMSS) (see Figure 8).

The only health infrastructure present within Chankom municipality belongs to the public sector of the Mexican health system and is represented by five community clinics (three from Seguro Popular and two from IMSS-Prospera) located in the five largest commissariats. All clinics are operated by medical students completing their final year of training, and have a limited supply of medications. Some of the clinics have permanent nursing staff. The second and third level of healthcare services provided by Seguro Popular and IMSS-Prospera are located outside the municipality, at least 41 km away from the municipal seat.

The people of Chankom also seek medical care from private general physicians who have their practices in other municipalities. There are out-of-pocket expenses for these services, as people do not have access to private insurance. Interestingly, many people use the private sector before using the public sector, due to mistrust of medical students and the lack of effective medications available at the public primary health clinics.

There are no pharmacies, imaging or clinical laboratory services, private medicine or rehabilitation services within the municipality. When people want to use the private healthcare sector or the public sector's second or third level services they need to travel outside the community. The only health-related service provided by Chankom's municipal government is the transportation of people to receive health care outside the community. This transportation only operates when individuals ask the municipal government authorities directly for the service.

1.4 Towards the development of a culturally sensitive community-based rehabilitation program in Chankom

I lived with my family near Chankom municipality for nine months to complete the first stage of the CONCORD project in this community. During this time, I used both quantitative and qualitative methods for data acquisition. In my role as a physiatrist, I supervised a census-based screening strategy to identify musculoskeletal diseases at this municipality, which involved the work of local Mayan interviewers and general physicians. I also confirmed all cases of osteoarthritis during this census, which involved the medical assessment of more than 300 people. In addition, I conducted assessments of people with confirmed osteoarthritis, identifying the presence of factors for disease progression, along with a thorough measurement of their physical function. Moreover, I collaborated with a physiotherapist to create individualized home-based rehabilitation

programs for all people diagnosed with osteoarthritis, including weight management, pain control and exercise.

The collection of qualitative data involved numerous interviews with the inhabitants of Chankom and various leaders from regional social development agencies and health institutions that have jurisdiction in Chankom. I completed both participant and non-participant observations on the events within daily life of the municipality and on special events, such as annual religious festivities. Systematic notes of all my observations and experiences in Chankom were documented in a field journal. Photographs and videos were also used to record my observations.

After the nine months of field work in Chankom, I continued to participate remotely in the coordination of the “community organization and partnership formation” activity of the CONCORD project’s second stage in Chankom (see Figure 1). This activity has involved community organization efforts and has been underway for 13 months. My participation involves coordinating weekly on-line meetings with team members of Chankom and Mexico City. I also visited the municipality for two weeks on three occasions during these 13 months. The work conducted to date during this activity has helped the community to define their main needs around the problem of musculoskeletal diseases and includes: a) creating 11 community groups, one per each commissariat, formed by leaders interested in addressing the problem of musculoskeletal diseases in their communities, b) providing educational sessions to increase awareness and general knowledge about arthritis for patients, leaders and the community, c) training community leaders on how to navigate the Mexican health system, d) training local health

providers about the detection, management and rehabilitation of musculoskeletal diseases, e) providing monthly specialized care from one rheumatologist, one internist and one rehabilitation professional at the community, and f) liaising with the regional health ministry.

1.5 Thesis structure

The work of this thesis is a result of the completion of the first stage and the beginning of the second stage of the CONCORD project in Chankom municipality (see Figure 1). This work examines the problems associated with the presence of arthritis in this rural indigenous community, contributing knowledge for the construction of rehabilitation interventions at the primary level of care, which is an important need within the discipline of Rehabilitation Sciences. In addition, this thesis demonstrates how the application and dialogue between quantitative and qualitative methods under a transdisciplinary, participatory-action research framework including the social sciences could represent a methodological alternative for the creation of culturally sensitive community-based rehabilitation programs in underserved communities. Substantively, the work of this thesis contributes knowledge about the arthritis-related disability in Mexican indigenous communities, laying the foundation for the development of interventions that improve health services and decrease the disabling effects of this chronic condition in these marginalized communities.

This thesis is structured in five chapters. Chapter two is the published manuscript that describes the details of the CONCORD project (18). This chapter describes the theoretical and practical foundations of the project. In addition, it includes some reflections about the differences between conducting this project at a rural indigenous municipality and at one urban non-indigenous community.

Chapters three, four and five are manuscripts submitted for publication that include findings around the issue of arthritis from the execution of the situational analysis stage in Chankom municipality. In addition, chapter five includes some findings from the ongoing program development stage.

Chapter three reports epidemiological findings on the prevalence of arthritis in Chankom municipality, the factors associated with this prevalence and the disability associated with this chronic health condition. Chapter four reports the findings on comprehensive assessments of function on persons living with osteoarthritis. It also includes the exploration of physical, psychological, social and behavioral factors associated with the functional status of this osteoarthritis subgroup. Chapter five presents qualitative findings describing the impact of living with arthritis in Chankom, the barriers faced by the people in their efforts to access healthcare and their needs in living with arthritis as defined within the community. Finally, chapter six presents a summary of the main contributions of the thesis along with some conclusions of lessons learned and implications for the future.

Figure 1. CONCORD project progress to date and thesis contributions

	TARGET COMMUNITIES	
	Nuevo León	Chankom
<u>Stage 1. Situation analysis</u>		
<i>Epidemiologic study</i>	In progress	Completed
<i>Ethnographic study</i>	In progress	Completed
<u>Stage 2. Program Development</u>		
<i>Community organization and partnership formation</i>	Uninitiated	In progress
<i>Evidence assessment, merging & summary</i>	Uninitiated	Uninitiated
<i>Stakeholder dialogue</i>	Uninitiated	Uninitiated
<u>Stage 3. Program implementation</u>		
	Uninitiated	Uninitiated
<u>Stage 4. Program evaluation</u>		
	Uninitiated	Uninitiated

THESIS
Arthritis
 Prevalence
 Disability
 Impact
 Barriers to access care
 Community needs

Figure 2.Chankom Municipality

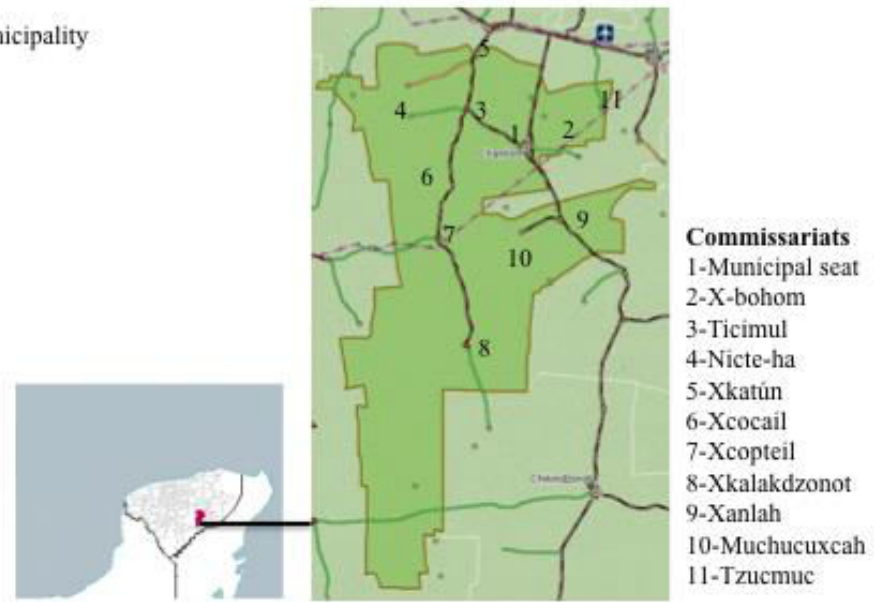


Figure 3. Photograph of the road connecting Xcocail with Ticimul and Xcoptail



Figure 4. Photograph of a man from Xcopteil cleaning and preparing the land for sowing



Figure 5. Photograph of a women from Ticimul washing clothes



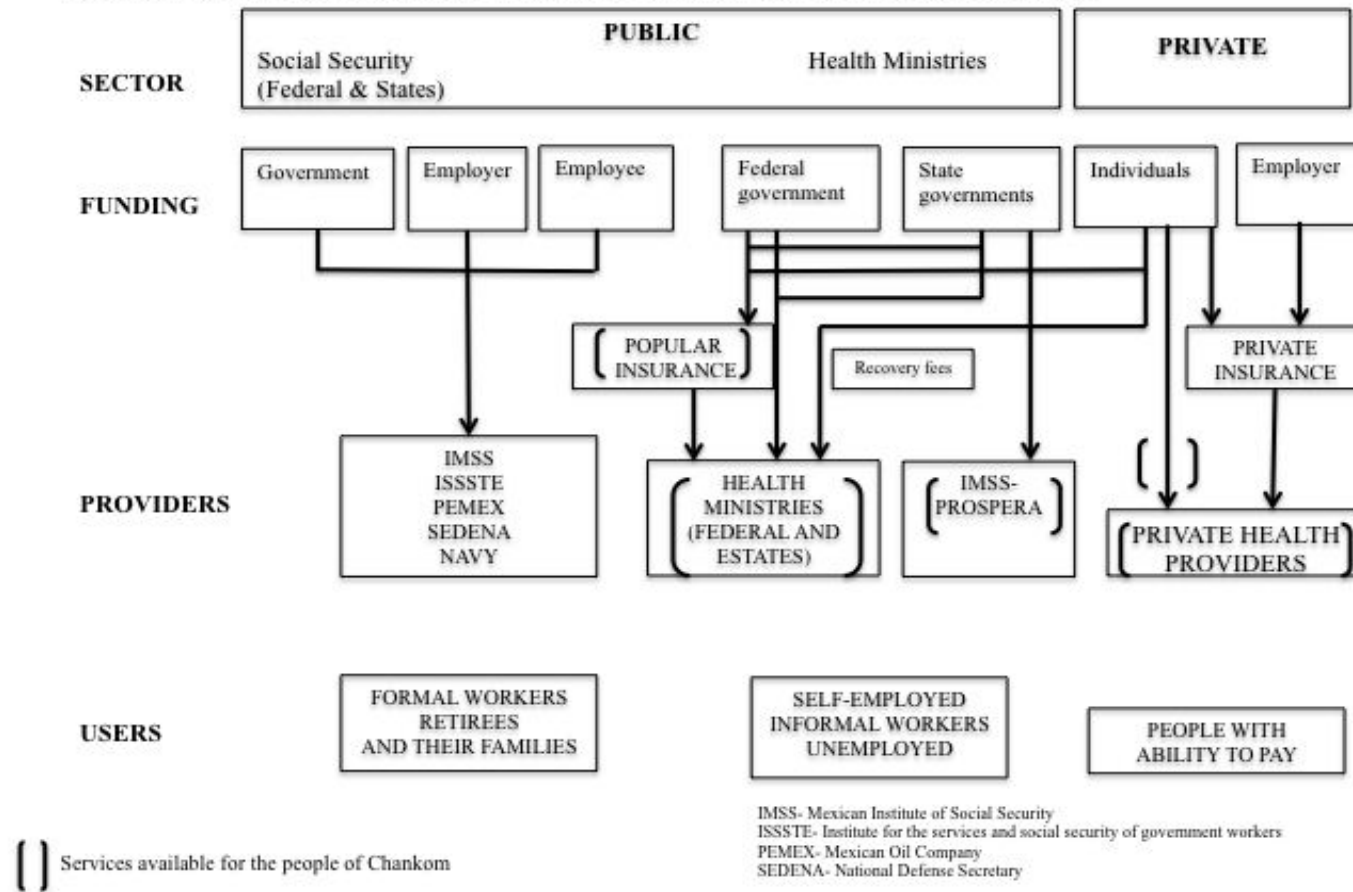
Figure 6. Photograph of Yucatan's Chaya (*Cnidoscolus chayamansa*), a type of spinach that is commonly used as a topical home remedy for joint pain. It provokes a burning sensation in the skin, which is associated with a therapeutic heating effect



Figure 7. Photograph of a Mayan H-Men (witchdoctor) doing a “Kesh” ceremony or change ceremony for a child



Figure 8. Healthcare services available for the people of Chankom within the Mexican Health system



CHAPTER TWO

DEVELOPING COMMUNITY-BASED REHABILITATION PROGRAMS FOR MUSCULOSKELETAL DISEASES IN LOW-INCOME AREAS OF MEXICO: THE COMMUNITY-BASED REHABILITATION FOR LOW-INCOME COMMUNITIES LIVING WITH RHEUMATIC DISEASES (CONCORD) PROTOCOL

PREFACE TO CHAPTER TWO

Authors: Adalberto Loyola-Sánchez, Julie Richardson, Ingris Peláez-Ballestas, John N. Lavis, Michael G. Wilson, Jacqueline Rodríguez-Amado, José Alvarez-Nemegyei, Rebeca T. Martínez-Villareal, Dora J. Onofre-Rodríguez, Raquel Benavides-Torres

Publication status: This manuscript was published in the *Journal of Medical Internet Research (JMIR) Research Protocols* under an open-access license. The manuscript is reprinted from: Loyola Sanchez, A., Richardson, J., Pelaez-Ballestas, I., Lavis, J. N., Wilkins, S., Wilson, M. G., Rodríguez-Amado, J., Alvarez-Nemegyei, J., Martínez-Villareal, R.T., Onofre-Rodríguez, D.J., Benavides-Torres, R. (2014). Developing community-based rehabilitation programs for musculoskeletal diseases in low-income areas of Mexico: The community-based rehabilitation for low-income communities living with rheumatic diseases (CONCORD) protocol. [Electronic version]. *JMIR Research Protocols*, 3(4), e57 under the Creative Commons Attribution License.

Summary: This manuscript describes the theoretical and practical foundations of the research program I proposed to develop, implement and evaluate culturally sensitive community-based rehabilitation programs directed at decreasing the disabling effects of musculoskeletal diseases in two low-socioeconomic communities of Mexico. Consequently, it includes a description of the methodology followed to obtain the data presented and analyzed in chapters three, four and five.

2.1 Abstract

Background: The negative impact of musculoskeletal diseases on the physical function and quality of life of people living in developing countries is considerable. This disabling effect is even more marked in low-socioeconomic communities within developing countries. In Mexico, there is a need to create community-based rehabilitation programs for people living with musculoskeletal diseases in low-socioeconomic areas. These programs should be directed to prevent and decrease disability, accommodating the specific local culture of communities.

Objective: The objective of this paper is to describe a research protocol designed to develop, implement, and evaluate culturally sensitive community-based rehabilitation programs aiming to decrease disability of people living with musculoskeletal diseases in two low-income Mexican communities.

Methods: A community-based participatory research approach is proposed, including multi and transdisciplinary efforts among the community, medical anthropology, and the health sciences. The project is structured in 4 main stages: (1) situation analysis, (2) program development, (3) program implementation, and (4) program evaluation. Each stage includes the use of quantitative and qualitative methods (mixed method program).

Results: So far, we obtained resources from a Mexican federal agency and completed stage one of the project at Chankom, Yucatán. We are currently receiving funding from an international agency to complete stage two at this same location. We expect that the project at Chankom will be concluded by December of 2017. On the other hand, we just

started the execution of stage one at Nuevo León with funding from a Mexican federal agency. We expect to conclude the project at this site by September of 2018.

Conclusions: Using a community-based participatory research approach and a mixed method program could result in the creation of culturally sensitive community-based rehabilitation programs that promote community development and decrease the disabling effects of musculoskeletal diseases within two low-income Mexican communities.

2.2 Introduction

2.2.1 Musculoskeletal Diseases and Disability

Musculoskeletal diseases are highly prevalent in communities of many developed and developing countries, resulting in important health problems for individuals and society [1-4]. Many epidemiological studies performed in developed countries have found high levels of disability and work absenteeism among people who suffer musculoskeletal disorders [5-8]. Furthermore, disability produced by musculoskeletal pain has a negative impact on the social and emotional well-being of people [9], especially in the older adult population [10].

The negative impact of musculoskeletal diseases on the physical function and quality of life of people is more marked within developing countries [11]. This could be linked to observations that increased disability is associated with lower socioeconomic levels [12,13]. A large epidemiological study conducted in Mexico reported that the prevalence of musculoskeletal pain was 26%, which was associated with 13% of physical disability [14]. This study also found significant differences in the regional prevalence of musculoskeletal pain and its causes across the country, implying the influence of different cultural, socioeconomic, and demographic factors within each geographical location [14].

In the Mexican northern state of Nuevo León, the prevalence of osteoarthritis is 17% [15], while the estimated national prevalence is 10.5% [14]. This shows that osteoarthritis is an important health problem for this region. In the southern state of Yucatán, the existence of chronic musculoskeletal diseases, such as osteoarthritis, back pain, and rheumatoid arthritis, produces a 6% prevalence of disability negatively affecting

the life of the people living in this region [16,17]. As a result, there is a growing interest in designing community-level interventions directed to decrease the musculoskeletal-related disability within these Mexican regions.

2.2.2 Rehabilitation Interventions

Specifically, the health professionals of the University Health Center of Nuevo León (UHC-Nuevo León) have a particular interest in addressing the health problems posed by musculoskeletal diseases in their community. The UHC-Nuevo León is a primary health care program run by the Autonomous University of Nuevo León that provides health services to a large community of low socioeconomic level. On the other hand, the Latin American Group for the Study of Rheumatic Conditions in Indigenous People (Grupo Latinoamericano para el Estudio de Enfermedades Reumaticas en Poblaciones de Origen, GLADERPO) is interested in creating interventions for decreasing the disabling effects of musculoskeletal diseases in a municipality called Chankom, which is an underserved Mayan community located in the state of Yucatan. Consequently, these two groups are looking to design rehabilitation interventions aimed to address the musculoskeletal-related disability within their communities of interest.

Rehabilitation is defined as an “enabling” process aimed at reversing the “disabling” effects of a pathological condition [18] or a social situation [19]. This process involves efforts directed both at the persons and their environments, allowing them to get “back on track” with their lives and to achieve equal opportunities to participate in their desired social roles [20]. There is evidence that rehabilitation is effective at reducing the burden of disability, enhancing opportunities for disabled people. This results in an

improvement of quality of life to the extent that the United Nations and the European Board of Physical and Rehabilitation Medicine consider “access to rehabilitation” as a human right [21,22].

Particularly, rehabilitation interventions have proven effective to decrease pain and improve physical function with people suffering from rheumatologic diseases [23]. Nevertheless, in Mexico only 1.7% of the people who suffer from musculoskeletal diseases receive rehabilitation [14]. Consequently, there is a need to develop community rehabilitation programs directed at decreasing the disabling effects of musculoskeletal diseases in both the community served by the UHC-Nuevo León (community-UHC-Nuevo León) and the Mayan community of Chankom.

2.2.3 Community-Based Rehabilitation and Community-Based Participatory Research

The concept of community-based rehabilitation (CBR) has evolved over 30 years of community work, mostly in developing countries. CBR started as an approach of biomedical service and gradually progressed to a “human-rights” approach supporting community development [24]. Therefore, this approach is now defined as a community development strategy for the social inclusion of people with disabilities through the equalization of opportunities [25]. Due to its participatory focus it has been proposed that CBR is a “democratic tool for social change” [26].

Nevertheless, there have been some limitations in the application of the CBR approach worldwide, which include a lack of cultural sensitivity [24]. Cultural sensitivity refers to the ability to accommodate a specific culture [27], and successful community

programs address this by including the knowledge, beliefs, and values of the target community [28]. Therefore, CBR programs should be culturally sensitive; in other words they need to be developed with primary consideration of the beliefs, perceptions, and values of the culture of the community where they will be implemented.

The concept of cultural sensitivity obtains significant relevance when dealing with very different communities, as in the case of the community-UHC-Nuevo León and Chankom. The 5 community health centers that form the community-UHC-Nuevo León provide care to 52 urban neighbourhoods (approximately 140,000 persons). The entire population of this community speaks Spanish and belongs to a low to middle-low socioeconomic level. On the other hand, the community of Chankom Municipality has 4340 inhabitants spread across 11 small rural settlements or commissariats. The majority of Chankom's population speaks Mayan and lives in very high levels of poverty. Given the sociocultural differences between these two communities, it is essential to adopt the concept of cultural sensitivity, and not to take a “one size fits all” approach for the development of the CBR programs.

Another important limitation of the CBR approach is the lack of formal research and scientific evaluation of its goals and processes [24,29-31]. Culturally sensitive CBR programs can be achieved through a “full and effective participation of the community” [25]. Consequently, participatory research strategies could represent a viable alternative to do research on CBR. There is one strategy, the community-based participatory research (CBPR), which has been proposed as an optimal method to develop culturally sensitive community-based health programs [32]. This strategy is part of the “participatory action”

research that conceptualizes reality as formed by objective and subjective perspectives. Perspectives are historically constituted and reconstituted by human agency and social action, which implies a need to establish a dialectic relationship among different forms of knowledge production [33]. As a result, the CBPR approach involves the use of different quantitative and qualitative strategies to generate knowledge, which then can be used to address community needs [34,35].

CBPR is based on the following principles: (1) acknowledgment of the community as a unit of identity, (2) development of community strengths and resources, (3) promotion and facilitation of equitable and participatory partnerships with community members in all phases of research, (4) promotion of co-learning and capacity building for all partnership members, (5) achievement of balance between knowledge generation and intervention for the mutual benefit of all partners, (6) focus on relevant problems for the community, (7) use of iterative and cyclical processes in all research, (8) involvement of all partners in the local and global dissemination of results, and (9) establishment of long-term commitment with partnership sustainability [32]. The application of these principles can result in knowledge that is owned by the community and is useful for the design, implementation, and evaluation of community interventions [32,35].

The use of CBPR strategies has resulted in increments of community capacity and positive effects on community health [36]. In Latin America, there is a long history of health-program development efforts through social participation, which have repeatedly failed to achieve all their goals [37]. Lessons learned from these experiences suggest that collaborative efforts established between communities and nongovernment institutions,

such as universities, are an efficient way to solve immediate health issues, improve resource utilization, and raise social and political awareness [37]. In consequence, a CBPR strategy that includes alliances between community and academic institutions could be effective, producing structured social participation to solve disability related problems in the community-UHC-Nuevo León and the Municipality of Chankom.

2.2.4 Main Intention and Objective

It has been stated that what really defines a social participation approach are the intentions and meanings given to the actions conducted by the people involved in it, and it is extremely important to be transparent about the intentions of using such a research strategy [38]. The main intention of this project is to organize and empower communities to develop a culturally sensitive CBR (csCBR) program in partnership with academics. This partnership will seek to form alliances with government and nongovernment institutions in order to ensure the success and continuation of the program. The csCBR program will aim to reduce the disabling effects of musculoskeletal diseases through supporting the efficient use of resources available in the communities and promoting micro and macro social changes.

The main objective of this protocol, which we named Community Based Rehabilitation for Low Income Communities Living With Rheumatic Diseases (CONCORD), is to develop, implement, and evaluate csCBR programs to decrease disability of people living with musculoskeletal diseases in the community-UHC-Nuevo León and the Municipality of Chankom. The hypothesis of this project is, “The execution of a CBPR strategy that permits a fusion of global and local knowledge will result in the

creation of csCBR programs that will promote community development, thereby increasing social integration of disabled people with musculoskeletal diseases living in the communities of interest”.

2.2.5 Theoretical Approach

The theoretical approach of this research project aligns with a social constructivist worldview, assuming that a successful CBR program can be developed through the construction of “new knowledge”. This new knowledge results from the “fusion of horizons” [39] between global knowledge (scientific/academic) and local knowledge (community beliefs and values). The new knowledge will be supported by community and academic members and will permit the definition of actions to facilitate its use for the benefit of the community. These actions will be structured as a complex intervention [40] in the form of a csCBR program and will involve collaborations with representatives of social and health policy institutions. In addition, we will use critical analytic approaches to disclose and resolve conflicts of power innate to every participatory action project.

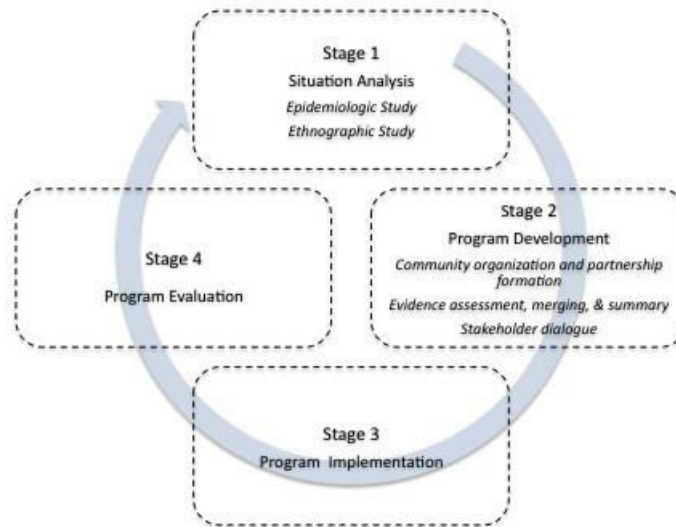
2.3 Methods

2.3.1 Research Strategy and Methodology Overview

The CBPR strategy in this project will include a multi and transdisciplinary effort that involves a dialogic relationship between medical anthropology and some health sciences such as rheumatology, epidemiology, rehabilitation, nursing, and primary health care. Following the 2010 World Health Organization (WHO) guidelines for the development of CBR programs [41], this project is structured in four main stages (Figure 1 shows these stages). Methodologically, this project is conceived as a mixed method

program, which involves the use of quantitative and qualitative methods in all its stages [42]. Following is a description of the main methodological elements that constitutes each of these stages. Differences on how each stage will be conducted in each of the communities of interest will also be noted.

Figure 1. The “Community-Based Rehabilitation for Low Income Communities Living With Rheumatic Diseases (CONCORD)” protocol.



2.3.2 Stage One: Situation Analysis

2.3.2.1 Objectives

This stage will be undertaken over a 6-month period with the objectives of: (1) generating knowledge about the physical function problems produced by musculoskeletal diseases in the target communities; and (2) understanding the specific contexts in which these problems occur within each community. To achieve these objectives we will conduct an epidemiologic study in parallel with an ethnographic study.

2.3.2.2 Epidemiologic Study

This will be a “pure quantitative” study [42] with the specific objectives of: (1) assessing the prevalence and factors associated with musculoskeletal diseases development and progression in both communities of interest; and (2) evaluating the impact of musculoskeletal diseases on the physical function and health status of the people living in both communities. We expect to understand the impact of musculoskeletal diseases within the communities and to identify the presence of potentially modifiable factors to prevent or decrease disability.

This will be an observational, cross-sectional, survey-based study. Due to the different population sizes, in Chankom we will conduct a census of all adults (≥ 18 years old) living in the community; whereas in the community-UHC-Nuevo León we will obtain a multistage probabilistic sample of 1516 adults (considering a precision of 3%, a 95% confidence level, an estimated osteoarthritis prevalence of 20%, observed in Nuevo León State, and the sample size adjustment recommended for multistage sampling procedures) [43]. The primary sampling unit of the probabilistic sampling will be neighbourhoods served by the UHC-Nuevo León. The secondary sampling unit will be blocks within selected neighbourhoods, and the tertiary sampling unit will be households within selected blocks. All procedures will be performed using a random-start systematic proportional sampling procedure. In order to control for within-household homogeneity, we will only survey one person per household.

The survey procedure will be structured following the Community Oriented Program for the Control of Rheumatic Diseases (COPCORD) methodology [44]. The

COPCORD is a screening strategy to detect rheumatologic disorders in the community and has proven to be effective when used in Mexico [45]. Briefly, the survey consists of a questionnaire designed to explore the presence of joint pain, stiffness, and inflammation along with factors associated with musculoskeletal diseases, physical activity, physical function, and health status.

Physical activity will be assessed using the well validated Mexican-Spanish version of the Rapid Assessment of Physical Activity questionnaire [46,47]. Health status will be evaluated through directly asking the participant, “How have you been with your illness?”, and physical function will be measured through the Health Assessment Questionnaire Disability Index (HAQ-DI). This questionnaire, which has shown good psychometric properties when applied to people with musculoskeletal chronic diseases [48], is available in Spanish [49] and has been validated within the Mexican population [50,51]. The survey will also include a socioeconomic assessment including education, income, home characteristics, and commodities.

Trained personnel will administer the survey to both communities in person. In the case of Chankom, a cross-cultural adaptation of the instrument to the Mayan language was conducted [52]. A trained general physician will assess all adults that reported any musculoskeletal symptoms at their homes using standardized criteria for the diagnosis of rheumatologic diseases. A specialist (rheumatologist or physiatrist) will confirm all cases identified with rheumatologic diseases.

The specialist will conduct a thorough medical assessment of all confirmed cases. This assessment will include radiographic evaluation, medical history, and physical

examination with the objectives of evaluating the impact of disease on physical function and the presence of factors for functional decline and disease progression.

Physical function will be evaluated according to Glass's tenses of "human functioning" [53]. These tenses are: (1) "enacted tense" or performance of meaningful activities within life context; (2) "hypothetical tense" or perceived capacity to do predefined activities; and (3) "experimental tense" or capability to do activities in standardized conditions. Performance of meaningful activities will be evaluated by self-report of main housework, work, and leisure activities, including an assessment of the concept "preclinical disability". Preclinical disability refers to the state in which, in spite of no interruptions in the execution of regular activities, there is a modification of the way and/or the frequency in which these activities are performed [54]. Perceived capacity to do predefined activities will be assessed using the HAQ-DI, described above. Finally, capability to do activities in standardized conditions will be evaluated through the 6-minute walk test (6MWT) and the functional dexterity test (FDT). The 6MWT measures the distance an individual can walk during 6 minutes on a hard, flat surface [55], and has shown good test-retest reliability when used with people with musculoskeletal conditions such as osteoarthritis [56,57]. The FDT evaluates the ability to use the hand for "functional daily tasks that require 3-jaw chuck prehension between the fingers and the thumb" [58] and has shown good intra and interrater reliabilities and construct-validity in diverse pathologic conditions of the hand [59].

A member of the research team will perform periodic screenings to ensure the quality of the database. We will estimate descriptive statistics (central and dispersion estimates). In the case of the community-UHC-Nuevo León, we will also estimate 95% confidence intervals correcting for the three-stage sampling. We will use linear and logistic regression models to evaluate the factors associated with disease presentation and with impact on health and physical function utilizing specialized statistical software (STATA version 12).

2.3.2.3 Ethnographic Study

This “pure qualitative” study [42] will be conducted over 6 months, in parallel with the epidemiologic study, with the objective to produce an ethnographically informed report on the “explanatory models of illness” within the medical-anthropological “health systems” [60] of Chankom and the community-UHC-Nuevo León. Explanatory models of illness refer to the different narratives present on the causes, manifestations, trajectories, and treatments of disease, whereas the medical-anthropological health systems include the popular, traditional, and professional contexts in which health is conceived [61].

We will conduct a study from the perspective of ethnography [62]. This implies the conducting of fieldwork where anthropologists and other researchers-in-training will live in or close by the target communities. Given the high rates of violence registered in Nuevo León during the last few years, we will conduct preliminary in-depth interviews and focus groups with community leaders and health providers of the UHC-Nuevo León to ensure that it is safe for a researcher to live in this area, and in case it is not, to define alternative strategies to complete the planned fieldwork.

The fieldwork will include purposeful sampling of key persons, activities, social and familiar events, and documents. Key persons will include: (1) community members who have musculoskeletal diseases involving different body regions; (2) community leaders involved in community development activities; (3) representatives of health professionals involved in the care of people with musculoskeletal diseases in these communities; (4) representatives of health providers not officially recognized by a professional association (eg, bonesetters, masseurs, etc); (5) representatives of the local government; and (6) representatives of social development institutions (state and nongovernmental). These persons will be interviewed through informal and formal (in-depth interviews and focus groups) techniques.

We will perform participant and nonparticipant observations of individual's activities (eg, occupation) and social, familiar, cultural, and provincial events. These observations will be chosen according to their relevance to the musculoskeletal disability problems within each community. Finally, we will obtain written documents that are relevant to understand the problem of musculoskeletal disability within each community (eg, local disability laws, social welfare rules, clinical practice guidelines, advertisements, etc).

All activities in Chankom will be conducted using Mayan translators who are fluent in Spanish and Mayan languages and are recognized by the community as members of their own. Access to each community will be negotiated with community leaders and local authorities. Data will be recorded by the use of field notes and audiotape recorders. We will aim to achieve thematic and/or theoretical saturation [63]. All data will be

transformed to written electronic format and will be organized and managed using specialized qualitative data software (Hyperresearch, version 3.5.2).

Data will be analyzed and interpreted by the research team. The team will work on concept generation, typology development, and execution of comparative strategies. Constant reflection about team members' emotions and prejudices that emerge while conducting the fieldwork will be executed. Data analysis and interpretation will be done through a continuous cycle of analysis-interpretation-reflection. The analysis-interpretation phase will feed into the data acquisition phase; hence they will occur simultaneously. An iterative analytic-interpretative process will be use in which theoretical ideas will be used to make sense of data and the data will be used to change theoretical ideas [64]. All analytic, interpretative, and methodological decisions will be carefully registered as memoranda within an audit trail book.

Completing this ethnography will help us understand the disability problems caused by musculoskeletal disorders in the communities of interest. This study will allow the identification of barriers and facilitators for the optimal function of the population who suffers from musculoskeletal diseases in Chankom and the community-UHC-Nuevo León. Understanding the local culture and the native perspective on the causes, management, impact, and prognosis of musculoskeletal diseases will help us define better the problematic related to musculoskeletal diseases within the communities. In addition, knowing the communities' local, regional, and national social structures along with their functional dynamics will orient us on how to proceed during the following stages of the project.

2.3.3. Stage Two: Program Development

2.3.3.1 Objectives

This stage will take 12 months to complete and has the following objectives: (1) to organize the communities and form a partnership among these and members of academia under the principles of equity and mutual respect; (2) to define the priority problems related to the disabling effects of musculoskeletal diseases, and to identify possible solutions to these problems; and (3) to define the components of the csCBR program along with the necessary actions to implement them, assuring the necessary resources to execute them. This stage will follow a “qualitative dominant” methods perspective [42] being composed of three main and sequential activities: (1) community organization and partnership formation; (2) evidence assessment, merging, and summary; and (3) stakeholder deliberation. In addition, an anthropologist will conduct ethnographic work including nonparticipant observations and in-depth interviews on all these activities in order to produce a reflective-critical analysis from a medical anthropology perspective.

2.3.3.2 Community Organization and Partnership Formation

We will present the information gathered during the initial stage of this project to the community through the organization of community meetings at different strategic locations. During these meetings we will form 2 types of committees labeled as “first-level” or “second-level” committees. In Chankom, we will hold 11 meetings, one at each commissariat, and in the community-UHC-Nuevo León we will conduct 5 meetings, one at each of the health care units that form this center. These information meetings have the goal of creating awareness about the disabling effects of the musculoskeletal conditions

explored within these communities. By the end of each meeting we will ask the community to choose 4 persons to constitute a first-level committee. A person from each of these first-level committees will participate in the second-level committee. There will be only one second-level committee, which includes representatives of all the strategic locations within our target communities (11 in Chankom and 5 in the community-UHC-Nuevo León).

The second-level committee of each community will be legally constituted as a “civil association”. This will be important for allocating and requesting financial resources, because in Mexico most government and nongovernment institutions can only serve organizations of this kind. The second-level committee will directly interact and work with representatives of the academic institutions involved in this project. During the first meeting of all committees, the members will define their roles as well as the rules for collaboration in relation to the processes of communication, decision-making, and conflict resolution. We will use a nominal group technique, which is a group decision-making method, based on procedures for ideas’ exposition, discussion, and ranking that allows everyone’s opinion to be taken into account, reaching the best possible solution that is constituted by a mixture of all group members’ ideas [65].

The second-level committee and the academics will be in charge of all methodological and administrative decisions for the project, as they will take on the role of the principal investigator. All decisions taken within this partnership between communities and academia, from now on referred to as “the partnership”, will be the result of an ongoing analytic-interpretive-consensus process. In addition, the information

and decisions generated within the partnership will be disseminated to the community via the first-level committees. In the same token, the community will be able to communicate with the second-level committee and academics through the first-level committees.

2.3.3.3 Evidence Assessment, Merging, and Summary

The first task for the partnership and the first-level committees will be to define the priority problems within their communities. The groups will use the knowledge generated during stage one of this project and the elements described by the WHO CBR matrix [41]. Priority problems refer to those issues that need to be urgently solved in order to decrease the disabling effects of musculoskeletal diseases in Chankom, and the community-UHC-Nuevo León. These issues will be organized and structured according to their main content in: (1) health, (2) education, (3) livelihood, (4) social, and (5) empowerment problems. The prioritization of problems will be based on their impact on the community's health and physical function. We will then think about possible solutions using both, the communities' social and cultural knowledge (local evidence) and the knowledge generated within the "scientific-academic" world (global evidence). These ideas will redefine community priority problems based on the cost, benefit, and efforts required to implement them.

The global evidence assessment will largely be the responsibility of the academic partners. This will be accomplished by combining the methodology for "overview of reviews" proposed by the Cochrane Collaboration [66] and the "evidence assessment" approach proposed by the "Grading of Recommendations Assessment, Development and Evaluation" group [67]. Once processed, this evidence will be formatted into a fourth

grade level of comprehension, so every member of the partnership and committees can understand it. Following this, the partnership will merge both local and global evidences in order to construct a plan to solve the disabling problems posed by musculoskeletal diseases in the communities. Therefore, it is expected that this plan will be both solid, in relation to its scientific foundation, and sensitive to the cultural and social realities of each of the target communities.

Priority problems and the plan to attend them will be defined and written as an evidence brief (ie, a document that summarizes how the available evidence pertains to a pressing problem, select options for addressing the problem, and key implementation considerations). This evidence brief will be structured following the ideas developed by the McMaster Health Forum [68,69], along with ideas from the “scenario planning” strategy for organization planning [70]. These briefs will include: (1) a clear description of each problem including its context; (2) a description of possible individual, community, programmatic, and systemic solutions to address each problem through the use of different scenarios; (3) a description of expected outcomes (benefits, costs, and harms) for each scenario; (4) a simple description of the grade of uncertainty behind the expected outcomes of each scenario; (5) a description of possible barriers for the implementation of each possible solution; and (6) a clear description about the sources from which the information of the possible solutions and scenarios came.

2.3.3.4 Stakeholder Dialogue

The components of the csCBR program will be defined using the principles of the Communicative Action Theory, which assumes that communication aimed at reaching

agreement is the base from which to coordinate the activities of social change [71].

Consequently, we will create a space for communication or forum to convene a stakeholder dialogue to support action for improving health outcomes through collective problem solving by different key decision makers. The stakeholder dialogue will be conducted based on the methods developed by the McMaster Health Forum [72]. In addition, we will attempt to achieve an “unforced consensus” [33], a goal not usually targeted by these kinds of forums. This consensus will be fundamental to assure the execution and sustainability of the csCBR program.

Key decision makers are defined as those knowledge users who are able to influence the decision-making processes of their respective areas. The partnership will identify key decision makers using the information gathered during the previous stage and sub stages of the project. We anticipate that identified key decision makers will represent at least one of the following areas: (1) traditional medicine, (2) professional health care, (3) government and nongovernment social welfare, and (4) health policy. During this part of the project we will intend to form an alliance with these key decision makers in order to create commitments that will ensure human and material resources for the execution of the csCBR program, independently from resources of this research project. We will recognize these key decision makers as “powerful allies”, based on the privileged position of power they held within their respective areas. Potential powerful allies will be invited to participate in the stakeholder dialogue through letters and person-to-person invitations.

The dialogue will be conducted over the course of several sessions in which participants will gather in a neutral, public location to talk about the information described in the evidence brief. A neutral facilitator, who will ensure a respectful and equitable communication among participants, will moderate the stakeholder dialogue. This facilitator will be responsible for all participants having the same chance to express their views during the dialogue. The final products from the stakeholder dialogue will include a dialogue summary (ie, a distillation of the key themes and insights that emerged during the dialogue) and the formation of a complex csCBR program composed by different components or actions along with a clear description of their respective expected outcomes. It is anticipated that these actions will include individual, community, and societal targets.

The components of the csCBR program will be defined through a nonforced consensus achieved through a process agreed on by all participants at the beginning of the dialogue. Once the dialogue is completed, the csCBR program will be written, and the resulting document will be shared with all participants in order to assure its fidelity in relation to what was agreed during the dialogue. Agreements with powerful allies will be confirmed and clinched by signing letters of commitment. This strategy aims to favor the long-term sustainability of the csCBR program within each targeted community.

2.3.4 Stage Three: Program Implementation

This stage will be completed over 6 months following a “quantitative dominant” approach [42]. The stage involves conducting a pilot test of the CBR program developed during stage two, and the implementation of an improved CBR program in the two

communities of interest. The pilot test will help in identifying barriers and facilitators for the program's implementation, allowing corresponding program adjustments. All partnership members will contribute to the design, execution, and interpretation of the results of this stage.

We will choose 1 strategic site at each community (ie, 1 commissariat in Chankom and 1 health center of the UHC-Nuevo León) to implement the csCBR program designed during stage two of this protocol. An anthropologist will assess the operational aspects of the csCBR program using nonparticipant observations, informal interviews, in-depth interviews, and focus groups. This qualitative information will be used to design two questionnaires to evaluate the presence of facilitators and barriers for the implementation of each of the components of the csCBR program in the community. There will be one questionnaire designed for users of the program and another one for personnel involved in the program's execution. Trained interviewers will apply the questionnaires to all participants of the pilot test through home visits, visits at jobsites, or telephone calls.

Qualitative data will be analyzed and interpreted by the anthropologist and some members of the partnership using content and thematic analysis techniques. This analysis then will be presented to all partners to decide the content of the questionnaires. We will use descriptive statistics to rank the frequency of facilitators and barriers observed during the pilot test. The partnership will use this information to make decisions about relevant changes to the original csCBR program and to elucidate implementation strategies aiming

to improve its successful implementation in the community. Once changes have been made, we will proceed to implement the updated csCBR program in both communities.

2.3.5 Stage Four: Program Evaluation

This stage will last for 18 months following a “pure mixed methods” approach [42] implying the simultaneous execution of quantitative and qualitative methods, each one producing results that will converge in a complete explanation of the researched phenomenon [73]. The objectives of this stage are: (1) to understand which components of the csCBR program are more effective, and what are their mechanisms of action; and (2) to evaluate the impact of the csCBR program on the functioning and quality of life (QoL) of the people living with musculoskeletal diseases in Chankom and the community-UHC-Nuevo León. This stage will allow us to get a complete explanation and understanding about the impact and mechanisms of action of the csCBR program developed.

Quantitative methods will consist of a longitudinal, prospective, and comparative pre/post intervention observational design. Qualitative data will be gathered through ethnographic fieldwork to understand the dynamics and mechanisms of action of each of the csCBR program components. The ethnographic work will also inform quantitative findings about the impact of the program on functioning and QoL.

The quantitative sampling strategies will vary between our two target communities. In Chankom, we will include all the people enrolled in the CBR program together with a sample of people with equivalent ethnic, cultural, and socioeconomic characteristics, who live outside Chankom and have not been exposed to the program

(control population). In the community-UHC-Nuevo León, we will assemble a random probabilistic sample of people with musculoskeletal diseases who are involved in the CBR program, and an equal sample of people with osteoarthritis living in a community with similar socioeconomic and cultural characteristics as the community-UHC-Nuevo León, but that has not been in contact with the program (control population). Quantitative results of stage one will provide us with the information needed to calculate appropriate sample sizes. The ethnographic work will require purposeful sampling of people who participated in activities that were implemented in the CBR program for at least 3 months, in both target communities. This will assure that sufficient experience with the program's processes and activities has been accumulated.

For the quantitative part, we will take baseline measurements, prior to the implementation of the program, and follow-up measurements every 6 months (4 measurements in total until 18 months) in both the target and control populations. Subjects of the control populations will be identified using the COPCORD screening methodology described in stage one of the project. We will measure: (1) 3 different tenses of physical function [53]; (2) QoL; and (3) outcomes related to each component of the csCBR program, whatever these may be.

As already mentioned, we anticipate that the csCBR program will include interventions at different levels, from the personal to the institutional level. In consequence, outcomes will be defined and measured according to the theoretical understanding of each level.

Hypothetical functioning will be measured through the WHO Disability Assessment Schedule 2 (WHODAS 2.0). The WHODAS 2.0 is a generic health-related disability assessment with excellent psychometric properties and was created through an extensive multicultural effort [74]. Experimental functioning will be evaluated using the 6MWT and the FDT. Both tests have shown excellent psychometric properties in musculoskeletal disease populations [57,59]. Enacted functioning will be measured subjectively through the Patient-Specific Functional Scale, which has shown excellent validity and reliability properties when applied in musculoskeletal-related pain populations [75], and semiobjectively using self-report, nonparticipant observations, and videos. QoL will be assessed through the WHO QoL Instrument. This instrument was developed through a multicultural collaboration and has been used with different populations, including older adults, showing excellent reliability and validity properties [76]. All questionnaires will be translated and culturally adapted to the Mayan language.

The ethnographic fieldwork will be conducted by a medical anthropologist and will include participant and nonparticipant observations, in-depth interviews, and focus groups. These qualitative methodologies will be conducted to understand the mechanisms of action of the different components of the program, along with their respective positive and negative aspects. In addition, the fieldwork data will help us in identifying relevant effects of the csCBR program, which can be measured quantitatively.

We will include descriptive and inferential statistic techniques to analyze the quantitative data. Inferential techniques will include multilevel modeling to explore effect modifiers on the outcomes of interest at different levels (eg, municipality, commissariat,

or household levels), including between-group comparisons among target and control populations. We will use the statistical software STATA version 12. Ethnographic data will be analyzed following an analytic-interpretative-reflexive strategy from a medical anthropology perspective. These analyses will be further enriched by discussions with the partnership. All analytic and methodological decisions will be carefully registered in an audit trail. The results of this stage four will support decision-making processes within the partnership, allowing planning and conducting of a new situational analysis, thus completing the cyclical nature of the project (see Figure 1). The cyclical nature of this project implies that the csCBR program's components will be constantly refined, and the outcomes expected by their implementation will be obtained after the execution of several cycles.

2.4 Results

The complexity of this project poses challenges for obtaining funding. Funding agencies in the developing world lack awareness of the need for this type of project and knowledge about the use of mixed methodologies. As such, we used different strategies for communicating the methods of the project to different audiences. In addition, we have applied for funding at diverse agencies, asking separate support for conducting the different parts of the project.

So far, we obtained resources from a GLADERPO study, founded by a Mexican federal agency, and completed stage one of the project at Chankom. We are currently receiving funding from an international agency to complete stage two at this same location. We expect that the project at Chankom will be concluded by December of 2017.

On the other hand, we just started the execution of stage one at the community-UHC-Nuevo León with funding from a Mexican federal agency. We expect to conclude the project at this site by September of 2018

2.5 Discussion

2.5.1 An Alternative Approach

This project represents an alternative approach for developing csCBR programs for low-income communities. This alternative considers both the research and the practice involved for the creation and execution of this type of program, and follows a participatory research approach. The main theoretical assumptions that give foundation to this project are: (1) a partnership between the community and academia is ideal, because they have different, non-competitive, but yet complementary agendas (communities are more interested in their social development and well-being, while academia is more interested in producing and disseminating knowledge); (2) it is possible to construct new knowledge from the fusion of horizons between the community and academia; (3) reaching agreement through communicative practices will result in actions that promote social change; and (4) it is possible to build, understand, and evaluate complex multilevel interventions through the application of quantitative and qualitative methods.

The primary motivation behind this project is a need for interventions directed to reducing musculoskeletal-related disability identified by health professionals and academics. This need was informed by diverse experiences of professionals and researchers interacting with disabled people in low-income communities. Therefore, this project is the result of a genuine real life concern about the lack of social justice present

in the lives of people living with musculoskeletal diseases in low socioeconomic geographic locations.

Historically, the development of CBR programs within developed and developing countries have presented some issues. These issues include the “one size fits all” strategy that is used to build such programs without considering the gap between what is needed and what is available within a community [77]. This is linked to the fact that many CBR programs have tried to import the model of “hospital rehabilitation care” directly to the community [31], resulting in “disempowering” practices [78] that aim to empower individuals without addressing “social inequalities” [79].

Our approach to csCBR program development acknowledges such problems and tries to address them through the application of a mixed method program that is “cognizant, appreciative, and inclusive of local sociopolitical realities, resources, and needs” [42]. This means that each community has to be considered as a unique entity and a general approach to build csCBR programs should incorporate efforts for adaptation to local contexts. In addition, we are proposing a grass-roots approach through the CBPR strategy. Instead of empowering individuals, this approach will aim to redistribute power, equalizing it between members of the community and academia. We believe that this strategy will counteract the inequality produced by the “charity model” [25,26] adopted by the welfare state of Mexico. In other words, instead of using the CBR program as a “band-aid” approach for solving immediate community problems [25], we are trying to promote the creation of democratic actions towards social change.

Projects of this nature will always be at risk of generating power imbalances between the members of the partnership and between the partnership and the powerful allies. This is why we are incorporating a real transdisciplinary collaboration, which involves the community and representatives from the health and social sciences. The work performed by the social scientist(s) within each stage of the project will help to disclose power imbalances, induce reflection about them, and remediate power differentials over time. This will also help to give a sense of ownership of the CBR program to all participants within the partnership and to make the collaboration with powerful allies more efficient.

Another substantial issue, registered during the development of CBR programs, is the lack of proper research and evaluation of the effects that these programs have on the disablement process within communities [41]. It is evident that evaluating these types of complex interventions is conceptually challenging. Using the traditional randomized controlled trial (RCT) approach is not feasible because of its lack of in-depth examination of the social, cultural, and organizational factors that could influence outcomes [80]. In addition, it is almost impossible to use randomization procedures within the real life situations in which CBR programs are implemented [80]. Finally, the information gathered through an RCT does not allow the capturing of the interactions between the individuals and their social and physical environments [80].

Our approach to the problem of evaluating CBR programs is to incorporate mixed methods research, in which both qualitative and quantitative methods are executed either in sequence or in parallel [42]. This implies the execution of quantitative and qualitative

techniques, each one producing results that either will inform one another or will converge on a complete explanation of what is researched [73].

We opted for an ethnographic approach, due to our need for understanding the knowledge, values, and emotions towards musculoskeletal disability of people living in low-income communities within their natural settings. On the other hand, we are taking a quantitative prospective and observational approach, which will allow the use of powerful statistic tools such as multilevel analysis [81]. In addition, we are considering executing some cost-effectiveness analyses to inform the policy arena. However, at this point we would rather wait until the partnerships are well established to make decisions on how to proceed about cost analyses in the project.

2.5.2 Differences Between Communities

There are important differences between the community-UHC-Nuevo León and the community of Chankom. These differences have methodological and organizational implications. Nuevo León's community is 100% urban, while the Mayan community of Chankom is completely rural. This situation influences the type and consequences of existing disabling situations within these communities. The community-UHC-Nuevo León is immersed in one of the most violent Mexican States, while Chankom is situated in the least violent state of Mexico, Yucatan. This could have many repercussions on the feasibility of conducting real ethnographic work in Nuevo León because of the need for the researcher to live there for a period of time. A solution could be to locate and involve local social scientists in that area. In addition, there are important differences between communities in relation to size and spoken language. Chankom is a small indigenous

community with little more than 4000 individuals who mostly speak Mayan; meanwhile, community-UHC-Nuevo León has more than 140,000 Spanish-speaking individuals. This will require constant translation efforts and the use of a significant amount of human resources. Differences between our target communities will allow us to compare between sites, advancing our understanding of the methodology required to conduct this type of project.

Another important difference between the sites involved in this project relates to the status of their local health structures and community organization development. The community-UHC-Nuevo León has a strong local primary health care system embedded in a well-organized community. Whereas, there is no local health care system in Chankom and the community is poorly organized to confront their health problems. Consequently, in the community-UHC-Nuevo León we will include and share power with the community through collaboration with local health providers and community leaders since the first stage (situational analysis) of the project, which is the traditional CBPR approach. However, in Chankom we are taking a modified CBPR approach in the sense that the situational analysis will be conducted as a project driven by people from outside the community. This strategy aims to use the initial research efforts and results to motivate community organization, which will facilitate the establishment of an authentic partnership for the conduction of the next stages of the project. Chankom's situation exemplifies the difficulties encountered by trying to apply an approach developed in more organized communities to a community where organization for solving health issues is nonexistent, as are the majority of poor rural communities in Mexico.

2.5.3 Conclusions

In conclusion, this project is intended to move forward the methodology for the development of csCBR programs in low-income communities. These programs will contribute to community development of these Mexican socially marginalized areas and will cover the need to receive adequate health care for people living with musculoskeletal diseases at these locations.

2.6 Acknowledgments

We thank Mr Diego Yeh Cen, community leader of Chankom for his invaluable input for the development of this protocol. ALS receives funding from CONACYT (Consejo Nacional de Ciencia y Tecnología de México. Becas para estudios en el extranjero) and from the CIHR-Vanier Scholarship in Canada for his PhD studies. Publication's costs were covered by the School of Rehabilitation Science at McMaster University.

2.7 References

1. Osborne A, Blake C, Fullen BM. Prevalence of musculoskeletal disorders among farmers: A systematic review. *Am J Ind Med* 2012;143-158. [doi: 10.1002/ajim.21033]
2. Bernard C, Tourne M. Musculoskeletal disorders in agriculture. *Rev Prat* 2007 Jun 15;57(11 Suppl):45-50. [Medline: 17708093]

3. Woolf AD, Pfleger B. Burden of major musculoskeletal conditions. Bull World Health Organ 2003;81(9):646-656 [FREE Full text] [Medline: 14710506]
4. Kohlmann T. Musculoskeletal pain in the population. Schmerz 2003 Dec;17(6):405-411. [doi: 10.1007/s00482-003-0250-x] [Medline: 14648312]
5. Buckle P. Ergonomics and musculoskeletal disorders: Overview. Occup Med (Lond) 2005 May;55(3):164-167 [FREE Full text] [doi: 10.1093/occmed/kqi081] [Medline: 15857895]
6. Handoll HH, Gillespie WJ, Gillespie LD, Madhok R. Moving towards evidence-based healthcare for musculoskeletal injuries: Featuring the work of the Cochrane bone, joint and muscle trauma group. J R Soc Promot Health 2007 Jul;127(4):168-173. [Medline: 17711062]
7. Ihlebaek C, Brage S, Natvig B, Bruusgaard D. Occurrence of musculoskeletal disorders in Norway. Tidsskr Nor Laegeforen 2010 Dec 2;130(23):2365-2368 [FREE Full text] [doi: 10.4045/tidsskr.09.0802] [Medline: 21139663]
8. Weigl M, Cieza A, Cantista P, Stucki G. Physical disability due to musculoskeletal conditions. Best Pract Res Clin Rheumatol 2007 Feb;21(1):167-190. [doi: 10.1016/j.berh.2006.10.006] [Medline: 17350551]
9. Tüzün Eh. Quality of life in chronic musculoskeletal pain. Best Pract Res Clin Rheumatol 2007 Jun;21(3):567-579. [doi: 10.1016/j.berh.2007.03.001] [Medline: 17603000]

10. Miranda VS, Decarvalho VB, Machado LA, Dias Jm. Prevalence of chronic musculoskeletal disorders in elderly Brazilians: A systematic review of the literature. *BMC Musculoskelet Disord* 2012;13:82 [FREE Full text] [doi:

10.1186/1471-2474-13-82] [Medline: 22642899]

11. Chopra A, Abdel-Nasser A. Epidemiology of rheumatic musculoskeletal disorders in the developing world. *Best Pract Res*

Clin Rheumatol 2008 Aug;22(4):583-604. [doi: 10.1016/j.berh.2008.07.001]

[Medline: 18783739]

12. Gjonça E, Tabassum F, Breeze E. Socioeconomic differences in physical disability at older age. *J Epidemiol Community*

Health 2009 Nov;63(11):928-935. [doi: 10.1136/jech.2008.082776] [Medline:

19608557]

13. Zitko Melo P, Cabieses Valdes B. Socioeconomic determinants of disability in Chile. *Disabil Health J* 2011 Oct;4(4):271-282. [doi:

10.1016/j.dhjo.2011.06.002] [Medline: 22014675]

14. Peláez-Ballestas I, Sanin LH, Moreno-Montoya J, Alvarez-Nemegyei J, Burgos-Vargas R, Garza-Elizondo M, Grupo de Estudio Epidemiológico de Enfermedades Músculo Articulares (GEEMA). Epidemiology of the rheumatic diseases in Mexico. A study of 5 regions based on the COPCORD methodology. *J Rheumatol Suppl* 2011 Jan;86:3-8. [doi:

10.3899/jrheum.100951] [Medline: 21196592]

15. Rodríguez-Amado J, Peláez-Ballestas I, Sanin LH, Esquivel-Valerio JA, Burgos-Vargas R, Pérez-Barbosa L, et al.

Epidemiology of rheumatic diseases. A community-based study in urban and rural populations in the state of Nuevo Leon, Mexico. *J Rheumatol Suppl* 2011 Jan;86:9-14. [doi: 10.3899/jrheum.100952] [Medline: 21196593]

16. Alvarez-Nemegyei J, Peláez-Ballestas I, Sanin LH, Cardiel MH, Ramirez-Angulo A, Goycochea-Robles MV. Prevalence of musculoskeletal pain and rheumatic diseases in the southeastern region of Mexico. A COPCORD-based community survey. *J Rheumatol Suppl* 2011 Jan;86:21-25. [doi: 10.3899/jrheum.100954] [Medline: 21196595]

17. Alvarez-Nemegyei J, Peláez-Ballestas I, Rodríguez-Amado J, Sanin Lh, Garcia-Garcia C, Garza-Elizondo Ma, et al.

Prevalence of rheumatic regional pain syndromes in adults from Mexico: A community survey using COPCORD for screening and syndrome-specific diagnostic criteria. *J Rheumatol Suppl* 2011 Jan;86:15-20. [doi: 10.3899/jrheum.100953] [Medline: 21196594]

18. Engineering COTOO, Medicine Io, Edward N. Jb. In: Pope AM, editor. *Enabling America: Assessing the role of rehabilitation science and engineering*. USA: National Academies Press; 1998.

19. Barnes C. Brogna P, transl Sanchez-Ventura M, editors. *Visiones y Revisiones de la Discapacidad*. 1st ed. Mexico, D. F.

Mexico: Fondo de Cultura Económica; 2009. Un chiste "malo": rehabilitar a las personas con discapacidad en una sociedad que discapacita? URL:

<http://www.independentliving.org/docs6/barnes2003a.html> [accessed 2014-10-04]

[WebCite Cache ID 6T4V7Efpn]

20. Hammell KW. Perspectives on disability & rehabilitation: Contesting assumptions, challenging practice. Edinburgh: Churchill Livingstone; 2006.

Rehabilitation fundamentals URL: <http://www.sciencedirect.com/science/article/pii/B9780443100598500104> [accessed 2014-10-04] [WebCite Cache ID 6T4VIFwS1]

21. United Nations. 2012. Enable URL: <http://www.un.org/disabilities/> [accessed 2014-06-09] [WebCite Cache ID 6QCpKW6di]

22. Gutenbrunner C, Ward AB, Chamberlain MA. Euro Medico-phys. 2006. editors. White book on physical and rehabilitation medicine in Europe URL: http://rehaupatras.com/wp-content/uploads/2013/10/White_book_PRM.pdf [accessed 2014-09-30] [WebCite Cache ID 6Sz4f03aD]

23. Kelley GA, Kelley KS, Hootman JM, Jones DI. Effects of community-deliverable exercise on pain and physical function in adults with arthritis and other rheumatic diseases: A meta-analysis. *Arthritis Care Res (Hoboken)* 2011 Jan;63(1):79-93. [doi: 10.1002/acr.20347] [Medline: 20824798]

24. Chung EY, Packer T, Yau M. When East meets West: Community-based rehabilitation in Chinese communities. *Disabil*

Rehabil 2011;33(8):697-705. [doi: 10.3109/09638288.2010.506240] [Medline: 20690860]

25. Pollard N, Sakellariou D. Operationalizing community participation in community-based rehabilitation: Exploring the factors. *Disabil Rehabil* 2008;30(1):62-70. [doi: 10.1080/09638280701192980] [Medline: 17852288]
26. Turmusani M, Vreede A, Wirz SL. Some ethical issues in community-based rehabilitation initiatives in developing countries. *Disabil Rehabil* 2002 Jul 10;24(10):558-564. [doi: 10.1080/09638280110113449] [Medline: 12171646]
27. Winkelman M. Glossary. In: *Culture and health: Applying medical anthropology*. San Francisco: Jossey-Bass; 2009.
28. Bernal G, Jumper-Thurman P, Edwards RW, Plested BA, Oetting E. Honoring the differences: Using community readiness to create culturally valid community interventions. In: *Handbook of racial & ethnic minority psychology*. Thousand Oaks, Calif: Sage Publications; 2003.
29. Grandisson M, Hébert M, Thibeault R. A systematic review on how to conduct evaluations in community-based rehabilitation. *Disabil Rehabil* 2014;36(4):265-275 [FREE Full text] [doi: 10.3109/09638288.2013.785602] [Medline: 23614357]
30. Wade DT. Community rehabilitation, or rehabilitation in the community? *Disabil Rehabil* 2003 Aug 5;25(15):875-881. [doi: 10.1080/0963828031000122267] [Medline: 12851098]
31. Mitchell R. The research base of community-based rehabilitation. *Disabil Rehabil* 1999;21(10-11):459-468. [Medline:

10579666]

32. Israel B, Eng E, Schulz A, Parker Ea, Satcher D. Introduction to methods in community-based participatory research for health. In: Methods in community-based participatory research for health. San Francisco: Jossey-Bass; 2005.

33. Denzin Nk, Lincoln Ys. Participatory action research: Communicative action and the public sphere. In: The SAGE handbook of qualitative research. Thousand Oaks: Sage Publications; 2005.

34. Flicker S, Savan B, Kolenda B, Mildemberger M. A snapshot of community-based research in Canada: Who? What? Why?

How? Health Educ Res 2008 Feb;23(1):106-1014 [FREE Full text] [doi: 10.1093/her/cym007] [Medline: 17322572]

35. Israel BA, Schulz AJ, Parker EA, Becker Ab. Review of community-based research: Assessing partnership approaches to improve public health. Annu Rev Public Health 1998;19:173-202. [doi: 10.1146/annurev.publhealth.19.1.173] [Medline: 9611617]

36. Viswanathan M, Ammerman A, Eng E. Evidence Report/Technology Assessment No. 99 (Prepared by RTI–University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication 04-E022-2. Rockville, MD: Agency for Healthcare Research and Quality. July. 2004. Community-based participatory research: Assessing the evidence URL: <http://archive.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf> [accessed 2014-09-30] [WebCite Cache ID 6Sz5z2gu1]

37. Ugalde A. Ideological dimensions of community participation in Latin American health programs. *Soc Sci Med* 1985;21(1):41-53. [Medline: 4035407]
38. Menendez E. Participación social en salud: las representaciones y las prácticas. In: *Participacion Social, Para Que?* (Spanish Edition). Buenos Aires: Lugar Editorial; 2005.
39. Gadamer HG, Weinsheimer J, Marshall Ds. The principle of history of effect. In: *Truth and method*. London: Continuum; 2004.
40. Faes MC, Reelick MF, Esselink RA, Rikkert Mg. Developing and evaluating complex healthcare interventions in geriatrics: The use of the medical research council framework exemplified on a complex fall prevention intervention. *J Am Geriatr Soc* 2010 Nov;58(11):2212-2221. [doi: 10.1111/j.1532-5415.2010.03108.x] [Medline: 21039367]
41. Organization Wh. Introductory booklet. In: *Community-based rehabilitation: CBR guidelines*. Switzerland: World Health Organization; 2010.
42. Johnson RB, Onwuegbuzie AJ, Turner LA. Toward a definition of mixed methods research. *Journal of Mixed Methods Research* 2007 Apr 01;1(2):112-133. [doi: 10.1177/1558689806298224]
43. Lwanga SK. Sample size determination in health studies: A practical manual. Switzerland: World Health Organization;

1991.

44. Darmawan J, World Health Organization-International League of Associations for Rheumatology Community Oriented Program for Control of Rheumatic Disease. Recommendations from the community oriented program for control of rheumatic disease for data collection for the measurement and monitoring of health in developing countries. Clin Rheumatol 2007

Jun;26(6):853-857. [doi: 10.1007/s10067-007-0553-x] [Medline: 17364136]

45. Goycochea-Robles MV, Sanin LH, Moreno-Montoya J, Alvarez-Nemegyei J, Burgos-Vargas R, Garza-Elizondo M, Grupo de Estudio Epidemiológico de Enfermedades Músculo Articulares (GEEMA). Validity of the COPCORD core questionnaire as a classification tool for rheumatic diseases. J Rheumatol Suppl 2011 Jan;86:31-35. [doi: 10.3899/jrheum.100955] [Medline: 21196597]

46. Topolski TD, LoGerfo J, Patrick DL, Williams B, Walwick J, Patrick Mb. The rapid assessment of physical activity (RAPA) among older adults. Prev Chronic Dis 2006 Oct;3(4):A118 [FREE Full text] [Medline: 16978493]

47. University of Washington Health Promotion Research Center. Cuál es su nivel de actividad física? Evaluación del nivel de intensidad de actividad física. 2006 URL: http://depts.washington.edu/hprc/docs/rapa_spanish.pdf [accessed 2014-06-09] [WebCite Cache ID 6QCsdAJDC]

48. Dziedzic KS, Thomas E, Hay EM. A systematic search and critical review of measures of disability for use in a population survey of hand osteoarthritis (OA). *Osteoarthritis Cartilage* 2005 Jan;13(1):1-12 [FREE Full text] [doi: 10.1016/j.joca.2004.09.010] [Medline: 15639631]
49. Stanford Patient Education Research Center. Spanish modified HAQ-20 item disability scale URL: <http://patienteducation.stanford.edu/research/haq20esp.html> [accessed 2014-06-09] [WebCite Cache ID 6QCswuDHg]
50. Cardiel MH, Abello-Banfi M, Ruiz-Mercado R, Alarcon-Segovia D. How to measure health status in rheumatoid arthritis in non-English speaking patients: Validation of a Spanish version of the health assessment questionnaire disability index (Spanish HAQ-DI). *Clin Exp Rheumatol* 1993;11(2):117-121. [Medline: 8508553]
51. Alvarez-Hernández E, Peláez-Ballestas I, Vázquez-Mellado J, Terán-Estrada L, Bernard-Medina AG, Espinoza J, REUMAIMPACT. Validation of the health assessment questionnaire disability index in patients with gout. *Arthritis Rheum* 2008 May 15;59(5):665-669 [FREE Full text] [doi: 10.1002/art.23575] [Medline: 18438898]
52. Peláez-Ballestas I, Granados Y, Silvestre A, Alvarez-Nemegyei J, Valls E, Quintana R, et al. Culture-sensitive adaptation and validation of the community-oriented program for the control of rheumatic diseases methodology for rheumatic disease in Latin American indigenous populations. *Rheumatol Int* 2014 Sep;34(9):1299-1309. [doi: 10.1007/s00296-014-2997-z] [Medline: 24682426]

53. Glass TA. Conjugating the "tenses" of function: Discordance among hypothetical, experimental, and enacted function in older adults. *Gerontologist* 1998 Feb;38(1):101-112. [Medline: 9499658]
54. Fried LP, Bandeen-Roche K, Williamson JD, Prasada-Rao P, Chee E, Tepper S, et al. Functional decline in older adults: Expanding methods of ascertainment. *J Gerontol A Biol Sci Med Sci* 1996 Sep;51(5):M206-M214. [Medline: 8808990]
55. Balke B. A simple field test for the assessment of physical fitness. *REP* 63-6. *Rep Civ Aeromed Res Inst US* 1963 Apr:1-8. [Medline: 14131272]
56. Kennedy DM, Stratford PW, Wessel J, Gollish Jd, Penney D. Assessing stability and change of four performance measures: A longitudinal study evaluating outcome following total hip and knee arthroplasty. *BMC Musculoskelet Disord* 2005;6:3 [FREE Full text] [doi: 10.1186/1471-2474-6-3] [Medline: 15679884]
57. Marks R. Obesity profiles with knee osteoarthritis: Correlation with pain, disability, disease progression. *Obesity (Silver Spring)* 2007 Jul;15(7):1867-1874. [doi: 10.1038/oby.2007.221] [Medline: 17636106]
58. Aaron DH, Jansen CW. Development of the functional dexterity test (FDT): Construction, validity, reliability, and normative data. *J Hand Ther* 2003;16(1):12-21. [Medline: 12611441]
59. Schoneveld K, Wittink H, Takken T. Clinimetric evaluation of measurement tools used in hand therapy to assess activity and participation. *J Hand Ther* 2009;22(3):221-235; quiz 236. [doi: 10.1016/j.jht.2008.11.005] [Medline: 19278825]

60. Kleinman A. Orientations 2: Culture, health care systems, and clinical reality. In: Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry. Berkeley: University of California Press; 1980.

61. Kleinman A. The illness narratives: Suffering, healing, and the human condition. New York: Basic Books; 1988.

62. Hammersley M, Atkinson P. Ethnography: Principles in practice. Milton Park, Abingdon, Oxon: Routledge; 2007. URL:

<http://graduateinstitute.ch/files/live/sites/iheid/files/sites/developpement/shared/developpement/cours/DE039/>

2007-%20Atkinson%20-what%20is%20ethnography.pdf [accessed 2014-09-30]
[WebCite Cache ID 6T0ZTnDgB]

63. Morse JM. The significance of saturation. Qualitative health research 1995 May 01;5(2):147-149. [doi:

10.1177/104973239500500201]

64. Hammersley M, Atkinson P. Chapter 8. The process of analysis. In: Ethnography: Principles in practice. Milton Park, Abingdon, Oxon: Routledge; 2007.

65. Israel B, Eng E, Schulz Aj, Parker Ea, Satcher D, Becker AB. Strategies and techniques for effective group process in

CBPR partnerships. In: Methods in community-based participatory research for health. San Francisco: Jossey-Bass; 2005.

66. Becker LA, Oxman AD. Cochrane handbook for systematic reviews of interventions version 5.: The Cochrane Collaboration;

2011. Chapter 22: Overviews of reviews URL: <http://handbook.cochrane.org/> [accessed 2014-10-01] [WebCite Cache ID

6T0a1hqSN]

67. Balshem H, Helfand M, Schünemann HJ, Oxman AD, Kunz R, Brozek J, et al. GRADE guidelines: 3. Rating the quality of evidence. J Clin Epidemiol 2011 Apr;64(4):401-406. [doi: 10.1016/j.jclinepi.2010.07.015] [Medline: 21208779]

68. Lavis JN, Permaand G, Oxman AD, Lewin S, Fretheim A. SUPPORT Tools for evidence-informed health policymaking

(STP) 13: Preparing and using policy briefs to support evidence-informed policymaking. Health Res Policy Syst 2009;7

Suppl 1:S13 [FREE Full text] [doi: 10.1186/1478-4505-7-S1-S13] [Medline: 20018103]

69. McMaster Health Forum. McMaster University. 2014 URL: <http://www.mcmasterhealthforum.org/> [accessed 2014-06-09] [WebCite Cache ID 6QCnOTGBW]

70. Chermack JT. Scenario planning in organizations: How to create, use, and assess scenarios (organizational performance).

USA: Berrett-Koehler Publishers; 2011.

71. Habermas J. The theory of communicative action. Cambridge, England: Polity Press; 1987.

72. Lavis JN, Boyko JA, Oxman AD, Lewin S, Fretheim A. SUPPORT tools for evidence-informed health policymaking (STP)

14: Organising and using policy dialogues to support evidence-informed policymaking. *Health Res Policy Syst* 2009;7

Suppl 1:S14 [FREE Full text] [doi: 10.1186/1478-4505-7-S1-S14] [Medline: 20018104]

73. Peláez-Ballestas I, Burgos-Vargas R. The qualitative approach in health: An alternative to clinical research in rheumatic diseases. *Reumatol Clin* 2005 Oct;1(3):166-174 [FREE Full text] [doi: 10.1016/S1699-258X(05)72737-6] [Medline: 21794257]

74. World Health Organization. WHODAS 2.0. Disability Assessment 2.0 URL: <http://www.who.int/classifications/icf/whodasii/en/> [accessed 2014-06-09] [WebCite Cache ID 6QCtuzydQ]

75. Stratford P, Gill C, Westaway M, Binkley J. *Physiother Can*. Assessing disability and change on individual patients: A report of a patient specific measure. *Physiother Can*; 1995. Assessing disability and change on individual patients: A report of a patient specific measure URL: <http://journals1.scholarsportal.info/browse/03000508/v47i0004> [accessed 2014-09-29] [WebCite Cache ID 6T0dpQRZD]

76. Hwang HF, Liang WM, Chiu YN, Lin MR. Suitability of the WHOQOL-BREF for community-dwelling older people in

Taiwan. Age Ageing 2003 Nov;32(6):593-600 [FREE Full text] [Medline: 14599999]

77. Lagerkvist B. Community-based rehabilitation--outcome for the disabled in the Philippines and Zimbabwe. Disabil Rehabil

1992;14(1):44-50. [Medline: 1586761]

78. Kassah AK. Commentary on: Community-based service delivery in rehabilitation: The promise and the paradox. Disabil

Rehabil 2001 Jan 15;23(1):18-21. [Medline: 11213318]

79. Kendall E, Muenchberger H, Catalano T. The move towards community-based rehabilitation in industrialised countries: Are we equipped for the challenge?

Disabil Rehabil 2009;31(26):2164-2173. [doi: 10.3109/09638280902939734] [Medline: 19903126]

80. Herens M, Wagemakers A, Vaandrager L. Evaluation design for community-based physical activity programs for socially disadvantaged groups:

Communities on the move. JMIR Res Protoc 2013. [doi: 10.2196/resprot.2327]

81. Kozlowski AJ, Heinemann AW. Using individual growth curve models to predict recovery and activities of daily living after spinal cord injury: An SCIR rehab

project study. Arch Phys Med Rehabil 2013 Apr;94(4 Suppl):S154-164.e1. [doi:

10.1016/j.apmr.2012.11.050] [Medline: 23527771]

CHAPTER THREE

THE IMPACT OF ARTHRITIS ON THE PHYSICAL FUNCTION OF A RURAL MAYA-YUCATECO COMMUNITY AND FACTORS ASSOCIATED WITH ITS PREVALENCE: A CROSS SECTIONAL, COMMUNITY-BASED STUDY

PREFACE TO CHAPTER THREE

Authors: Adalberto Loyola-Sánchez, Julie Richardson, Ingris Peláez-Ballestas, José Alvarez-Nemegyei, John N. Lavis, Michael G. Wilson, Seanne Wilkins

Publication status: This manuscript is under review in *Clinical Rheumatology*.

Summary: This manuscript reports quantitative epidemiological findings from the execution of stage one “situation analysis” of the research program in the rural Mayan municipality of Chankom, Yucatán México. The manuscript describes and analyses findings on the prevalence of arthritis in Chankom, the factors associated with this prevalence and the disability associated with the presence of this chronic health condition in this community.

3.1 Abstract

Objectives

To evaluate the impact of arthritis on the physical function of people living in a Mayan rural community and to assess the association of known modifiable risk factors with the prevalence of arthritis and its main types (osteoarthritis and rheumatoid arthritis).

Methods

Using a cross-sectional, community-based census design, data collected from the adult population (≥ 18 years) of the Municipality of Chankom, Yucatán, México were analysed ($n=1523$). Participants' physical function was assessed using a culturized version of the Health Assessment Questionnaire Disability Index. Social, physical and behavioral factors linked to arthritis, osteoarthritis and rheumatoid arthritis were assessed through the COPCORD questionnaire. A physiatrist and a rheumatologist confirmed all arthritis cases using the American College of Rheumatology criteria.

Results

Of those reporting musculoskeletal symptoms ($n=823$), arthritis was confirmed in 169 cases (22%, 95%CI: 19% -25%), of which 144 had osteoarthritis, 17 had rheumatoid arthritis and eight had non-specific arthritis. Arthritis was associated with a higher prevalence of disability after controlling for age, gender and number of comorbidities (Odds ratio: 4.0, 95%CI: 3.0-6.0). Higher level of wealth was associated with lower arthritis prevalence (Odds ratio: 0.9, 95%CI: 0.8-0.9). Higher body mass index was associated with higher hip and/or knee osteoarthritis prevalence (Odds ratio: 1.1, 95%CI: 1.03-1.1).

Conclusions

Arthritis is common in Chankom and is highly associated with disability. It is necessary to develop community-based interventions to prevent and decrease the impact of this chronic condition, addressing social factors and reducing body mass index in the adult population of this rural indigenous community.

Keywords

Arthritis; Disability Evaluation; Mexico, Indians North American; Observational Study

3.2 Introduction

Disability is a public health priority [1]. The level of disability is inversely associated with socioeconomic position [2]. Musculoskeletal diseases (MSK) are the most common cause of disability worldwide [3] and their disabling effects are more severe in developing countries [4].

Arthritis is a common term used to group different chronic MSK diseases of the joints, mainly osteoarthritis (OA) and rheumatoid arthritis (RA) [5, 6]. Arthritis is considered a leading cause of disability [5]. One out of nine persons with arthritis experience disease-related limitations in fulfilling their life roles [7].

The level of disability associated with arthritis, is higher for people living in low socioeconomic conditions [7, 8]. For example, the functional status of people living with knee and/or hip OA in middle and low-income countries is lower than those living in high-income countries [9]. Consequently, the negative effects of arthritis are likely to be associated with social determinants that are associated with increased disability within low-socioeconomic areas in developing countries.

Arthritis is one of the leading musculoskeletal diseases in the Mexican Southern state of Yucatán [10]. This state includes several indigenous rural communities from the Maya-Yucateco culture. Mexican indigenous communities experience low socioeconomic living conditions and limited access to appropriate health care services [11]. As a result, these communities are more vulnerable to the disabling effects of arthritis, underscoring the need to develop rehabilitation interventions aimed at preventing and decreasing these effects.

Developing rehabilitation interventions for arthritis requires an understanding of its impact on physical function and identifying modifiable factors associated with the manifestation of this condition. This will help in designing actions to decrease and prevent the prevalence and disabling effects of arthritis at the community level. This study was part of a project designed to develop a community-based rehabilitation program to ameliorate the disabling effects provoked by MSK diseases in a rural, lower-socioeconomic and underserved Maya-Yucateco community in Yucatán [12].

The objectives of this study were:

1. To evaluate the impact of arthritis on the physical function of people living in the Mayan municipality of Chankom, Yucatán, México.
2. To evaluate the association between modifiable factors and the prevalence of overall arthritis and its main types (OA and RA) in this community.

3.3 Materials and Methods

3.3.1 Study Design

This was an observational, cross-sectional, community-based study undertaken in three stages: a) a survey, b) a home-based assessment and c) a confirmatory assessment (see Figure 1). These stages were based on the Community Oriented Program for the Control of Rheumatic Diseases (COPCORD) phase one methodology, as described elsewhere [13]. The survey stage consisted of a census conducted in the adult population (≥ 18 years) of the municipality of Chankom, Yucatán. Trained local personnel applied a cross-culturally validated questionnaire [14] designed to detect MSK symptoms and quantify relevant clinical and socioeconomic factors (Appendix A). Two family

physicians, trained in rheumatologic evaluation and assisted by local translators, assessed all people who reported MSK symptoms in their homes (home-based assessment stage) within the same week in which the surveys had been applied. During the confirmatory assessment stage, a physiatrist and a rheumatologist evaluated all possible OA or RA cases, respectively, within one month of the initial contact and with the help of local Mayan translators.

3.3.2 Setting

This study was conducted in the rural municipality of Chankom, which is located at the Southeast of Yucatán, Mexico and comprised of 11 small rural villages inhabited entirely by people of the Maya-Yucateco ethnicity. The municipality of Chankom has a population of 4,464 habitants of which 80% are considered to be living in poverty [15]. All stages were conducted between June and December 2012. The confirmatory assessments were performed at various locations, including people's homes, villages' public facilities and a municipal evaluation center. People identified as having possible OA received a radiographic evaluation at the nearest public hospital.

This study was approved by the Hamilton Health Sciences /McMaster University Research Ethics Board (12-544), the Ethics Committee of the Faculty of Medicine, Universidad Anáhuac-Mayab, and the Ethics Committee of the “Hospital General de México, Dr. Eduardo Liceaga” (DI/11/4044B/3/123) (Appendix B). All participants signed an informed consent before participating in the study.

3.3.3 Participants

Osteoarthritis diagnoses were confirmed by the physiatrist following the American College of Rheumatology (ACR) clinical criteria for hand OA [16] and radiological and clinical criteria for hip and knee OA [17, 18]. A rheumatologist certified by the Mexican Board of Rheumatology and with ≥ 15 years of clinical practice evaluated all participants detected with inflammatory arthritis and confirmed all cases of RA. Cases with clear signs of arthritis but which did not fulfill OA or RA criteria were classified as “unspecific arthritis”.

3.3.4 Measurements

3.3.4.1 Confounders

Factors known to be associated with physical function such as age, gender and number of co-morbidities were evaluated at the survey stage through self-report. These factors were considered to be confounders for determining the association between arthritis and disability after no interaction effects were found between these and the association of interest [19]. The number of co-morbidities was determined by adding the number of reported diseases by participant from a list including: diabetes, hypertension, cardiovascular disease, dyslipidemia, gastritis, anxiety and depression, resulting in a continuous variable ranging from 0 to 7.

3.3.4.2 Physical function

Physical function was evaluated through the Health Assessment Questionnaire Disability Index (HAQ-DI) applied during the survey stage. The HAQ-DI has shown good psychometric properties when used in OA [20] and RA [21] populations. This instrument was cross-culturally translated, adapted and validated for use in the Mayan-

Yucateco population [14] and demonstrated good test-retest reliability (ICC= 0.69) when applied to a sample of 30 individuals living with MSK diseases in Chankom [22]. The HAQ-DI was scored following standard procedures [23] and then transformed to a dichotomous variable to indicate the presence or absence of disability using a cut-off point score of 0.25, as reported in a population-based study [24].

3.3.4.3 Modifiable risk factors

Arthritis prevalence has been associated with several modifiable social, physical and behavioral factors [25, 26]. On the one hand, OA prevalence has been associated with gender-related factors that either provoke joint vulnerability, such as low socioeconomic status, or increase joint loading, such as body mass index (BMI) and the execution of repetitive movements that augments the mechanical stress within the joints [27]. On the other hand, RA prevalence has been associated with low level of wealth, high BMI and smoking [26, 28].

The participants' level of wealth, or property that can be sold and converted to cash for the benefit of the owner, was assessed during the survey stage. Property owned by participants was registered, selected and classified by local staff according to the type of properties that better differentiate between people's level of wealth in the community. Property related to entertainment, electro-domestic appliances, communication and transportation were organized into a hierarchical format and combined to derive a "level of wealth" variable ranging from 0 "no properties owned" to 14 "ownership of the highest-valued properties".

Body mass index was registered as the Quetelet's index (weight/ height²). Weight and height were measured during the survey stage following Lohman's technique [29]. Weight was measured with a portable digital scale (Tanita Model 804), and height was measured with a portable ultrasonic digital stadiometer (ADE, Ultraschall/Messstab/MZ10020, Germany).

Finally, the following behavioral variables were assessed during the survey: self-reported smoking status, as a yes/no question and the regular performance of repetitive movements, by asking participants to define their lifetime's principal occupation and whether this occupation involved frequent repetitive movements such as: jolting hands, lifting or pushing ≥ 20 kg, climbing, standing, kneeling for longer than 30 minutes and constant shifting from sit to stand positions. Two variables were then created to reflect the cumulative mechanical stress within the joints, one for static stress formed by standing and kneeling longer than 30 minutes (0 to 2) and one for dynamic stress formed by jolting hands, lifting and pushing ≥ 20 kg, climbing stairs or slopes and constant shifting from sit to stand positions (0-5).

3.3.5 Statistical Analyses

Descriptive statistics were generated through the calculation of means and frequencies. T-tests adjusting for unequal variances (Satterthwaite's approximation) and χ^2 tests were used to compare means and frequencies between those participants assessed for diagnostic confirmation and between participants with and without arthritis. A logistic regression model was used to evaluate the relationship between the presence of

overall arthritis (independent variable) and the presence of disability (dependent variable), adjusting for previously described confounders.

Modifiable risk factor analyses were conducted separately for overall arthritis, OA and RA using logistic regression models considering the presence of disease as the dependent variable and all the factors evaluated as the independent variables. The OA analysis was adjusted for age and gender. Gender-based sub-group analyses were conducted for hand and lower extremity (hip and/or knee) OA, adjusting by age. Penalized maximum likelihood estimation (Firth's method) was used to estimate logistic regression parameters and profile penalized likelihood confidence intervals in the RA, hand and lower extremity OA analyses, accounting for the observed phenomenon of complete separation in the data [30].

All regression models were constructed following a complete-case analysis strategy. Assumptions and the models' goodness of fit were confirmed using likelihood ratio tests, hat^2 tests, Hosmer & Lemenshow tests and the area under the curve. Hypothesis testing was deemed statistically significant at $\alpha=0.05$. Two statistical analysis packages (STATA 12.1. and R 3.1.1) were used.

3.4 Results

Fifteen hundred and twenty three adults answered the questionnaire during the survey stage and 823 (54%) reported MSK symptoms. Forty-four participants (5%) who reported MSK symptoms could not be seen by a specialist during the confirmatory assessment stage because either they refused or were not found at their homes after 5 visits and were excluded from the analysis. Proportionally, more men (70% vs. 39%,

$\chi^2 [1]=17.78$, $p<0.0001$) and more smokers (21% vs. 9%, $\chi^2 [1]= 5.95$, $p=0.01$) were not assessed for diagnostic confirmation. Arthritis was confirmed in 169 cases (22%) (see Figure 1).

Table 1 shows the general characteristics of the population. The mean age of the whole population was 45 years, while for the group of OA and RA the means were 63 years and 55 years, respectively. In total, 61% of the population was female, whereas 74% of the hand OA and 76% of the RA groups were women. The OA population reported twice the average number of comorbidities than the rest of the population. Mean BMI was higher in the arthritis group than in the rest of the population. The smoking prevalence in the whole population was 9%, while 0% of the RA population reported this behavior. On average, the level of wealth was significantly higher in the non-arthritis group (6 vs 5, $T=3$, $n=1478$, $p= 0.002$).

Disability was present in 165 participants without arthritis (13%), 23 participants with hand OA (63%), 60 participants with hip or knee OA (48%) and 10 participants with RA (59%). Having arthritis was significantly associated with having disability after adjusting for gender, age and number of co-morbidities [Prevalence Odds ratio (POR)- 3.8 (95%CI: 2.6-5.6); Wald test: 5.1, $p<0.0001$].

Table 2 shows the frequency of participants' performance of regular repetitive movements during their main occupations. All men with hand OA reported doing repetitive jolting-hand and sit to stand movements. Performance of repetitive activities such as lifting, pushing, climbing, standing, kneeling, walking and sitting to standing were reported less often in the RA group than in the non-arthritis group.

Prevalence odds ratios expressing the associations between modifiable risk factors and the presence of arthritis, OA and RA are presented in Table 3. Body mass index was directly associated with higher arthritis prevalence, while levels of wealth and static cumulative mechanical joint stress were associated with lower arthritis prevalence. Only BMI was significantly associated with a higher prevalence of OA, and only static cumulative mechanical joint stress was significantly associated with a lower prevalence of RA.

Adjusted by age prevalence odds ratios estimated during the OA sub-group analyses are presented in Table 4. Body mass index was significantly associated with a higher prevalence of lower extremity OA in women and men. Repetitive lifting of ≥ 20 kg was significantly associated with a lower prevalence of hand OA in men. Finally, repetitive standing for longer than 30 minutes was significantly associated with a lower prevalence of lower extremity OA in men.

3.5 Discussion

3.5.1 Principal Findings

Overall, the presence of arthritis is common in the municipality of Chankom, which aligns with what has been reported in other Mexican [31] and international reports [6]. The disability prevalence ratio between the arthritis and non-arthritis populations is 2.8, as calculated by Zhang's method [32]. This means that people living with arthritis in this community are 2.8 times as likely to have disability as the people living without arthritis after controlling for age, gender and number of comorbidities. Consequently, this

group of chronic conditions have important disabling effects in this community, as has been observed in other populations [7].

The results from the evaluation of associations between modifiable risk factors and the overall prevalence of arthritis and its main types show that this group of chronic diseases are linked with factors that either increase the vulnerability or increase the loading of the joint, as has been previously suggested [27]. On the one hand, social factors, such as low level of wealth, may have increased joints' vulnerability to be affected by degenerative and/or inflammatory processes. On the other hand, physical and behavioral factors, such as BMI or doing repetitive movements, may have increased the loading within the joints facilitating the manifestation of joint degeneration.

Being wealthier was associated with less probability of presenting overall arthritis in this community, similar to what has been reported in a population-based study conducted in Brisbane, Australia [25]. Chankom is a Mexican indigenous community, where the people face health inequities [11]. These inequities impede the delivery of timely and appropriate care for MSK problems for all community members, increasing vulnerability to develop arthritis. Having less wealth in Chankom could also be associated with inadequate nutritional intake and/or decreased access to appropriate healthcare for solving initial MSK problems, fostering the progression of joint degeneration and/or inflammation.

Factors that increase joint loading, such as BMI were significantly associated with a higher prevalence of overall arthritis in this community. This association only held for the prevalence of lower extremity OA, which has been consistently reported in other

epidemiologic studies [33]. A person with a BMI of 29 was 1.5 times more likely to present with lower extremity OA than a person with a BMI of 24.

The lack of a significant association observed between BMI and hand OA prevalence does not support the suggested systemic effects of obesity in OA [34]. Consequently, it is possible that in our analysis BMI acted only as a joint loading factor and not as a systemic factor that increased joint vulnerability through serologic inflammatory markers, as has been proposed in the literature [35].

Results related to cumulative mechanical joint stress, the other joint-load increasing factor addressed in this study, were inconsistent and conflict with what has been reported in the literature. On the one hand, static cumulative joint mechanical stress was associated with a lower prevalence of overall arthritis. This association only held for the prevalence of RA, and, except for jolting hands, persons in the RA group reported doing regular repetitive climbing, standing, kneeling and sitting to standing less often than people without RA (see Table 3). A recent cross-sectional study conducted in Colombia found that people with RA usually performed low levels of physical impact work [36]. This implies that our findings could be related to a lower engagement in physically demanding activities by the RA group, which can be considered a case of “inversed causality” [37].

On the other hand, the OA subgroup analyses showed that for men, repetitive jolting tasks with their hands and sit- to- stand movements approached significance and were associated with a higher prevalence of hand OA. In fact, all men detected with hand OA reported doing these repetitive activities, supporting the notion that dynamic

cumulative mechanical joint stresses were linked to the manifestation of this condition. However, repetitive lifting, which is also considered a dynamic joint stress factor, was significantly associated with a lower prevalence of hand OA. In the same way, repetitive standing for longer than 30 minutes was significantly associated with a lower prevalence of low extremity OA in men; while this factor has been linked with a higher prevalence of hip and knee OA in other epidemiologic studies [38].

The inconsistent findings observed in the analyses about joint mechanical stress associated with cumulative repetitive movements could be related to the high frequency with which participants reported doing repetitive movements during their main occupation. More than 60% of the population reported doing ≥ 2 static and dynamic cumulative repetitive movements (data not shown). This indicates some homogeneity among the occupations performed by the members of this community; usually, men do the same type of agricultural work while women do similar housework activities. This homogeneity makes it difficult to explore differences between-groups. Consequently, we cannot conclude anything solid about the role that joint mechanical stress has on the manifestation of arthritis in this population.

Interestingly, smoking behavior was not significantly associated with RA prevalence in this study, which contradicts several reports in the literature [26, 28]. It has been suggested that only heavy smoking and therefore the dosage, and not just the presence of smoking, is associated with the manifestation of the “seropositive” type of RA [39]. We do not have serologic markers to assess whether all the RA cases detected in this study were seronegative. However, we are sure that none of the participants with

confirmed RA in Chankom, where smoking is uncommon, reported this behavior.

Considering that the prevalence of RA observed in this community (1%) aligns with the prevalence reported worldwide [28], we could argue against the existence of a real association between smoking and the manifestation of RA.

3.5.2 Strengths and Limitations

The main strengths of this study are related to the methods used for screening and defining arthritis cases and the use of locally grounded measurement instruments. The census strategy, involving the majority of adults living in Chankom, allowed us to conduct a comprehensive analysis of the arthritis problems in this community. The COPCORD methodology we followed has been validated and used with success in detecting MSK diseases at the community level in Mexico [40], increasing our confidence in the validity of the prevalence estimates observed. Finally, the use of a cross-culturally validated instrument, which involved the participation of local people in its development, increased confidence about the local relevance of observed results. For example, people who lived in Chankom decided the properties on which to differentiate levels of wealth among community members, increasing the cultural relevance of the measurements “level of wealth”.

The main limitations of this work are related to the cross-sectional design, the measurement of disability and the measurement of regular repetitive movements’ performed in the main occupation. The cross-sectional nature of this study precludes us from establishing causal associations between known risk factors and arthritis incidence. For instance, the accuracy of the counterintuitive associations observed between

mechanical joint stress and a lower prevalence of hand and low extremity OA in men can only be established through longitudinal data. The cross-sectional design also prevents the further assessment of “non-specific arthritis” cases, limiting the possibility of observing how these cases progress over time and with which type of arthritis (inflammatory or degenerative) they will ultimately be diagnosed. Responding to this design-related limitation, we initiated a longitudinal surveillance of this population and results will be available in the near future.

The measurement of disability is complex and it has been suggested that considering only one dimension of physical function, such as what people think they can do from a pre-defined list of activities contained in a questionnaire is not enough to understand the whole disabling effects of an illness [41]. Therefore, we may not have detected the entire disabling effects of arthritis for people living in Chankom. This is a common limitation in epidemiologic studies of arthritis-related disability. Finally, we did not incorporate a measurement of the actual time (hours, days, months or years) spent on doing the repetitive movements explored in the main occupation. The lack of this temporal component limits our analysis and interpretations about the role that cumulative joint mechanical stress plays in the presentation of arthritis in this community.

3.5.3 Implications for practice and policy

Overall, arthritis produces high rates of disability in this indigenous population. From a “social determinants of health” perspective, it seems that the conditions of social disadvantage faced by this rural community result in health inequities that condition the manifestation of arthritis. This social disparity has also been observed in a large Mexican

multilevel epidemiological study where the prevalence of OA was clearly associated with higher social underdevelopment [42].

Consequently, there is a need to develop a culturally appropriate community-based rehabilitation intervention directed to prevent the manifestation of arthritis and decrease the associated disabling effects. Appropriate local and regional health policy analyses and strategies need to be undertaken to increase community access to proper health care for people living with chronic MSK diseases in Chankom and other indigenous rural communities. These strategies should also target a reduction of BMI of the adult population as a way to decrease the prevalence of arthritis in these communities.

3.5.4 Implications for research

The disabling effects of arthritis need to be further assessed by incorporating measurements of other dimensions of physical function such as the execution of standardized tasks or the limitations conditioned by the disease on the performance of real life activities. In addition, it is important to evaluate the presence of modifiable factors linked with the progression of arthritis in this community and how these relate with its disabling effects. The association between social factors, such as the level of wealth, and the prevalence of arthritis in Mayan rural communities, should be further explored using quantitative and qualitative methods. Finally, there is a need for longitudinal studies that explore possible causal associations between the significant factors detected in this study and the prevalence of the various arthritis types, especially for those unexpected and counterintuitive associations (i.e. cumulative mechanical joint stress analyses).

3.5.5 Conclusions

Overall, arthritis is a common chronic condition in Chankom and an important source of disability. Higher level of wealth was associated with lower arthritis prevalence, while higher body mass index was associated with higher OA prevalence. Action is required to decrease the prevalence and disabling effects of these chronic diseases in this community.

3.6 Acknowledgements

We like to thank Mr. Diego Yeh Cen and Mr. Carlos Castillo Kuyoc for their valuable contributions to the analysis and data acquisition in this study. We also thank research assistants Maria Lizbeth Escudero and Beatriz Quintero, for their great work capturing data and maintaining the database. This project was funded by the Consejo Nacional de Ciencia y Tecnología [CONACYT] (grant #162154). ALS received funding from CONACYT's doctoral scholarship for studying abroad (scholarship #209621) and from the Doctoral Vanier Canada Scholarships (# 268078).

3.7 References

1. Lollar DJ, Crews JE (2003) Redefining the role of public health in disability. *Annu Rev Public Health* 24:195-208
2. Gjonca E, Tabassum F, Breeze E (2009) Socioeconomic differences in physical disability at older age. *J Epidemiol Community Health* 63:928-935
3. Woolf AD, Pfleger B (2003) Burden of Major Musculoskeletal Conditions. *Bulletin of the World Health Organization* 81:646-656

4. Chopra A, Abdel-Nasser A (2008) Epidemiology of rheumatic musculoskeletal disorders in the developing world. *Baillieres Best Pract Res Clin Rheumatol* 22:583-604
5. Reginster JY (2002) The prevalence and burden of arthritis. *Rheumatology (Oxford, England)* 41:3-6
6. Helmick CG, Felson DT, Lawrence RC et al (2008) Estimates of the prevalence of arthritis and other rheumatic conditions in the United States. Part I. *Arthritis Rheum* 58:15-25
7. Theis KA, Murphy L, Hootman JM, Wilkie R (2013) Social participation restriction among us adults with arthritis: A population-based study using the international classification of functioning, disability and health. *Arthritis Care Res (Hoboken)* 65:1059-1069
8. Baldassari AR, Cleveland RJ, Callahan LF (2013) Independent influences of current and childhood socioeconomic status on health outcomes in a North Carolina family practice sample of arthritis patients. *Arthritis Care Res (Hoboken)* 65:1334-1342
9. Cross M, Smtih EU, Hoy D et al (2014) Severity of osteoarthritis in global populations. *Osteoarthritis Cartilage* 22:S208
10. Alvarez-Nemegyei J, Pelaez-Ballestas I, Sanin LH, Cardiel MH, Ramirez-Angulo A, Goycochea-Robles MV (2011) Prevalence of musculoskeletal pain and rheumatic diseases in the southeastern region of Mexico. A COPCORD-based community survey. *J Rheumatol Suppl* 86:21-25

11. Leyva-Flores R, Infante-Xibille C, Gutierrez JP, Quintino-Perez F (2013) Persisting health and health access inequalities in Mexican indigenous population, 2006-2012. *Salud Publica Mex* 55:S123-8
12. Loyola Sanchez A, Richardson J, Pelaez-Ballestas I et al (2014) Developing Community-Based Rehabilitation Programs for Musculoskeletal Diseases in low-income areas of Mexico: The Community-Based Rehabilitation for Low-Income Communities Living With Rheumatic Diseases (CONCORD) Protocol. *JMIR Res Protoc* 3:e57
13. Darmawan J (2007) Recommendations from the Community Oriented Program for Control of Rheumatic Disease for data collection for the measurement and monitoring of health in developing countries. *Clin Rheumatol* 26:853-857
14. Pelaez-Ballestas I, Granados Y, Silvestre A et al (2014) Culture-sensitive adaptation and validation of the Community-Oriented Program for the Control of Rheumatic Diseases methodology for rheumatic disease in Latin American indigenous populations. *Rheumatol Int* 34:1299-309
15. Consejo Nacional de Evaluación de la Política de Desarrollo Social (2014) Informe Anual sobre la Situación de Pobreza y Rezago Social. Chankom, Yucatán. [Annual inform on the Poverty and Social Lag Situation. Chankom, Yucatán]. SEDESOL. http://www.sedesol.gob.mx/work/models/SEDESOL/Informes_pobreza/2014/Municipios/Yucatan/Yucatan_017.pdf. Accessed September 2014
16. Altman R, Alarcon G, Appelrouth D et al (1990) The American College of Rheumatology criteria for the classification and reporting of osteoarthritis of the hand. *Arthritis Rheum* 33:1601-1610

17. Altman R, Alarcon G, Appelrouth D et al (1991) The American College of Rheumatology criteria for the classification and reporting of osteoarthritis of the hip. *Arthritis Rheum* 34:505-514
18. Altman R, Asch E, Bloch D et al (1986) Development of criteria for the classification and reporting of osteoarthritis. Classification of osteoarthritis of the knee. Diagnostic and Therapeutic Criteria Committee of the American Rheumatism Association. *Arthritis Rheum* 29:1039-1049
19. Kleinbaum DG, Kupper LL, Nizam A, Muller KE (2008) 11. Confounding and interaction in regression. In: Kleinbaum DG, Kupper LL, Nizam A, Muller KE (eds) *Applied Regression Analysis and Other Multivariable Methods*. 4th edn. Brooks/Cole CENGAGE Learning, USA, pp 189-216
20. Dziedzic KS, Thomas E, Hay EM (2005) A systematic search and critical review of measures of disability for use in a population survey of hand osteoarthritis (OA). *Osteoarthritis Cartilage* 13:1-12
21. Felson DT, Anderson JJ, Boers M et al (1993) The American College of Rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. The Committee on Outcome Measures in Rheumatoid Arthritis Clinical Trials. *Arthritis Rheum* 36:729-740
22. Alvarez-Nemegyei J, Peláez-Ballestas I, Loyola-Sánchez A (2013) Traducción y validación transcultural del instrumento Health Assessment Questionnaire al idioma Maya-Yucateco. [Translation and transcultural validation of the Health Assessment Questionnaire instrument to the Maya-Yucateco language]. *Reumatol Clin* 9:C1-C017

23. Bruce B, Fries JF (2003) The Stanford Health Assessment Questionnaire: a review of its history, issues, progress, and documentation. *J Rheumatol* 30:167-178
24. Krishnan E, Sokka T, Hakkinen A, Hubert H, Hannonen P (2004) Normative values for the Health Assessment Questionnaire disability index: benchmarking disability in the general population. *Arthritis Rheum* 50:953-960
25. Brennan SL, Turrell G (2012) Neighbourhood disadvantage, individual-level socioeconomic position, and self-reported chronic arthritis: a cross-sectional multilevel study. *Arthritis Care Res (Hoboken)* 64:721-728
26. Canizares M, Power JD, Perruccio AV, Badley EM (2008) Association of regional racial/cultural context and socioeconomic status with arthritis in the population: A multilevel analysis. *Arthritis Care Res (Hoboken)* 59:399-407
27. Felson DT (2004) Risk factors for osteoarthritis: understanding joint vulnerability. *Clin Orthop* 427:S16-21
28. Alamanos Y, Drosos AA (2005) Epidemiology of adult rheumatoid arthritis. *Autoimmun Rev* 4:130-136
29. Lohman TG, Roche AF, Martorell R (1988) Anthropometric standardization reference manual. Human Kinetics, IL
30. Heinze G, Schemper M (2002) A solution to the problem of separation in logistic regression. *Stat Med* 21:2409-2419
31. Pelaez-Ballestas I, Sanin LH, Moreno-Montoya J, Alvarez-Nemegyei J, Burgos-Vargas R, Garza-Elizondo M, Rodriguez-Amado J, Goycochea-Robles MV, Madariaga M, Zamudio J, Santana N, Cardiel MH. Grupo de Estudio Epidemiológico de

Enfermedades Musculo Articulares (GEEMA) (2011) Epidemiology of the rheumatic diseases in Mexico. A study of 5 regions based on the COPCORD methodology. *J Rheumatol Suppl* 86:3-8

32. Zhang J, Yu KF (1998) What's the relative risk? A method of correcting the odds ratio in cohort studies of common outcomes. *JAMA* 280:1690-1691

33. Goekoop RJ, Kloppenburg M, Kroon HM et al (2011) Determinants of absence of osteoarthritis in old age. *Scand J Rheumatol* 40:68-73

34. Guilak F (2011) Biomechanical factors in osteoarthritis. *Baillieres Best Pract Res Clin Rheumatol* 25:815-823

35. Gkretsi V, Simopoulou T, Tsezou A (2011) Lipid metabolism and osteoarthritis: lessons from atherosclerosis. *Prog Lipid Res* 50:133-140

36. Beltran D, Saavedra-Martinez G, Villarreal L, Palomino A, Bello-Gualtero J, Santos-Moreno P (2014) Occupational characterization in a cohort of rheumatoid arthritis patients-correlation with disease activity and functional status. *Ann Rheum Dis* 73

37. Hernández-Prado B, Velazco-Mondragón H (2007) VIII. Encuestas transversales. In: Hernández-Avila M (ed) *Epidemiología: Diseño y análisis de estudios*. 1st edn. Editorial Médica Panamericana, Mexico, pp 191-192

38. Sandmark H, Hogstedt C, Vingard E (2000) Primary osteoarthrosis of the knee in men and women as a result of lifelong physical load from work. *Scand J Work Environ Health* 26:20-25

39. Hutchinson D, Moots R (2001) Cigarette smoking and severity of rheumatoid arthritis. *Rheumatology (Oxford)* 40:1426-1427

40. Cardiel MH, Burgos-Vargas R (2011) Towards elucidation of the epidemiology of the rheumatic diseases in Mexico. COPCORD studies in the community. *J Rheumatol Suppl* 86:1-2
41. Glass TA (1998) Conjugating the "tenses" of function: discordance among hypothetical, experimental, and enacted function in older adults. *Gerontologist* 38:101-112
42. Rodriguez-Amado J, Moreno-Montoya J, Alvarez-Nemegyei J et al (2014) The Social Gap Index and the prevalence of osteoarthritis in the community: a cross-sectional multilevel study in Mexico. *Clin Rheumatol* doi:10.1007/s10067-014-2776-y

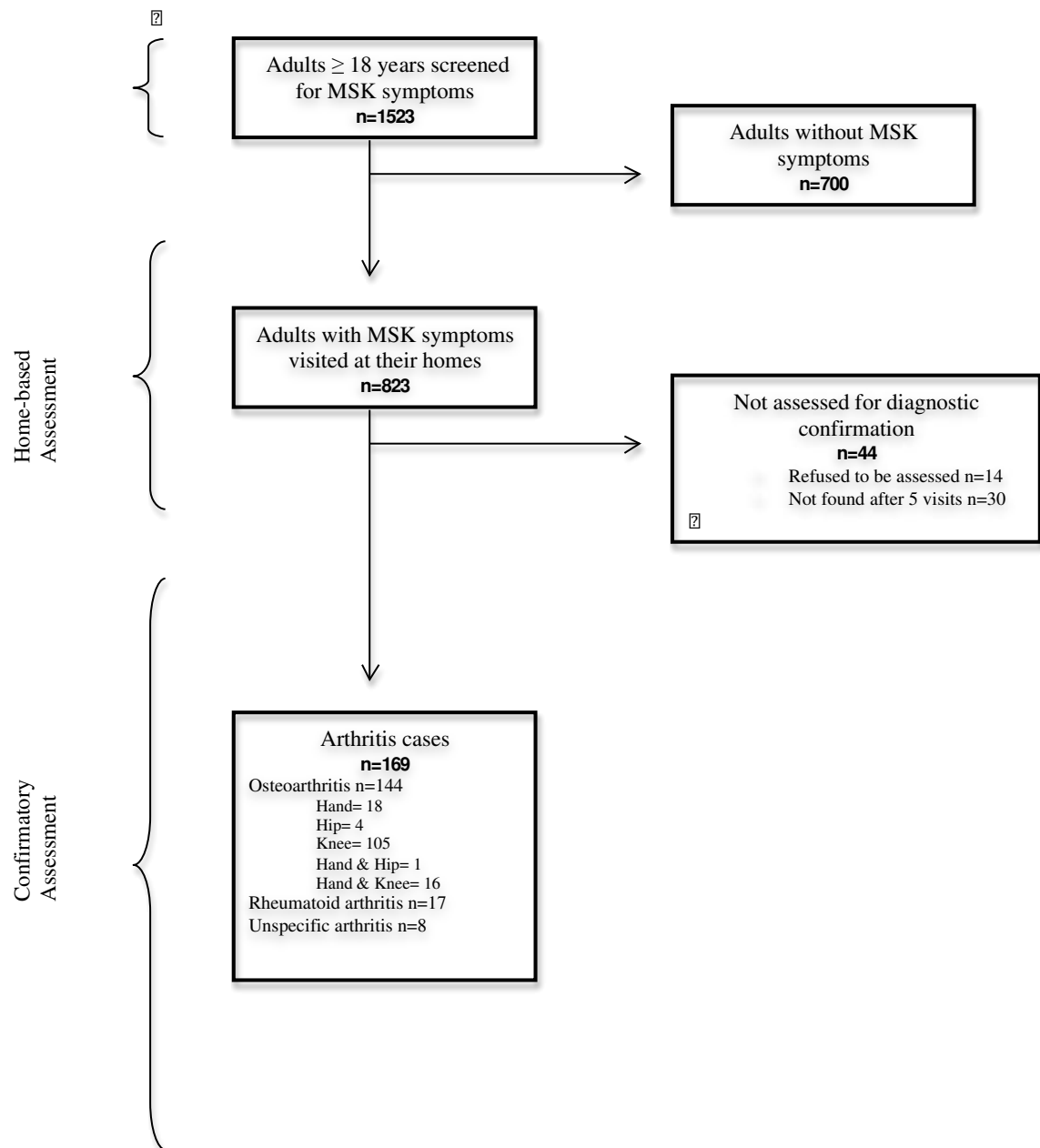


Figure 1. Study stages and participants' flowchart.

Table 1. Participants' general characteristics.

	Total^a	Arthritis^b		
	(n=1479)			
		Hand OA ^c	Hip or Knee	RA
		(n=35)	OA ^c	(n=17)
			(n=126)	
Mean years of age (SD)	45 (18)	63 (12)	63 (13)	55 (13)
Female gender (%)	904 (61)	26 (74)	68 (54)	13 (76)
Mean comorbidities (SD)	1 (1.2)	2 (1)	2 (1)	1 (0.4)
Disability (%)	251 (17)	23 (63)	60 (48)	10 (59)
Mean level of wealth	6 (3)	5 (3)	5 (3)	5 (2)
(SD)	[missing: 1]			
Mean BMI (SD)	28 (5)	29 (5)	29 (5)	29 (4)
	[missing: 22]			[missing:1]
Smokers (%)	139 (9)	2 (6)	10 (8)	0 (0)

SD- standard deviation; BMI- Body mass index; missing- number of participants with missing data; OA- osteoarthritis; RA- rheumatoid arthritis;^aData from participants not assessed for diagnostic confirmation are not included.^bData from participants diagnosed with non-specific arthritis are not described; ^cCases with combined hand & hip or hand & knee OA were considered in the estimation of both the hand and the hip or knee osteoarthritis parameters.

Table 2. Frequency of regular repetitive movements performance during principal occupation.

	Arthritis				No_Arthritis ^b	
	Hand OA ^a		Hip or Knee OA [*]		RA	
	Women	Men	Women	Men		
	(n=26)	(n=9)	(n=68)	(n=58)	(n=17)	(n=1310)
Jolting hands (%)	21 (81)	9 (100)	54 (79)	47 (81)	14 (82)	981 (76)
						[missing-11]
Lifting 20kg (%)	10 (38)	5 (56)	30 (44)	46 (79)	4 (24)	777 (60)
						[missing-11]
Pushing 20kg (%)	11 (42)	6(67)	34 (50)	45 (78)	5 (29)	846 (65)
						[missing-12]
Climbing (%)	12 (46)	4(44)	36 (53)	24 (41)	4 (24)	635 (49)
						[missing-12]
Standing>30min	19 (73)	8 (89)	60 (88)	46 (79)	5 (29)	1,169 (90)
(%)						[missing-12]
Kneeling>30min	14 (54)	6 (67)	42 (61)	39 (67)	7 (41)	786 (61)
(%)						[missing-12]
Sit-to-stand (%)	19 (73)	9 (100)	57 (83)	50 (86)	11 (65)	1080 (83)
						[missing-12]

OA- osteoarthritis; RA- rheumatoid arthritis; missing- number of participants with missing data.^aCases with combined hand & hip or hand & knee OA were considered for both, hand and hip or knee OA parameters' estimation.^b Includes data from participants without musculoskeletal symptoms and participants diagnosed with other than arthritis during the confirmatory stage.

Table 3. Prevalence odds ratios for the associations between selected risk factors and arthritis, OA and RA.

Risk Factors	Arthritis (95% CI)	OA (95% CI) ^a	RA (95% CI) ^b
Wealth	0.9 (0.8,0.9)*	1.1(0.9,1.1)	0.9 (0.7,1.1)
BMI	1.1 (1.03,1.1)*	1.01 (1.06,1.15)*	1.0 (0.9,1.1)
Smoking	0.7 (0.4,1.3)	0.1 (0.5, 1.9)	0.4 (0,3.0)
Static mechanical stress	0.7 (0.5,0.9)*	0.1 (0.7,1.3)	0.3 (0.1,0.6)*
Dynamic mechanical stress	1.0 (0.9,1.2)	1.1(0.9,1.3)	1.0 (0.7,1.4)

BMI- Body mass index; OA- osteoarthritis; RA- rheumatoid arthritis; ^aAdjusted by age and gender; ^bFirth logistic regression and profile penalized likelihood confidence intervals; *Significant at $\alpha=0.05$.

Table 4. Adjusted^a prevalence odds ratios for the associations between selected risk factors and hand OA and hip or knee OA in women and men.

Risk Factors	Hand OA (95% CI) ^b		Hip or Knee OA (95% CI) ^b	
	Women	Men	Women	Men
Wealth	1.0 (0.9,1.2)	0.9 (0.7,1.3)	0.9 (0.9,1.0)	1.0 (0.9,1.1)
BMI	1.1(0.9,1.1)	1.0 (0.8,1.2)	1.1 (1.1,1.2)*	1.1 (1.1,1.2)*
Smoking	0.70 (0.0,11.4)	1.4 (0.2,5.7)	2.4 (0.2,16.6)	0.9 (0.4,1.9)
Jolting hands	1.8 (0.7,5.7)	4.9 (0.6,609)	1.4 (0.7,2.8)	1.3 (0.6,2.9)
Lifting 20kg	1.2 (0.3,5.7)	0.1 (0.0,0.8)*	1.1 (0.4,2.7)	0.8 (0.2,4.8)
Pushing 20kg	0.9 (0.2,3.5)	7.5 (0.4,129)	1.0 (0.4,2.4)	1.5 (0.3,8.5)
Climbing	1.7 (0.6,4.7)	1.2 (0.3,5.4)	1.5 (0.8,2.9)	1.0 (0.5,2.0)
Standing>30min	0.4 (0.1,1.2)	1.5 (0.1,20.2)	1.3 (0.5,3.6)	0.3 (0.1,0.7)*
Kneeling>30min	1.0 (0.4,2.7)	0.6 (0.1,3.5)	0.9 (0.5,1.9)	1.4 (0.6,3.2)
Sit to stand	0.5 (0.2,1.4)	3.2 (0.3,447)	0.9 (0.4,2.0)	1.0 (0.4,2.6)

Education- completed school years; BMI- Body mass index; OA- osteoarthritis; RA- rheumatoid arthritis;

^aAdjusted by age; ^b Firth logistic regression and profile penalized likelihood confidence intervals;*

Significant at $\alpha=0.05$.

CHAPTER FOUR

PHYSICAL FUNCTION ASSESSMENT OF A RURAL MAYAN POPULATION LIVING WITH OSTEOARTHRITIS: A CROSS-SECTIONAL, COMMUNITY- BASED STUDY

PREFACE TO CHAPTER FOUR

Authors: Adalberto Loyola-Sánchez, Julie Richardson, Ingris Peláez-Ballestas, José Alvarez-Nemegyei, John N. Lavis, Michael G. Wilson, Seanne Wilkins

Publication status: This manuscript is under review in *Rural and Remote Health*.

Summary: This manuscript reports quantitative epidemiological findings from the execution of stage one “situation analysis” of the research programme in the rural Mayan municipality of Chankom, Yucatán México. The manuscript describes and analyses findings from a comprehensive physical function assessment performed in people living with osteoarthritis in this rural community. In addition, the manuscript includes an exploration of physical, psychological, social, behavioral and social factors related to the functional status of people from this arthritis subgroup.

4.1 Abstract

Background

Osteoarthritis (OA) is the most prevalent musculoskeletal disease in Mexico and its disabling effects on marginalized and rural communities are unknown. The objectives of this study were a) to assess the physical function of people living with OA in a Mexican indigenous rural community and b) to explore factors associated with the progression of this chronic disease.

Methods

Physical function and social (levels of education and wealth), physical (number of comorbidities, body mass index, level of pain, range of motion and muscle strength), psychological (anxiety, depression and level of self-efficacy) and behavioural (physical activity level) factors linked with OA progression were evaluated in all adults detected with hand, hip and/or knee OA through a census conducted in the Mayan community of Chankom, a socially marginalized indigenous municipality located at the State of Yucatán in Southeast Mexico. Local staff applied a cross-culturally validated questionnaire to identify people with musculoskeletal symptoms. Family physicians then visited people who were symptomatic at their homes to establish presumptive diagnoses. A physiatrist confirmed suspected cases of hand, hip and/or knee OA using the American College of Rheumatology criteria and assessed the “physical function” of these confirmed cases from 3 perspectives: hypothetical-what people think they “can do” through the Health Assessment Questionnaire Disability Index (HAQ-DI), experimental- what people “could do” in standardized conditions through the 6-minute walk test (6MWT) and the

Functional Dexterity Test (FDT), and enacted- what people “actually do” in real life through self-report of personal care, work and leisure activities. Descriptive and stepwise linear, logistic and ordinal logistic regression model analyses were conducted along with by age (above or below the population mean) and by gender subgroup analyses setting a statistical significance at $p \leq 0.01$.

Results

One-hundred-and-forty-four out of 228 suspected OA cases were confirmed (63%). Eighty % of participants confirmed with OA reported “mild” hypothetical disability ($HAQDI \leq 1$). Average scores observed for 6MWT (206 meters, $\sigma = 76.9$) and FDT (64 seconds, $\sigma = 32$) expressed low experimental physical function. Thirty-five %, 78%, and 59% of participants reported enacted personal care, work and leisure disability, respectively. Levels of: wealth ($\beta = 5$ [95%CI: 1-9] for 6MWT), pain ($OR = 3$ [95% CI: 1-4] for HAQ-DI), muscle strength ($\beta = 54$ [95%CI: 20-87] for 6MWT), self-efficacy ($OR = 12$ [95% CI: 6-27] for enacted work ability), and physical activity ($OR = 12$ [95% CI: 6-27] for enacted work ability) were all associated with variations in physical function as measured from different perspectives. Subgroup analyses showed that physical activity levels were associated with hypothetical disability ($OR = 0.1$ [95% CI: 0.1-0.3]) in men and levels of wealth ($OR = 0.7$ [95% CI: 0.5-0.9]) and self-efficacy ($OR = 0.5$ [95% CI: 0.3-0.8]) were associated with hypothetical disability in women.

Conclusions

People who live with OA in this rural indigenous community have significant function problems. Higher levels of wealth, muscle strength, self-efficacy, and physical activity

were associated with better physical function, whereas pain was associated with more disability. A multi-dimensional intervention that considers gender differences is needed to address the disabling effects of OA in this community.

Keywords

Osteoarthritis; Disability Evaluation; Mexico; Population Groups, Indigenous Populations.

4.2 Introduction

Osteoarthritis (OA) is the most common type of joint disease worldwide; its prevalence is rapidly increasing with the ageing population and is considered a major source of disability [1, 2]. The negative effects of chronic musculoskeletal (MSK) diseases, such as OA, on the physical function and quality of life of individuals are more severe in developing countries [3]. The disabling effects of OA are likely to be more pronounced in low-socioeconomic areas within developing countries. Epidemiologic observations involving older adults show that the severity of disability is inversely associated with socioeconomic position [4] and a population-based study found that socioeconomic factors were independently associated with the presence of disability in Chile [5].

The prevalence of OA is estimated to be 10.5% in Mexico, making it the leading MSK disease [6]. Osteoarthritis is also the leading cause of MSK pain in the Mexican State of Yucatán [7], where there are many Maya-Yucateco rural indigenous communities. These communities are characterized by living in low socioeconomic conditions without access to adequate health services [8]. Therefore, the disabling effects of OA on people living in these Maya-Yucateco areas could be important, highlighting the need to assess this population's physical function.

The epidemiologic assessment of physical function in OA has been inconsistent and many measurement strategies have been used [9]. Physical function in OA has been measured either through self-report of difficulty to do pre-defined activities [10-12], execution of controlled standardized activities [13], or self-report and observation of real

life activities' performance [14]. Glass (1998) proposed a “conjugation of 3 tenses” of physical functioning [15]: a) the hypothetical or perceived “capacity” to do activities; b) the experimental or “capability” for executing activities in controlled situations; and c) the enacted tense or the actual “performance” of real life activities [15].

Epidemiologic studies of OA have mainly focused on the hypothetical and experimental tenses of functioning [20-24]. Failing to consider the enacted tense means ignoring the context in which an individual wishes and needs to function [15]. In addition, assessing the enacted tense allows exploration of early function loss or “pre-clinical disability” [21], as it is manifested by the emergence of compensatory strategies.

This study is part of a project aimed at developing a community-based rehabilitation program to decrease the disabling effects of MSK diseases in Chankom, a Mexican rural indigenous municipality located in Yucatán [22]. A physical function evaluation of the people living with OA in this community was undertaken for the purpose of developing strategic interventions' designed to decrease and prevent the disabling effects of this chronic disease. Consequently, our main objectives were to: a) assess the physical function of people living with OA in Chankom using Glass's 3 “functioning tenses”; and b) explore associations between known risk factors for OA progression and each of the functioning tenses assessed.

4.3 Methods

4.3.1 Study Design

This was a three-stage observational, cross-sectional, community-based study consisting of: a) a survey, b) a home-based assessment and c) a physiatric assessment.

The first two stages were based on the Community Oriented Program for the Control of Rheumatic Diseases (COPCORD) phase one methodology, as described elsewhere [23]. Briefly, trained community personnel applied a cross-culturally validated questionnaire [24] designed to detect MSK symptoms and other relevant clinical and socioeconomic variables to the adult population (≥ 18 years) of Chankom, following a census strategy. Two trained family physicians assessed all people who reported MSK symptoms during the survey at their homes. These assessments occurred within the same week in which the survey had been administered.

During the physiatric assessment, consenting participants identified with possible hand, hip and/or knee OA were seen by a physiatrist for OA confirmation, physical function evaluation and exploration of factors associated with OA progression (Appendix C). Assessments were conducted in the community with the help of local Mayan translators.

4.3.2 Setting

This study was conducted in the rural municipality of Chankom, located in the southeast of Yucatán, Mexico. Chankom has a total population of 4464 habitants from which 80% are considered to be living in poverty [25, 26]. The survey and home-based assessment were conducted between June and November 2012, while the physiatric assessment was conducted between September and December 2012.

4.3.3 Participants

Osteoarthritis diagnoses were confirmed following the American College of Rheumatology (ACR) clinical criteria for hand OA [27] and radiological and clinical criteria for hip and knee OA [28, 29].

4.3.4 Physical function evaluations

4.3.4.1 Hypothetical functioning: Hypothetical function was evaluated using the Health Assessment Questionnaire Disability Index (HAQ-DI) applied by trained local staff in participants' homes. The HAQ-DI has shown good psychometric properties when applied to people with OA [30, 31] and was cross-culturally translated, adapted and validated for its use in the Mayan-Yucateco population [24] (Appendix A). The HAQ-DI was scored following standard procedures [32] and then transformed to an ordinal variable by grouping scores into 3 categories (mild, moderate and severe disability) as previously reported [33].

4.3.4.2 Experimental functioning: Experimental function was measured using the six-minute walk test (6MWT) and the Functional Dexterity Test (FDT). The 6MWT measures the distance an individual can walk during 6 minutes on a hard, flat surface [34], and has demonstrated good test-retest reliability when used in people with hip and knee OA [35]. The test was executed on a flat corridor 30 meters long using a mechanical road distance measuring wheel (the Measure Meter, Truometer 5500; Imperial House, UK) and a timer. Participants wore their usual clothes and were instructed to walk at a comfortable pace, while a Mayan assistant provided verbal encouragement every 30 seconds.

The FDT evaluates the dexterity to do 3-jaw chuck precision grip, has shown good psychometric properties in the hand OA population [36], and was applied following standardized procedures, described elsewhere [37]. Only results from the dominant hand were considered in the analysis.

4.3.4.3 Enacted functioning: Enacted function was evaluated through self-report of activities within three major areas of life. Participants described their main personal care, work and leisure activities and then were asked if at that moment they were doing “ALL” activities in each area. Persons who answered affirmatively were asked if they had modified the way and/or reduced the frequency in which they performed these activities. The answers were structured as three ordinal variables, “enacted personal care”, “enacted work”, and “enacted leisure”, composed by three categories: ability (currently performs ALL activities without modification), preclinical disability (currently performs ALL activities but have modified and/or reduced frequency of performance in at least one activity), and disability (currently does not perform ALL activities).

4.3.5 Exploration of known factors for OA progression

Modifiable known factors associated with OA clinical progression in hand [38], hip and knee [10, 39, 40] OA populations were assessed and assigned to the following groups: social, physical, psychological and behavioral.

4.3.5.1 Social factors: Participants’ level of education and wealth were registered during the survey stage (Appendix A). Level of education was captured by years of education completed. Level of wealth was defined by the number and type of commodities owned by participants. Entertainment, electro-domestic appliances,

communication and transportation commodities were selected and classified by local staff according to their ability to differentiate levels of wealth within the community, resulting in a variable ranging from 0 “no commodities owned” to 14 “ownership of the highest-valued commodities”.

4.3.5.2 Physical factors: We defined the number of co-morbidities by the cumulative self –report of concurrent diseases explored from a pre-defined list [24] (Appendix A). Height and weight were measured during the survey application stage following Lohman’s technique [41]. Weight was measured with a portable digital scale (Tanita Model 804), height was measured with a portable ultrasonic digital stadiometer (ADE, Ultraschall/Messstab/MZ10020, Germany). We calculated participants’ body mass index (BMI) using Quetelet’s formula.

We assessed participants’ pain using the HAQ visual analog scale (VAS). The original VAS format was changed to a 5-category ordinal scale to accommodate cultural customs [24]. Careful inspection and palpation techniques were used to register tender and swollen joints. Active and passive joint range of movement (ROM) was measured with a goniometer. Joint ROM values were further classified as “functional” or “not functional” using reported thresholds [42].

Grip strength in the dominant hand was evaluated as kilograms of force using a hydraulic hand dynamometer (JAMAR, Sammons Preston Rolyan, IL 60622). Hip flexion and knee extension strength were measured as kilograms of force using a handheld dynamometer (Lafayette Instrument Company, IN 47903), following the “make” technique [43] and averaging three trials executed with 1-minute rests between

them. We constructed a “muscle strength” variable by summing all measurements and dividing them by body weight [44].

4.3.5.3 Psychological factors: Anxiety and depression were assessed through self-report. We evaluated self-efficacy by asking participants about the amount of confidence they had to perform their personal care and work activities using a dichotomous scale (“none-to-little” and “sufficient-to-very-much”).

4.3.5.4 Behavioral factors: Level of aerobic physical activity was assessed using the Rapid Assessment of Physical Activity questionnaire part 1 (RAPA1). The validity of this instrument has been well established [45] and it has been translated to Mexican-Spanish [46].

4.3.6 Statistical analyses

Means and standard deviations for continuous variables and frequencies for dichotomous/categorical variables were estimated. Confidence intervals were constructed using normal and binomial distributions. Student’s T and χ^2 tests were used to compare means and frequencies. Associations between groups of risk factors for OA progression (independent variables) and the functioning tensors assessed (dependent variables) were explored using linear (LR), logistic (LogR), and ordinal logistic (OLR) hierarchical stepwise regression. Subgroup analyses were conducted for the physical function assessment, dividing the population by age (below and equal or above the mean age), and for the modifiable factors’ evaluation, dividing the population by gender.

Representatives from each group of independent variables were selected according to their plausibility, model contribution and lack of redundancy. The

variable(s) selected were then ordered and entered to the final models using a stepwise approach following the theoretical premises proposed by Glass [15]. Hypothetical function is the result of an abstract estimation of what is possible to do; therefore, we followed this order of entry: psychological-physical-social-behavioral. Experimental function is a simulation of what can be objectively done in circumscribed conditions; hence, we followed this order of entry: physical-psychological-social-behavioral. Enacted function is what is actually done under determined socio-cultural contexts; consequently, we followed this order of entry: social-behavioral-physical-psychological.

All regression models' assumptions were assessed. The variable “enacted personal care” was further reduced into two categories (presence or absence of functioning problems) due to the small number of cases observed in the disability category (n=2). The RAPA1's 5 categories were condensed to 3 due to the small number of cases observed in the first 2. Statistical significance was set to a p-value ≤ 0.01 accounting for model over fitting. Analyses were conducted using STATA 12.1.

4.3.7 Ethics approval

This study was approved by the Hamilton Health Sciences /McMaster University Research Ethics Board (12-544), the Ethics Committee of the Faculty of Medicine, Universidad Anáhuac-Mayab, and the Ethics Committee of the “Hospital General de México, Dr. Eduardo Liceaga” (DI/11/4044B/3/123) (Appendix B). All participants signed an informed consent before participating in the study.

4.4 Results

Two hundred and twenty eight adults with suspected OA (96%) consented to assessment for diagnostic confirmation. The mean age and HAQ-DI scores significantly differed between persons who consented and persons who declined. The group who declined was on average younger (-11 years [95%CI: -2.7 to -19], $p=0.009$) and with less disability (-0.46 HAQ-DI points [95%CI: -0.02 to -0.9], $p=0.03$). Hand, hip and/or knee OA was confirmed in 144 participants (63% [95%CI: 56 to 69]) and alternative diagnoses were established. The knee was the most commonly affected joint, followed by the hand, a combination of hand and knee, the hip, and a combination of hand and hip (see Figure 1). The mean age of the population was 62 years (standard deviation=12.6 years) and there were more women than men (56% vs. 44%).

4.4.1 Physical function assessment

Table 1 shows the physical function assessment estimates for the entire population and by age. The HAQ-DI scores showed that 115 participants (80%) had mild disability. The mean distance walked during the 6MWT was 206 meters; the mean FDT score was 64 seconds. Fifty-five participants (38%) reported performance disability for work and 36 (25%) reported disability for performing leisure activities. Fifty-two (36%) and 49 (34%) participants reported preclinical disability for performing work and leisure activities, respectively. Participants ≥ 62 years old showed lower functioning levels than participants younger than 62 years in all the physical function measures.

4.4.2 Known modifiable factors for OA progression

Table 2 shows the descriptive estimates of all factors obtained for the whole population and by gender. The population's mean level of education was 2.3 years and

the mean level of wealth score was 5. On average, participants reported 2 co-morbidities and presented a median of 2 joints affected with OA. Eighty-percent of participants reported some level of pain. Women had higher mean BMI than men, whereas men had higher mean muscle strength than women. Participants reported sufficient-to-very-much self-efficacy to perform personal care, work and leisure activities in 81%, 49% and 61% of the cases. Men were significantly more physically active than women.

4.4.3 Associations between modifiable factors for OA progression and physical function

Psychological (partial Likelihood ratio test (pLRT)= 22, $p<0.00001$), physical (pLRT= 25, $p<0.00001$) and social (pLRT= 8, $p=0.01$) factors were associated with the HAQ-DI. Pain was associated with higher levels of disability. Subgroup analyses showed that physical activity level was associated with less disability in men, while higher self-efficacy and level of wealth were associated with less disability in women (see Table 3).

Physical (r^2 change=0.19), psychological (r^2 change=0.12), and social (r^2 change=0.07) factors were significantly associated with the 6MWT. Higher levels of muscle strength, self-efficacy and level of wealth were associated with greater distance walked (see Table 3).

Physical (r^2 change=0.19) and psychological (r^2 change=0.04) factors were significantly associated with the FDT. The significance of these hypothesis' tests remained after conducting a model re-estimation with the logarithmic transformation of FDT to eliminate residuals' heteroscedasticity and non-normality. We have not reported

the estimates of the transformed model due to difficulty in interpreting unit-changes (log seconds) in the dependent variable.

Behavioral (pLRT=10, $p=0.005$), physical (pLRT=7, $p=0.01$) and psychological (pLRT=10, $p=0.002$) factors were significantly associated with personal care-enacted function. Higher levels of physical activity and self-efficacy were associated with fewer functional problems (see Table 3).

Behavioral (pLRT=24, $p=0.004$) and psychological (pLRT=46, $p<0.00001$) factors were significantly associated with work-enacted function. Higher levels of physical activity and self-efficacy were associated with a higher functional level (see Table 3).

The psychological factor self-efficacy (pLRT=13, $p=0.0003$) was significantly associated with leisure-enacted function. Higher levels of self-efficacy were also associated with a higher functional level (see Table 3).

4.5 Discussion

4.5.1 Principal findings

The experimental and enacted functions were considerably compromised in this population, overshadowing the “mild disability” observed during the hypothetical function evaluation. While the HAQ-DI scores showed mainly mild levels of disability, participants’ experimental function was low compared to that reported in the literature. For instance, the mean 6MWT scores (239 meters) of the <62 years old subgroup was markedly reduced in comparison to other OA populations (487 meters) [47], and their mean FDT scores (55 seconds) are considered “non functional” [37]. In addition, the

majority of participants reported problems in performing their work and leisure activities. Considering that work is the central element of life in this population, the hypothetical function evaluation failed to capture this important aspect of disability.

All groups of factors previously linked with OA progression [10, 38, 39, 40] were associated with one or more of the 3 functioning domains explored. Increased levels of wealth were associated with increased mobility capability. Pain was associated with decreased capacity, while higher muscle strength was associated with increased mobility capability. High self-efficacy was associated with increased mobility capability and increased performance of personal care, work and leisure activities. Higher levels of physical activity were associated with increased performance of work and leisure activities.

For women, lower levels of wealth were associated with lower capacity, which may be related to gender differences in nutritional intake [48]. For women, low self-efficacy was associated with low capacity, probably due to catastrophizing [49]. Finally, for men higher levels of physical activity were associated with increased capacity as previously reported [50].

4.5.2 Strengths and limitations

This study provides a community-based and theoretically driven physical function assessment of all people diagnosed with OA living in Chankom, confirming the comprehensiveness and applicability of findings to this community. Moreover, the strict methodology followed to identify and confirm OA cases increases the confidence of the

associated estimates. Finally, involving local people in the development and execution of the study increases the validity of results.

The limitations of the study includes potential selection bias evidenced by the significant differences observed in the mean age and functional capacity between people who agreed and those who refused to be assessed for OA confirmation, which could have resulted in an overestimation of the presence and severity of disability. Moreover, the cross-sectional design of this study limits our causal inferences between the factors and the functioning tensions evaluated.

4.5.3 Implications for practice and policy

Our results underscore the importance of developing a multi-dimensional intervention considering gender and social, physical, psychological and behavioral factors to decrease the disabling effects of OA in this community. There is also a need to create local and regional health policy changes addressing social, cultural and economical barriers for the appropriate health care access of people living with OA in rural poor communities.

4.5.4 Implications for research

The results of this study contribute empirical value to the physical functioning tensions proposed by Glass (1998) [15] and the existence of preclinical disability [51]. Our findings suggest that there is a difference between what people perceive they can do and what they actually do in real life conditions. This difference is explained by contextual familial, cultural and socio-economic factors, which in real life conditions may act as barriers or as facilitators for the fulfilment of meaningful roles. Incorporating the concept

of preclinical disability to the enacted function assessment confirmed the existence of a functioning gradient, which includes changes in frequency and/or modifications to performance before it's completely lost.

4.5.5 Conclusions

People living with OA in Chankom present important capability and performance problems. Higher levels of wealth, muscle strength, self-efficacy, and physical activity were associated with better physical function, whereas pain was associated with more disability. A multi-dimensional intervention that considers gender differences is needed to address the disabling effects of OA in this community.

4.6 Acknowledgements

We like to thank Mr. Diego Yeh Cen and Mr. Carlos Castillo Kuyoc for their valuable contributions to the analysis and data acquisition in this study. We also thank research assistants Maria Lizbeth Escudero and Beatriz Quintero, for they great work capturing data and maintaining the database. This project was funded by the Consejo Nacional de Ciencia y Tecnología [CONACYT] (grant #162154). ALS received funding from CONACYT's doctoral scholarship for studying abroad (scholarship #209621) and from the Doctoral Vanier Canada Scholarships (# 268078).

4.7 References

1. Zhang Y, Jordan JM. Epidemiology of osteoarthritis. *Rheumatic Disease Clinics of North America* 2008; 34(3): 515-529.

2. Wenham CY, Conaghan PG. New horizons in osteoarthritis. *Age and Ageing* 2013; 42(3): 272-278.
3. Chopra A, Abdel-Nasser A. Epidemiology of rheumatic musculoskeletal disorders in the developing world. *Best Practice & Research Clinical Rheumatology* 2008; 22(4): 583-604.
4. Gjonca E, Tabassum F, Breeze E. Socioeconomic differences in physical disability at older age. *Journal of Epidemiology & Community Health* 2009; 63(11): 928-935.
5. Zitko Melo P, Cabieses Valdes B. Socioeconomic determinants of disability in Chile. *Disability and Health Journal* 2011; 4(4): 271-282.
6. Grupo de Estudio Epidemiológico de Enfermedades Musculo Articulares (GEEMA). Epidemiology of the rheumatic diseases in Mexico. A study of 5 regions based on the COPCORD methodology. *Journal of Rheumatology Supplement* 2011; 86: 3-8.
7. Alvarez-Nemegyei J, Pelaez-Ballestas I, Sanin LH, Cardiel MH, Ramirez-Angulo A, Goycochea-Robles MV. Prevalence of musculoskeletal pain and rheumatic diseases in the southeastern region of Mexico. A COPCORD-based community survey. *Journal of Rheumatology Supplement* 2011; 86: 21-25.
8. Leyva-Flores R, Infante-Xibille C, Gutierrez JP, Quintino-Perez F. Persisting health and health access inequalities in Mexican indigenous population, 2006-2012. *Salud Pública de México* 2013; 55(Suppl 2): S123-8.

9. Carpa Study Group. Course of functional status and pain in osteoarthritis of the hip or knee: a systematic review of the literature. *Arthritis & Rheumatism* 2006; 55(5): 779-785.
10. Chapple CM, Nicholson H, Baxter GD, Abbott JH. Patient characteristics that predict progression of knee osteoarthritis: A systematic review of prognostic studies. *Arthritis Care & Research* 2011; 63(8): 1115-1125.
11. Dahaghin S, Bierma-Zeinstra SM, Ginai AZ, Pols HA, Hazes JM, Koes BW. Prevalence and pattern of radiographic hand osteoarthritis and association with pain and disability (the Rotterdam study). *Annals of Rheumatic Diseases* 2005; 64(5): 682-687.
12. Zhang Y, Niu J, Kelly-Hayes M, Chaisson CE, Aliabadi P, Felson DT. Prevalence of symptomatic hand osteoarthritis and its impact on functional status among the elderly: The Framingham Study. *American Journal of Epidemiology* 2002; 156(11): 1021-1027.
13. Sharma L, Song J, Felson DT, Cahue S, Shamiyeh E, Dunlop DD. The role of knee alignment in disease progression and functional decline in knee osteoarthritis. *Journal of the American Medical Association* 2001; 286(2): 188-195.
14. Kjekken I, Dagfinrud H, Slatkowsky-Christensen B, Mowinckel P, Uhlig T, Kvien TK, et al. Activity limitations and participation restrictions in women with hand osteoarthritis: Patients' descriptions and associations between dimensions of functioning. *Annals of Rheumatic Diseases* 2005; 64(11): 1633-1638.
15. Glass TA. Conjugating the "tenses" of function: Discordance among hypothetical, experimental, and enacted function in older adults. *The Gerontologist* 1998; 38(1): 101-112.

16. Dieppe P, Cushnaghan J, Tucker M, Browning S, Shepstone L: The Bristol 'OA500 study': Progression and impact of the disease after 8 years. *Osteoarthritis and Cartilage* 2000; 8(2): 63-68.
17. Dougados M, Gueguen A, Nguyen M, Thiesce A, Listrat V, Jacob L, et al. Longitudinal radiologic evaluation of osteoarthritis of the knee. *Journal of Rheumatology* 1992; 19(3): 378-384.
18. Davis MA, Ettinger WH, Neuhaus JM, Mallon KP. Knee osteoarthritis and physical functioning: Evidence from the NHANES I Epidemiologic Follow-up Study. *Journal of Rheumatology* 1991; 18(4): 591-598.
19. Ettinger WH, Davis MA, Neuhaus JM, Mallon KP. Long-term physical functioning in persons with knee osteoarthritis from NHANES I: Effects of comorbid medical conditions. *Journal of Clinical Epidemiology* 1994; 47(7): 809-815.
20. Sharma L, Cahue S, Song J, Hayes K, Pai YC, Dunlop D. Physical functioning over three years in knee osteoarthritis: role of psychosocial, local mechanical, and neuromuscular factors. *Arthritis and Rheumatism* 2003; 48(12): 3359-3370.
21. Fried LP, Bandeen-Roche K, Williamson JD, Prasada-Rao P, Chee E, Tepper S, et al. Functional decline in older adults: expanding methods of ascertainment. *The Journals of Gerontology Series A* 1996; 51(5): M206-14.
22. Loyola-Sanchez A, Richardson J, Pelaez-Ballestas I, Lavis J, Wilkins S, Wilson M, et al. Developing community based rehabilitation programs for musculoskeletal diseases in low-income areas of Mexico: The “community- based rehabilitation for low income communities living with rheumatic diseases [CONCORD] ” protocol. *Journal of*

Medical Internet Research Research Protocols 2014; 3(4): e57. Online (2014) Available: <http://www.researchprotocols.org/2014/4/e57/> (accessed Sep 2 2014)

23. Darmawan J. Recommendations from the Community Oriented Program for Control of Rheumatic Disease for data collection for the measurement and monitoring of health in developing countries. *Clinical Rheumatology* 2007; 26(6): 853-857.
24. Pelaez-Ballesteros I, Granados Y, Silvestre A, Alvarez-Nemegyei J, Valls E, Quintana R, et al. Culture-sensitive adaptation and validation of the Community-Oriented Program for the Control of Rheumatic Diseases methodology for rheumatic disease in Latin American indigenous populations. *Rheumatology International* 2014; 34(9): 1299-309.
25. Instituto Nacional de Estadística y Geografía. 11 Censo de Población y Vivienda. [National census of the population and households]. México, 2005.
26. Consejo Nacional de Evaluación de la Política de Desarrollo Social. Informe Anual sobre la Situación de Pobreza y Rezago Social. Chankom, Yucatán. [Annual inform on the Poverty and Social Lag Situation. Chankom, Yucatán]. México, SEDESOL: 2014.
27. Altman R, Alarcon G, Appelrouth D, Bloch D, Borenstein D, Brandt K, et al. The American College of Rheumatology criteria for the classification and reporting of osteoarthritis of the hand. *Arthritis and Rheumatism* 1990; 33(11): 1601-1610.
28. Altman R, Alarcon G, Appelrouth D, Bloch D, Borenstein D, Brandt K, et al. The American College of Rheumatology criteria for the classification and reporting of osteoarthritis of the hip. *Arthritis and Rheumatism* 1991; 34(5): 505-514.

29. Altman R, Asch E, Bloch D, Bole G, Borenstein D, Brandt K, et al. Development of criteria for the classification and reporting of osteoarthritis. Classification of osteoarthritis of the knee. Diagnostic and Therapeutic Criteria Committee of the American Rheumatism Association. *Arthritis and Rheumatism* 1986; 29(8): 1039-1049.
30. Dziedzic KS, Thomas E, Hay EM. A systematic search and critical review of measures of disability for use in a population survey of hand osteoarthritis (OA). *Osteoarthritis and Cartilage* 2005; 13(1): 1-12.
31. Alvarez-Nemegyei J, Peláez-Ballestas I, Loyola-Sánchez A. Traducción y validación transcultural del instrumento Health Assessment Questionnaire al idioma Maya-Yucateco. [Translation and transcultural validation of the Health Assessment Questionnaire instrument to the Maya Yucateco language]. *Reumatología Clínica* 2013; 9(Suppl 1): C1-C017.
32. Bruce B, Fries JF. The Stanford Health Assessment Questionnaire: a review of its history, issues, progress, and documentation. *Journal of Rheumatology* 2003; 30(1): 167-178.
33. Bruce B, Fries JF: The Stanford Health Assessment Questionnaire: Dimensions and practical applications. *Health and Quality of Life Outcomes* 2003; 1: 20. Online (2003). Available: <http://www.hqlo.com/content/1/1/20> (Accessed August 10 2014).
34. Balke B. A simple field test for the assessment of physical fitness [rep 63-6]. *Rep Civ Aeromed Res Inst US* 1963; 53: 1-8.

35. Kennedy DM, Stratford PW, Wessel J, Gollish JD, Penney D. Assessing stability and change of four performance measures: a longitudinal study evaluating outcome following total hip and knee arthroplasty. *BMC Musculoskeletal Disorders* 2005; 6: 3.
36. Schoneveld K, Wittink H, Takken T. Clinimetric evaluation of measurement tools used in hand therapy to assess activity and participation. *Journal of Hand Therapy* 2009; 22(3): 221-235.
37. Aaron DH, Jansen CW. Development of the Functional Dexterity Test (FDT): construction, validity, reliability, and normative data. *Journal of Hand Therapy* 2003; 16(1): 12-21.
38. Kalichman L, Hernandez-Molina G. Hand osteoarthritis: An epidemiological perspective. *Seminars in Arthritis and Rheumatism* 2010; 39(6): 465-476.
39. Dekker J, Van Dijk GM, Veenhof C. Risk factors for functional decline in osteoarthritis of the hip or knee. *Current Opinion in Rheumatology* 2009; 21(5): 520-524.
40. Michaelsson K, Byberg L, Ahlbom A, Melhus H, Farahmand BY. Risk of severe knee and hip osteoarthritis in relation to level of physical exercise: A prospective cohort study of long-distance skiers in Sweden. *PLoS One* 2011; 6(3): e18339.
41. Lohman TG, Roche AF, Martorell R (eds). *Anthropometric standardization reference manual*. IL: Human Kinetics, 1988.
42. Taboadela CH (ed). *Goniometría : una herramienta para la evaluación de las incapacidades laborales*. Buenos Aires: Asociart ART, 2007.

43. Burns SP, Spanier DE. Break-technique handheld dynamometry: Relation between angular velocity and strength measurements. *Archives of Physical Medicine and Rehabilitation* 2005; 86(7): 1420-1426.
44. Hurd WJ, Morrey BF, Kaufman KR. The effects of anthropometric scaling parameters on normalized muscle strength in uninjured baseball pitchers. *Journal of Sport Rehabilitation* 2011; 20(3): 311-320.
45. Topolski TD, LoGerfo J, Patrick DL, Williams B, Walwick J, Patrick MB. The Rapid Assessment of Physical Activity (RAPA) among older adults. *Preventing Chronic Disease* 2006; 3(4): A118.
46. University of Washington Health Promotion Research Center. Cuál es su nivel de actividad física? Evaluación del nivel de intensidad de actividad física. USA: University of Washington, 2006.
47. Jones A, Silva PG, Silva AC, Colucci M, Tuffanin A, Jardim JR, et al. Impact of cane use on pain, function, general health and energy expenditure during gait in patients with knee osteoarthritis: A randomised controlled trial. *Annals of Rheumatic Diseases* 2012, 71(2): 172-179.
48. Sharkey JR, Branch LG. Gender difference in physical performance, body composition and dietary intake in homebound elders. *Journal of Women & Aging* 2004; 16(3-4): 71-90.
49. Keefe FJ, Lefebvre JC, Egert JR, Affleck G, Sullivan MJ, Caldwell DS. The relationship of gender to pain, pain behavior, and disability in osteoarthritis patients: The role of catastrophizing. *Pain* 2000; 87(3): 325-334.

50. Strawbridge WJ, Camacho TC, Cohen RD, Kaplan GA. Gender differences in factors associated with change in physical functioning in old age: A 6-year longitudinal study. *The Gerontologist* 1993; 33(5): 603-609.
51. Fried LP, Bandeen-Roche K, Chaves PH, Johnson BA. Preclinical mobility disability predicts incident mobility disability in older women. *The Journals of Gerontology Series* 2000; 55(1): M43-52.

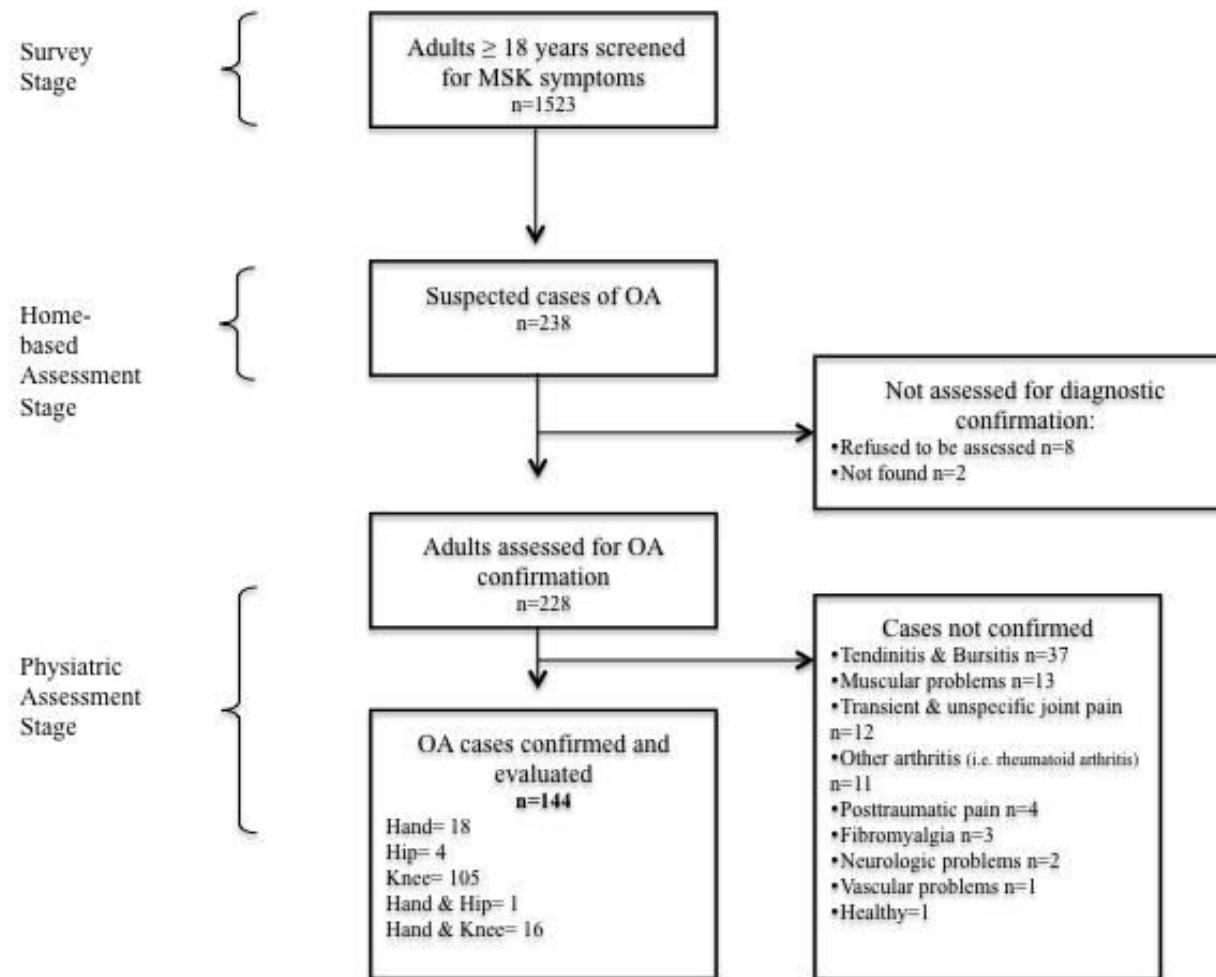


Figure 1. Study stages and participants' flowchart

Table 1. Descriptive estimates for the physical function assessment			
	Total	Age	
Functioning Tenses		< 62 years	≥ 62 years
	N= 144	N= 70	N= 74
Hypothetical			
HAQ-DI (%)			
Mild	115 (80)	67 (96) [*]	48 (65) [*]
Moderate	20 (14)	2 (3) [*]	18 (24) [*]
Severe	9 (6)	1 (1) [*]	8 (11)
Experimental			
Mean 6MWT [†] (σ)	206 (76.9) miss=2	239 (66) ^{**}	175 (77) ^{**} miss=2
Mean FDT [‡] (σ)	64 (32)	55 (28) [*]	73 (36) [*]
Enacted			
Personal care (%)			
Ability	94 (65)	56 (80) [*]	38 (51) [*]
Preclinical disability [§]	48 (34)	14 (20) [*]	34 (46)
Disability	2 (1)	0 (0)	2 (3)
Work (%)			
Ability	37 (26)	26 (37) [*]	11 (15) [*]
Preclinical disability [§]	52 (36)	28 (40) [*]	24 (32)
Disability	55 (38)	16 (23) [*]	39 (53)
Leisure (%)			
Ability	46 (31)	28 (40) [*]	18 (24) [*]
Preclinical disability [§]	49 (34)	26 (37) [*]	23 (31)
Disability	36 (25)	10 (14) [*]	26 (35)
No leisure activities	13 (9)	6 (9)	7 (9)

HAQ-DI- Health Assessment Questionnaire-Disability Index; 6MWT- six-minute walk test; FDT- Functional Dexterity Test; σ- standard deviation; miss- missing data. [†]Meters. [‡]Seconds obtained from the dominant hand, including penalizations for touching the board, supinating the wrist and/or dropping the pegs.

[§]Reported modifications on the way and/or the frequency of activities' performance were always associated with the presence of osteoarthritis. Chi², p<0.01. ^{*}T-test, p <0.01.

Table 2. Descriptive estimates for known factors associated with osteoarthritis progression			
Risk Factors	Total	Gender	
	(n= 144)	Men (n=63)	Women (n=81)
Social			
Mean years of education (σ)	2.3 (2.5)	2.7 (2.6)	2 (2.4)
Mean level of wealth score [†] (σ)	5 (2.6)	5 (2.6)	5 (2.7)
Physical			
Mean number of comorbidities (σ)	2.14 (1.63)	2 (1.6)	2 (1.6)
Mean BMI (σ)	29 (5)	27 (4)	31 (5)
Pain intensity (%)			
Nothing	28 (19)	13 (21)	15 (19)
A little	27 (19)	10 (16)	17 (21)
Not very strong	28 (19)	14 (22)	14 (17)
Strong	49(34)	23 (36)	26 (32)
Very strong	12 (9)	3 (5)	9 (11)
Median number of joints affected	2	2	2
Functional range of motion in all joints (%)	125 (87)	50 (79)	75 (93)
Mean normalized muscle strength (σ)	1.2 (0.3) miss=3	1.4 (0.3) * miss=1	1 (0.2) * miss=2
Psychological			
Self-reported anxiety (%)	66 (46)	22 (35)	44 (54)
Self-reported depression (%)	55 (38)	21 (33)	34 (42)
Sufficient to very much self-efficacy, personal care (%)	117 (81)	51 (81)	66 (81)
Sufficient to very much self-efficacy, work (%)	70 (49)	26 (41)	44 (54)
Sufficient to very much self-efficacy, leisure (%)	80 (62) miss=1	33 (62) miss=1	47 (61)
Behavioral			
RAPA 1 (%)			
SURL	23 (16)	7 (11)**	16 (20)**
UR	65 (45)	19 (30)**	46 (57)**
A	56 (39)	37 (59)**	19 (23)**

BMI- Body Mass Index; RAPA1- Rapid Assessment of Physical Function questionnaire part 1 (aerobic activity); SURL- sedentary to underactive regular light activities; UR- underactive regular; A- active; miss- missing values. [†]Owned entertainment, electro domestic, communication and transportation commodities, weighted by their market price and social utility. ^{||} Σ (muscle strength measurements) / body weight (kg force/kg weight). *T-test, $p \leq 0.001$. **Chi², $p \leq 0.001$.

Table 3. Regression models' estimates			
	Estimates (95%CI)		
	Total	Men	Women
Dependent variable			
HAQ-DI [†]			
Self-efficacy	0.7 (0.5-1.0)	1.2 (0.6-2.3)	0.5 (0.3-0.8)
Pain	2.5 (1.4-4.4)	1.8 (0.8-4.2)	4.0 (1.7-9.7)
BMI	0.9 (0.8-1.0)	0.7 (0.5-1.0)	0.9 (0.8-1.1)
Muscle strength	0.1 (0.0-1.1)	0.1 (0.0-7.0)	0.1 (0.0-2.0)
Level of education	0.8 (0.6-1.1)	0.6 (0.3-1.2)	1.2 (0.7-1.9)
Level of wealth	0.8 (0.6-1.0)	0.8 (0.6-1.3)	0.7 (0.5-0.9)
Level of physical activity [§]	0.3 (0.1-1.4)	0.0 (0.0-0.3)	1.9 (0.2-22)
6MWT			
Muscle strength	55 (22-89)	38 (-18-94)	49 (-13-110)
Functional joint range of movement	30 (-2-61)	27 (-17-71)	37 (-20-95)
Self efficacy	9 (4-15)	10 (1-19)	10 (2-17)
Level of education	4 (-1-8)	5 (-2-11)	3 (-4-10)
Level of wealth	6 (2-10)	12 (5-18)	3 (-2-9)
Level of physical activity [§]	15 (-18-48)	7 (-53-66)	16 (-28-59)
Personal care enacted function [†]			
Level of education	0.9 (0.8-1.1)	0.9 (0.7-1.2)	0.9 (0.7-1.1)
Level of physical activity	0.2 (0.1-0.5)	0.1 (0.0-0.7)	0.2 (0.1-0.9)
Functional joint range of movement	0.3 (0.1-1.0)	0.2 (0.0-0.9)	0.9 (0.1-6.3)
Self-efficacy	0.2 (0.1-0.6)	0.3 (0.1-1.7)	0.1 (0.0-0.5)
Work enacted function [†]			
Level of wealth	1.1 (0.9-1.2)	0.9 (0.7-1.2)	1.1 (0.9-1.3)
Level of physical activity [§]	14 (3-55)	>50(0->50)	15 (2.7-83)
Pain	0.8 (0.6-1.1)	0.8 (0.5-1.2)	0.8 (0.6-1.2)
Self efficacy	12 (6-27)	5.4 (1.4-20)	14 (4.7-42)
Leisure enacted function [†]			
Level of wealth	1.1 (1.0-1.2)	1.0 (0.8-1.2)	1.2 (1.0-1.4)
Level of physical activity [‡]	2.3 (0.8-6.3)	2.9 (0.4-21)	3.8 (0.9-15)
Pain	0.8 (0.6-1.1)	3 (0.4-23)	0.8 (0.6-1.1)
Self efficacy	3.5 (1.8-7)	4.2 (1.2-14)	3.4 (1.3-8.8)

HAQ-DI- Health assessment questionnaire disability index; 6MWT- Six-minute walk test; CI- Confidence intervals.

[†]Prevalence Odds ratios obtained through ordinal logistic regression (HAQ-DI, Work and leisure enacted function) or logistic regression (Personal care enacted function). ^{||} Linear β coefficients obtained through linear regression. [§]

Sedentary to underactive regular (light activities) vs. active. [‡] Sedentary to underactive regular (light activities) vs. underactive regular. *p<0.01.

CHAPTER FIVE

BARRIERS TO ACCESSING THE CULTURALLY SENSITIVE HEALTHCARE THAT COULD DECREASE THE DISABLING EFFECTS OF ARTHRITIS IN A RURAL MAYAN COMMUNITY: A QUALITATIVE INQUIRY.

PREFACE TO CHAPTER FIVE

Authors: Adalberto Loyola-Sánchez, Julie Richardson, Seanne Wilkins, John N. Lavis, Michael G. Wilson, José Alvarez-Nemegyei, Ingris Peláez-Ballestas

Publication status: This manuscript is under review in *Clinical Rheumatology*.

Summary: This manuscript reports qualitative ethnographic findings from the execution of stage one “situation analysis” and the beginning of stage two “program development” of the research programme in the rural Mayan municipality of Chankom, Yucatán México. The manuscript describes and analyses findings on the impact of living with arthritis in Chankom, the healthcare needs of people living with arthritis in this indigenous municipality and the barriers faced by this population during their efforts to access healthcare services.

5.1 Abstract

The impact of living with arthritis in a rural Mexican Mayan community along with the barriers encountered by people living with this chronic condition were investigated in this study. The community needs around this health issue were investigated by conducting an ethnographic study using data obtained during two time periods (August 2012-April 2013 and December 2013-December 2014). During the first period, fieldwork observations and interviews with 65 individuals, which included people with arthritis, health professionals, traditional health providers and community leaders were undertaken. During the second period, 46 community meetings were conducted to identify the needs associated with arthritis in the municipality. Data were analyzed following a modified version of the “Framework” approach. The results show that arthritis reduces the health-related quality of life of the people in Chankom through a process of disablement. The community defined accessing “good medical care” as the principal need for the people living with this chronic condition, which included local health infrastructure and increased cultural awareness by health professionals. Barriers to accessing healthcare in this community were identified. These barriers were related to availability, attainability and acceptability of services, which result from power imbalance between indigenous and non-indigenous people. Our findings highlight the need to involve the Mayan people in the design and implementation of health policies to improve their access to culturally sensitive healthcare. This includes developing a community-based rehabilitation program to diminish the disabling effects of arthritis in Chankom.

Keywords

Arthritis; Qualitative Research; Health Services, Indigenous; Health Policy

5.2 Introduction

Arthritis is an umbrella term used to refer to different chronic diseases primarily affecting the joints, including osteoarthritis (OA) and rheumatoid arthritis (RA) [1]. It is one of the leading causes of disability worldwide [2] producing a significant burden to society [3, 4]. The disabling effects of arthritis are more prevalent and pronounced in low socio-economic areas [5]. In Mexico, the presence of RA has been associated with catastrophic health expenses that lead to impoverishment, especially for people at a lower socioeconomic level [6]. In addition, social inequities have been linked with an increased prevalence of OA [7].

A recent epidemiological study conducted by our research group in the municipality of Chankom, a rural underserved Mexican indigenous community, showed an 11% prevalence of arthritis, which was associated with a higher risk of disability (Submitted January 2014 to a special supplement in Clinical Rheumatology). However, there is still a gap in understanding how arthritis impacts people's daily lives in this community.

Furthermore, it is well known that rural and indigenous communities in Latin America have problems in accessing healthcare services [8, 9]. Therefore, it is important to understand how people living with arthritis in Chankom access these services. In addition, there is a lack of information about the perceived needs of Mexican indigenous communities living with chronic diseases, such as arthritis. Consequently, this work aims to describe the impact of living with arthritis in the municipality of Chankom, identify the perceived health needs around this issue and to understand the barriers for accessing health care services in this community.

5.3 Methodology

5.3 1 Setting

This work is part of an on-going project being conducted in the Municipality of Chankom since 2012, designed to develop, implement, and evaluate a community based rehabilitation program (CBRP) to decrease the prevalence and disabling effects of musculoskeletal diseases [10]. The Mexican municipality of Chankom, located in the Southeast State of Yucatán, has a population of 4464 inhabitants [11] living in 11 small rural villages or commissariats, all from the Maya-Yucateco ethnicity. More than eighty percent of Chankom's population lives in poverty [12]. The main productive activities in Chankom are agriculture and craftsmanship. There is also an increasing group of people who work outside the community in the tourist areas of Chichén-Itzá and Cancún. Ninety-seven percent of the people from Chankom have government-funded health insurance known as “Seguro Popular” [13]. Primary healthcare services are located within the municipality, while the secondary and tertiary healthcare services lie outside Chankom. Medical and nursing students completing a year of compulsory community service provide primary healthcare services. In addition, local health promoters or “auxiliares de salud” provide some primary care services. Health promoters are community members trained by Yucatán's Ministry of Health to provide health promotion and basic healthcare procedures, such as cleaning wounds and prescribing basic medications. The only health service provided by the municipal government is the transportation of people who seek medical attention outside the municipality.

5.3.2 Study design

The overall theoretical approach for this project aligns with a social constructivist worldview [14]. We followed an ethnographic approach, which implies that the fieldwork in which the data were collected occurred within the natural context in which phenomena occur [15]. The data were collected during two periods.

The purpose of the first data collection period, which occurred between August 2012 and April 2013, was to understand the medical-anthropological “explanatory models of illness” within the “popular, folk and professional” health systems in Chankom as defined by Kleinman [16, 17]. During this time, an anthropology student, an anthropologist and a physiatrist (ALS) lived periodically in the area and conducted in-depth and informal interviews along with non-participant and participant observations, which were systematically recorded as field notes (Appendix D). Sixty-five individuals were interviewed, resulting in 76 interviews as some participants were interviewed a second time for clarification. These interviews involved: people living with arthritis (n=16 with hand, hip or knee OA, n=14 with RA and n=2 with non-specific arthritis), family members of people living arthritis (n=4), local health promoters (n=11), community leaders (n=5), traditional health providers (n=2 witchdoctors or “H-Men”, n=1 bone-setter and n=1 herbalist), medical and nursing students (n=5), general physicians (n=3), and municipal authority (n=1). Most interviews were conducted with the help of local Mayan/Spanish translators. All interviews were audio-recorded and transcribed.

The second data collection period was between December 2013 and December 2014. During this time, we began a process of community organization in which we arranged information sessions to increase awareness of arthritis. These sessions resulted in the creation of

11 commissariat groups, with one per commissariat. Four to five commissariat leaders led each group. These leaders were selected by each commissariat to identify the community health needs related to arthritis. These commissariat groups held regular meetings and conducted information sessions to maintain open communication. The leaders discussed their individual community's health needs with other commissariat leaders at municipal meetings. The needs of the municipality were then summarized and presented to each commissariat, as a community checking exercise (see Figure 1). A total of 40 commissariat and six municipal meetings were held and facilitated by the local project coordinator, who received training on meeting facilitation. Different techniques for analyzing community problems were used during the meetings (e.g. the “But why?” technique or the Force field analysis technique) using the University of Kansas free online Community Tool Box [18]. An anthropologist attended all meetings and took notes that she later used to write reports.

This study was approved by the Hamilton Health Sciences /McMaster University Research Ethics Board (12-544), the Ethics Committee of the Faculty of Medicine, Universidad Anáhuac-Mayab, and the Ethics Committee of the “Hospital General de México, Dr. Eduardo Liceaga” (DI/11/4044B/3/123) (Appendix B). Participants were only included if they provided written informed consent, obtained through local Mayan interpreters.

5.3.3 Analysis

A physiatrist (ALS) and a medical anthropologist (IPB) analyzed the data, using a modified version of the “Framework” approach, which is formed by 5 analytic stages: familiarization, identification of a thematic framework, indexing, charting and

mapping/interpretation [19]. The familiarization stage was executed by one researcher (ALS). During this stage, all data sources (76 interview transcripts and 46 meeting reports) were reviewed and preliminary themes and subthemes identified, annotating the sources that inspired and supported those themes and subthemes. In addition, the content of each source was assessed for richness of information about the impact of arthritis, healthcare access, and community needs.

Sensitizing concepts, or concepts that bring together different ideas [20], were identified and structured as a codebook during the “identification of a thematic framework”. This codebook was continuously refined, using constant reflection and data-interrogation, and reviewed by two researchers (ALS, IPB). During the indexing stage, one researcher (ALS) coded the data sources with the richest and most representative information for each sensitizing concept. In addition, extensive field notes, taken by this researcher (ALS), were included in the coding process, providing context and incorporating participant and non-participant observations into the analysis.

During the charting stage, tables were used to construct themes and subthemes through abstraction and synthesis of sensitizing concepts. Two researchers (ALS, IPB) discussed the tables and made conceptual connections using conceptual maps. These maps permitted a dialogue between the themes and existing concepts and theories from the literature. The maps were further refined as figures that helped in the construction of the study main findings during the interpretation of results (mapping and interpretation stage). The organization and management of all data sources was done using the software HyperResearchTM, version 3.7.1.

5.3.3.1 Rigor. Different triangulation efforts were conducted to assure the rigor or authenticity of the findings. Our results were checked by: a) using various sources of data (data

triangulation), b) linking various data acquisition methodologies (methodological triangulation), and c) involving multiple researchers (investigator triangulation). In addition, the validity of our results was checked by presenting them to key informants and community members. Moreover, all themes constructed are well supported by the data because data saturation was reached. All analytic decisions were recorded with a written audit trail.

This was a cross-language study; therefore, we undertook methodological efforts to compensate for language barriers between researchers and participants, which are known to affect the rigor of qualitative research [21]. Data were collected with the assistance of a male Mayan interpreter, who is a Baptist church pastor in one commissariat of Chankom municipality. This interpreter has had extensive experience working in non-governmental organizations for social development, which has gave him sufficient sociolinguistic skills to communicate in Mayan and Spanish, including the use of complex sentence structures and substantial vocabulary in both languages.

The preservation of conceptual equivalence was sought through various mechanisms. First, the interpreter became a collaborator in the data collection process, as has been recommended to ensure the conservation of conceptual meaning [22]. Second, neither of the researchers was fluent in Mayan; hence, data analyses were conducted in Spanish. Once themes and interpretations were constructed and refined, they were translated to English, because keeping the analyses in the original language as long as possible has been recommended to avoid loss in meaning [23]. Third, after themes and interpretations were translated into English, discussion sessions were held among Spanish and English speaking researchers using “fluid descriptions of meanings” going back and forth to the original codes, assuring that intended messages were not lost in translation [23].

5.4 Results

The three main themes constructed in this study were: 1) living with arthritis, 2) seeking “good medical care” and 3) accessing health care. Tables one, two and three present representative quotes from each of the subthemes that form these main themes.

5.4.1 Living with arthritis (see Table 1)

Arthritis produces pain, loss of joint mobility and decreased muscle strength, which impede activities that involve the upper and lower extremities. The natural environment in which the people of Chankom perform all their roles is very physically demanding, requiring high levels of physical activity. This demanding environment acts as a barrier for people living with arthritis to being completely productive in their society, in accordance with their cultural norms. Productivity loss has several consequences. First, it has an emotional impact on people, producing feelings of frustration, anger, sadness and shame. Second, not being able to work, people spend money looking for solutions to compensate for decreased productivity, which results in economic hardship. Third, family members have to pay for medicines and healthcare services and spend time helping their relatives fulfill their roles.

5.4.2 Seeking “good medical care” (see Table 2)

All 11 commissariats of Chankom’s municipality agreed that the main need for people living with arthritis in their communities is to have “good medical care”. In addition, the

community described the essential attributes of “good medical care” related to the characteristics of health providers and the local health services.

5.4.2.1 Health provider characteristics. The community identified the need for skilled, permanent health providers to detect and manage arthritis, which would include drug and exercise prescriptions. In addition, the community recognized that it is essential that health providers are sensitive and respectful of their Mayan culture, competent in the Mayan language, and supportive in their navigation of the Mexican health system.

5.4.2.2 Local health services’ characteristics. The community identified the need for local health imaging and clinical laboratory services and spaces to exercise. An efficient local health transportation service, access to effective medications and preventive services to decrease arthritis were also important.

5.4.3 Accessing healthcare (see Table 3)

There is a lack of health infrastructure within the municipality. Drugstores, x-rays, clinical laboratories, spaces to perform exercise and rehabilitation services are not available. People travel outside the community for services, resulting in physical and emotional stress and personal financial cost. Accessing financial resources for travelling outside the community to receive care is a challenge. Consequently, without funds people cease to seek health services. There is also the perception that there is a dearth of accessible information available, that the health system is complicated and that health providers are sometimes hostile. Hence, health services are underutilized and people often make poorly informed decisions while navigating the health system.

Most of the services available to the people living with arthritis in Chankom are not acceptable for various reasons. First, the health transportation services provided by the local government are not perceived as efficient. The users access these services through a direct request to municipal authorities. Transportation services are often provided in exchange for political support, and non-supporters are not granted access. There are insufficient vehicles, which are also used for other purposes, such as student transportation. Second, participants' stories describe mistreatment, or ethnic discrimination from health professionals inside and outside the municipality, resulting in a reluctance to seek professional health services. Third, local health promoters are poorly compensated for their work and have multiple jobs; nevertheless, the Ministry of Health requires them to work long hours and provide weekend coverage during medical students' absences. This affects the quality of the services they deliver, diminishing user satisfaction. Fourth, health professionals lack knowledge and competence about the diagnosis and management of arthritis, disability and rehabilitation. Patients are not able to form sustained relationships due to the constant change of providers. Finally, language differences between users and health professionals coupled with insensitivity towards the Mayan culture result in users' mistreatment.

5.5 Discussion

The themes constructed from the data in this study were further interpreted with the help of different concepts and theories available in the literature on the topics of disability, access to healthcare and social inequity. The main findings resulting from these interpretations show that arthritis reduces the health-related quality of life of people living in Chankom through a process

of disablement. This process determines the need of Chankom's inhabitants to access culturally sensitive healthcare. Finally, there are different barriers to accessing culturally sensitive healthcare in Chankom, which are explained by the presence of structural violence, a term coined by Johan Galtung (1969) and recently used to analyze the socioeconomic and cultural factors behind the manifestation of disease and health inequities [24].

Using the taxonomy of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) [25] and the socio medical "disablement process" theory [26] it is clear how living with arthritis negatively impacts on the health-related quality of life in Chankom (see Figure 2). The "disablement process" theory states that social participation restrictions, resulting from body impairments and activity limitations conditioned by a pathologic process, are explained by a gap between a person's capacity to execute activities and the environmental demands required for executing them [26]. Consequently, the presence of arthritis in Chankom reduces the capacity of individuals to respond to an extremely physically demanding environment resulting in an inability to fulfill culturally defined social roles.

As shown in Figure 2, in Chankom's culture being productive or a "good worker" in all areas of life is one of the main values for the community [27]; therefore participation restrictions associated with arthritis negatively impact psychological, familial and economic aspects of their lives. The people of Chankom need to be physically productive to thrive. When this capacity is lost, their lives and the lives of the people around them are affected. Consequently, any disablement process that threatens the capacity for the people of this community to participate in their culturally defined roles will interfere with their work ethic. This results in life

dissatisfaction and reduced well-being, which are the central constructs of health-related quality of life [28].

Our findings related to the arthritis-related disablement process confirm the results of other qualitative research conducted with people living with RA [29]. The family psychosocial burden associated with arthritis has also been observed in English cities [30]. As well, the negative impact on social participation associated with living with OA and RA has also been documented in other communities within high-income countries [31, 32].

Even though Chankom's community literally defined obtaining "good medical care" as the main need for people living with arthritis, it is clear from their definition of this concept that they refer to a type of care that goes beyond the physician-patient interaction; therefore, it is interpreted that the main need associated with the presence of arthritis in this community is access to culturally appropriate healthcare, which can be labeled as culturally sensitive healthcare. The WHO defines appropriate healthcare services as those, which are available, accessible, acceptable, and of good quality [33]. Our findings show that the healthcare services available to Chankom's people do not meet any of these attributes; hence, healthcare for this community is not appropriate, violating the human right to "obtain the highest attainable standard of health" [33]. Unfortunately for indigenous people, this finding is not new, as problems with access to appropriate healthcare services have been consistently identified in rural and indigenous communities of Latin America [8, 9]. Moreover, lack of access to appropriate healthcare has been identified for patients with arthritis living in rural and low socioeconomic areas in Ontario, Canada [34].

Using the conceptual framework describing "access to healthcare", proposed by McIntyre et al (2009) [35] the barriers faced by people living with arthritis in Chankom to accessing

culturally sensitive healthcare were interpreted along with their underlying factors, issues and roots. As shown in Figure 3, the roots underlying the barriers to access culturally sensitive healthcare can be explained by the existence of structural violence. Structural violence refers to the interference with community and individual development resulting from socially validated economic, political, legal, religious or cultural structures [24]. Reflecting on the socioeconomic structures present in Chankom and the way they function, we propose that power imbalance between indigenous and non-indigenous people is at the core of this structural violence.

This power imbalance can be traced historically to the process of colonialism. Colonialism, in this case, refers to the practice of domination of European people over indigenous people that began with the arrival of Spaniards to America. A consequence of this practice was the emergence of a “logic of subordination”[36] of indigenous cultures that has endured to this present day, hindering the social development of indigenous people in Latin America [37, 38].

The lack of social development in Chankom results in four main phenomena, which are the main underlying issues linked to the factors constituting the barriers to accessing culturally sensitive healthcare in this community (see Figure 3): 1) Conditions of poverty, such as a poor health infrastructure in the municipality, forces people to travel outside their communities to seek care. In addition, the inability to pay for outside services, and the lack of health literacy associated with low levels of education interferes with the ability to navigate the Mexican health system. 2) Political patronage results in healthcare access inequities. 3) Exploitation of the local health promoters as a result of diminished recognition of their work by the Health Ministry reduces the quality of their services. 4) Ethnic discrimination results in mistreatment or treatment devoid of cultural consideration during the patient-provider encounter. This ethnic discrimination

has also been recently reported in indigenous people living with arthritis in Canada [39]. Moreover, discrimination at the system level explains why constantly changing and inexperienced health professionals are in charge of primary healthcare services in rural and indigenous communities.

Figure 3 also shows that the factors fundamental to the barriers to access culturally sensitive healthcare in Chankom come from the subthemes presented in the results under the main theme: “accessing healthcare” (see Table 3). These factors group to form the dimensions of availability, attainability and acceptability barriers to culturally sensitive healthcare access. The original “affordability” dimension of access to healthcare proposed by McIntyre et al [35] was expanded to include issues beyond economic factors, such as paucity of information and a complicated health system; therefore, in incorporating these extra factors this dimension was renamed “attainability”.

In sum, structural violence generated by power imbalances between indigenous and non-indigenous people in favour of the latter, produces availability, attainability and acceptability barriers that limit access to culturally appropriate healthcare for people living with arthritis in Chankom. This access limitation conditions a community-perceived need to improve their healthcare services towards reducing the negative impact of arthritis in this marginalized community.

5.5. 1 Strengths and limitations

The strengths of this study include a strong methodology and a thorough representation of stakeholders involved in the problem of arthritis in Chankom. The data used in this study came from well-established ethnography fieldwork, which allowed us to obtain interview data at

different points in time and systematic observations from different researchers. This methodology helped us to achieve saturation and to triangulate our sources and types of data to enhance our results. Our design also ensured the inclusion of a comprehensive sample of people representing a good variety of users and health care providers, which improves the representativeness of our results and strengthens our interpretations.

The most important limitation of this study concerns the cross-language nature of the project. Our interpreter's translations were not validated by an external translator and a professional translator was not involved in the translation of findings and participants' quotes to the English language, as is recommended for cross-language qualitative studies [21, 23]. Consequently, we cannot ensure a complete preservation of conceptual equivalence during the two waves of translation (Mayan to Spanish and Spanish to English) and this could have affected the trustworthiness of our results and interpretations. However, we conducted some methodological strategies to compensate for language differences in the study as described in the "rigor" subsection of the analysis. Another limitation is related to the fact that one of the researchers (ALS) initiated his work in the community taking the role of a physician. Initially, this situation affected the quality of his interviews as many participants thought they were interviewed for medical reasons. Anthropologists partially compensated for this situation by re-interviewing some of the participants interviewed by this researcher and by discussing and triangulating the information with him.

5.5.2 Implications for policy

Our findings suggest that Mexican laws and policies have not been enacted. Mexican laws protect the right of indigenous people to access appropriate health care, involving them in the design of health policies. The Mexican political constitution (article 2) mandates consultation with indigenous people to design health policies that affect them [40]. The law for the protection of rights of the Mayan people living in Yucatan states that regional and municipal governments must guarantee the involvement of indigenous communities in community health program design [41]. However, the participation of Mayan people in the design of their health programs has not been instituted. This gap between the law itself and its enactment supports the peoples' perception of lack of appropriate healthcare, highlighting a need to design health policies that assure the implementation of these laws. Implementing these strategies at the municipal level, an approach advocated by the United Nations development program, is more likely to ensure the creation of effective local policies that will result in the desired outcomes [37].

In 2011 the Mexican federal government promulgated a law to protect the rights of people living with disabilities [42]. This law requires the federal Ministry of Health to create infrastructure and programs for the rehabilitation of people living with disabilities in rural and indigenous areas. In response, the Yucatan government promulgated a law, which directs the responsibility to the State and municipal governments for assuring access to rehabilitation services for people living with disabilities in Yucatán [43]. The lack of rehabilitation services in the municipality of Chankom highlights a gap in these laws' enactment, and identifies a need for designing policies that facilitate the development of rehabilitation services for this community.

Our findings also show that the quality of health care provided by the public health insurance program “Seguro Popular” for people living with arthritis in Chankom is less than optimal. The Mexican General Health Law outlines that all health units that provide services to

persons who receive this health insurance need to complete an accreditation process that includes an assessment of quality of service [44]. This quality assessment requires the presence of personnel with intercultural competences in the case of units that provide care to indigenous populations [45]. Consequently, our findings show the need to implement strategies to increase health providers' intercultural competencies within the primary, secondary and tertiary healthcare services provided by “Seguro Popular” in Yucatán.

5.5.3 Implications for practice

Our findings expose the need of an intervention to improve access to optimal health care for people living with arthritis in Chankom. The people in this municipality in collaboration with their local government and the regional health ministry must design this intervention. Unless the people of Chankom are engaged to participate in developing their health programs, culturally sensitive healthcare is unlikely to be achieved due to the existence of health inequities. Both, the municipal and the regional government authorities have the constitutional mandate of promoting the participation of the Mayan community in the development of culturally appropriate rehabilitation programs that reduce the disabling effects of arthritis.

The disablement process resulting from arthritis highlights the importance of considering persons living with this chronic disease not only as biological entities but also as social beings. These findings also underline the importance of taking physical environmental demands into account when designing solutions for people living with arthritis.

Finally, we, the non-indigenous researchers and health providers, have a moral obligation to continue identifying the existence and influence of health inequities within indigenous communities in order to take action. We also need to deepen our understanding of the processes

behind structural violence by attending to the historical generation of the current social, economic, cultural and political structures, as well as our own individual prejudices towards indigenous people.

5.6 Acknowledgements

We like to thank the group of anthropologists that participated in the data acquisition for this work: Anthropologists Gabriela Cruz, Johan Sanín Matamoros and Daniela Flores.

We thank Mr. Diego Yeh Cen for his services as an interpreter and Mr. Carlos Castillo Kuyoc along with all participants from Chankom municipality for their time and effort to complete this work.

We like to thank Psychologist Guillermo Pérez for his hard work transcribing the extensive material used for the creation of this manuscript.

We thank the municipal authorities of Chankom and the authorities from the Jurisdicción Sanitaria No. 2, Valladolid for supporting the conduction of this research study.

This work was funded by the “International League Against Rheumatism (ILAR)” and the “Consejo Nacional de Ciencia y Tecnología [CONACYT]” (grant #162154). ALS received funding from CONACYT’s doctoral scholarship for studying abroad (scholarship #209621) and from the Doctoral Vanier Canada Scholarships (# 268078).

5.7 References

1. Reginster JY (2002) The prevalence and burden of arthritis. *Rheumatology* (Oxford, England) 41:3-6
2. Arthritis Community Research and Evaluation Unit (2013) Arthritis in Canada. CAN2013-1
3. Gabriel SE (2001) The epidemiology of rheumatoid arthritis. *Rheum Dis Clin North Am* 27:269-281
4. Gabriel SE, Crowson CS, O'Fallon WM (1995) Costs of osteoarthritis: estimates from a geographically defined population. *J Rheumatol Suppl* 43:23-25
5. Baldassari AR, Cleveland RJ, Callahan LF (2013) Independent influences of current and childhood socioeconomic status on health outcomes in a North Carolina family practice sample of arthritis patients. 65:1334-1342
6. Alvarez-Hernandez E, Pelaez-Ballestas I, Boonen A et al (2012) Catastrophic health expenses and impoverishment of households of patients with rheumatoid arthritis. *Reumatol Clin* 8:168-173
7. Rodriguez-Amado J, Moreno-Montoya J, Alvarez-Nemegyei J et al (2014) The Social Gap Index and the prevalence of osteoarthritis in the community: a cross-sectional multilevel study in Mexico. *Clin Rheumatol*. doi: 10.1007/s10067-014-2776-y
8. Targa LV, Couper ID, Worley P (2014) A new ally for the promotion of better rural health in Latin America. *Rural Remote Health* 14:3376
9. Montenegro RA, Stephens C (2006) Indigenous health in Latin America and the Caribbean. *Lancet* 367:1859-1869
10. Loyola Sanchez A, Richardson J, Pelaez-Ballestas I et al (2014) Developing Community-Based Rehabilitation Programs for Musculoskeletal Diseases in Low-Income Areas of Mexico:

The Community-Based Rehabilitation for Low-Income Communities Living With Rheumatic Diseases (CONCORD) Protocol. JMIR Res Protoc 3:e57

11. INEGI (2005) 11 Conteo de Población y Vivienda.

12. Consejo Nacional de Evaluación de la Política de Desarrollo Social (2014) Informe Anual sobre la Situación de Pobreza y Rezago Social. Chankom, Yucatán. [Annual inform on the Poverty and Social Lag Situation. Chankom, Yucatán]. Yucatán_017

13. Frenk J, Gonzalez-Pier E, Gomez-Dantes O, Lezana MA, Knaul FM (2007) [Comprehensive reform to improve health system performance in Mexico]. Salud Publica Mex 49:S23-36

14. Berger PL, Luckmann T (1966) The Social Construction of Reality. Anchor Books: a division of Random House Inc., NY, US

15. Hammersley M, Atkinson P (1995) Ethnography. Principles in Practice. Routledge, NY

16. Kleinman A (1980) Orientations 3. Core Clinical Functions and Explanatory Models. In: Leslie C (ed) Patients and Healers in the Context of Culture. University of California Press, London, UK, pp 71-118

17. Kleinman A (1980) Orientations 2: Culture, Health Care Systems, and Clinical Reality. In: Leslie C (ed) Patients and Healers in the Context of Culture. 1st edn. University of California Press, London, UK, pp 24-70

18. Community Tool Box. (2014). <http://ctb.ku.edu/en/about-the-tool-box>. Accessed 2 Feb 2015

19. Ritchie J, Spencer L (2002) Qualitative data analysis for applied policy research. In: Huberman AM, Miles MB (eds) The Qualitative Researcher's Companion. Sage Publications, Inc., Thousand Oaks, pp 305-330

20. Hammersley M, Atkinson P (2007) 8. The process of analysis. In: Hammersley M, Atkinson P (eds) *Ethnography. Principles in practice*. Third edn. Routledge. Taylor & Francis Group, NY, USA, pp 158-190
21. Squires A (2009) Methodological challenges in cross-language qualitative research: a research review. *Int J Nurs Stud* 46:277-287
22. Larkin PJ, Dierckx de Casterle B, Schotsmans P (2007) Multilingual translation issues in qualitative research: reflections on a metaphorical process. *Qual Health Res* 17:468-476
23. van Nes F, Abma T, Jonsson H, Deeg D (2010) Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing* 7:313-316
24. Farmer PE, Nizeye B, Stulac S, Keshavjee S (2006) Structural violence and clinical medicine. *PLoS Med* 3:e449
25. World Health Organization (2001) *International Classification of Functioning, Disability, and Health*. World Health Organization, Geneva
26. Verbrugge LM, Jette AM (1994) The disablement process. *Soc Sci Med* 38:1-14
27. Redfield R, Villa Rojas A (1934) *Chankom. A Mayan village*. University of Chicago Press, USA
28. Ferrans CE, Johnson Zerwic J, Ellen Wilbur J, Larson JL (2005) Conceptual Model of Health-Related Quality of Life. *J Nurs Scholarsh* 37:336-342
29. Stack RJ, Sahni M, Mallen CD, Raza K (2013) Symptom complexes at the earliest phases of rheumatoid arthritis: a synthesis of the qualitative literature. *Arthritis Care Res (Hoboken)* 65:1916-1926
30. Matheson L, Harcourt D, Hewlett S (2010) 'Your whole life, your whole world, it changes': partners' experiences of living with rheumatoid arthritis. *Musculoskelet care* 8:46-54

31. Victor CR, Ross F, Axford J (2004) Capturing lay perspectives in a randomized control trial of a health promotion intervention for people with osteoarthritis of the knee. *J Eval Clin Pract* 10:63-70
32. Eyckmans L, Hilderson D, Westhovens R, Wouters C, Moons P (2011) What does it mean to grow up with juvenile idiopathic arthritis? A qualitative study on the perspectives of patients. *Clin Rheumatol* 30:459-465
33. World Health Organization (2013) The right to health. 323
34. Badley EM, Canizares M, Gunz AC, Davis AM (2015) Visits to rheumatologists for arthritis: the role of access to primary care physicians, geographic availability of rheumatologists, and socioeconomic status. *Arthritis Care Res (Hoboken)* 67:230-239
35. McIntyre D, Thiede M, Birch S (2009) Access as a policy-relevant concept in low- and middle-income countries. *Health Econ Policy Law* 4:179-193
36. Kohn M (2014) Colonialism. In: Zalta EN (ed) *The Stanford Encyclopedia of Philosophy*. Spring 2014 edn. <http://plato.stanford.edu/archives/spr2014/entries/colonialism/>. Accessed 23 December 2014
37. Programa de las Naciones Unidas para el desarrollo (PNUD) (2010) Informe sobre el desarrollo humano de los pueblos indígenas en México: El reto de las desigualdad de oportunidades. Programa de las Naciones Unidas para el desarrollo, Mexico
38. Quijano A (2014) Colonialidad del poder y clasificación social. In: De Souza Santos B, Meneses MP (eds) *Epistemologías del sur (Perspectivas)*. Ediciones Akal, S.A., España, pp 67-108

39. Thurston WE, Coupal S, Jones CA et al (2014) Discordant indigenous and provider frames explain challenges in improving access to arthritis care: a qualitative study using constructivist grounded theory. *Intern J Equity Health* 13:46
40. Constitución Política de los Estados Unidos Mexicanos. (2001) Artículo Segundo. La nación Mexicana es única e indivisible
41. Ley para la protección de los derechos de la comunidad Maya del Estado de Yucatan. (2011) Decreto 407 Diario Oficial del Gobierno del Estado de Yucatán
42. Ley general para la inclusión de las personas con discapacidad. (2011) Diario Oficial de la Federación 30/05/2011
43. Ley para la protección de los derechos de las personas con discapacidad del Estado de Yucatán. (2011) Decreto 469
44. Gomez Dantes O, Sesma S, Becerril VM, Knaul FM, Arreola H, Frenk J (2011) [The health system of Mexico]. *Salud Publica Mex* 53:s220-32
45. Santacruz Varela J, Castillo Carrión JC (2014) Manual del sistema de acreditación y garantía de calidad en establecimientos para la prestación de servicios de salud.

Table 1. Quotations for the main theme: Living with arthritis

Subtheme	Quotation
Feeling pain, loss of mobility and muscle weakness	<i>I couldn't, it hurt so much...I couldn't get up, so I stayed without moving for a long time...and now I do not have enough strength. (Man, 75 years old with RA for 8 years).</i>
Dealing with a demanding environment	<i>By the end of this working day at the milpa, I concluded that cutting up trees for firewood requires vigorous physical activity producing an important load on the all the joints of the body... (Field notes, physiatrist).</i>
Losing productivity	<i>I kept working but slowly so I worked little. Before, I could work 100 mecates^a of milpa^b, now I cannot even work half of a mecate...I cannot work hard...How am I suppose to continue living? (Man, 63 years old with knee OA for 12 years).</i>
Feeling bad	<i>Sometimes I sit and cry thinking about my plants. I cannot grow plants anymore...I cannot water them. When people flatter the plants at my home I feel ashamed, because they are not the result of my work. I am very angry for not being able to do what I want to do. (Woman, 72 years old with knee OA for 25 years).</i>
Losing money and income	<i>I cannot remember how many thousands of pesos I have spent on private doctors. (Woman, 63 years old with RA for 8 years).</i> <i>This year, I paid someone else to work my milpa. (Man, 65 years old with hip OA for 25 years).</i>
Depending on others	<i>My sons help me. They buy my medicines and took me to the doctor. (Man, 63 years old with knee OA for 12 years).</i> <i>I have to take care of my wife... when she cannot get out of her hammock I need to take care of the children and prepare the food so I cannot go to work...I cannot leave her alone for long... nobody else can take care of her, so I cannot leave the community to find a well-paid job. (Husband of a woman with RA).</i>

^a A “mecate” is a measurement of area commonly used by the Mayans. One mecate equals to 20 m².

^b The milpa is a popular term among the Mayans used to refer to all of their usual agricultural activities.

Table 2. Quotations for the main theme: Seeking “good medical care”

Subtheme	Quotation
We need health providers who are:	
Permanent and skillful	<i>All participants commented that they need a permanent doctor, not a student. “A student doesn’t know, he is just learning”. (1st municipal meeting).</i>
Sensitive and respectful of Mayan culture	<i>The current doctor discriminates and mistreats people in the community. This case has been reported to the health authorities. The response from this doctor was “nobody can harm me, you cannot interfere with me getting my medical degree”. (Commissariat group, Xkalakdzonot).</i>
Competent in Mayan language	<i>That is why you always need to go (to the doctor) with an escort, and even if the escort speaks Spanish, the doctors use technical terms. (Commissariat group, Ticimul)</i>
Supportive for navigating the health system	<i>We need to know what doors to knock on, whom to talk to, and how to move in the health system. (Commissariat meeting, Xkalakdzonot)</i>
We need these health services:	
Local imaging and clinical laboratory	<i>We need specialists, medications, clinical laboratory services and imaging services. (6th Municipal Meeting)</i>
Adequate spaces to do exercise	<i>Even the children do not have a place to do exercise. (1st Municipal meeting).</i>
Efficient local health transportation	<i>Municipal ambulances are used for other things and they leave the sick waiting. They are not used appropriately. (2nd Municipal meeting).</i>
Effective medications	<i>Public: We need to talk but not only that. We need medicines now! (Commissariat meeting, Xkalakdzonot).</i>
Disease prevention	<i>We need to show a video to the people so they can understand better about reumas (rheumatic diseases). Doing this we can increase awareness and prevent the disease. (Commissariat meeting, Ticimul).</i>

Table 3. Quotations for the main theme: Accessing healthcare

Subtheme	Quotation
Lack of health infrastructure and specialized services	<i>He told us (a person living with RA) that each trip to get medical consultation to Valladolid costs him 240 pesos and sometimes he needs to make 2 trips every two weeks because the drugs are not always available the first time he goes. (Field notes, physiatrist). We urgently need a specialist that comes to the community...because we have to look how to take him (referring to his grandfather)...we try everything...we switch buses and cars and this is too much of a burden for him. (Grandson of a person with RA).</i>
Lack of money	<i>I was lying on my hammock for one month. Honestly, we did not have money so my husband tried to get some to take me to the doctor but it took him a while. (Woman, 63 years old with RA for 8 years).</i>
Lack of information within a complicated health system	<i>Minutes later, the internal medicine resident received the hospital voluntary discharge form...and ask Don D to sign it. Don D thought that by signing this letter he could leave his brother at the hospital and go home...we then explained him that the form was to take his brother back home releasing the hospital from any responsibility of what could happened to him. Hearing this, Don D refused to sign and decided to stay at the hospital, as this was required for his brother to continue receiving service. (Field notes, physiatrist).</i>
Inefficient health transportation	<i>If one (person) supports the party opposed to the Municipal president's political party, then the service (transportation) is denied. (Woman, health promoter) We play with the ambulances, the ambulances are used for everything...the ambulances leave at five in the morning to carry students...(Man, Municipal government authority).</i>
Mistreatment	<i>I visited her at the hospital in Valladolid...she recognized me and smiled; however we could not communicate due to our language differences...she was asking for something but nobody even tried to listen to her...her son arrived and told me that she was cold...it struck me that not a single nurse attended to this woman's request. (Field notes, physiatrist).</i>
Exploited local health promoters	<i>I think we do more than what physicians do. I am the one who does everything around here and he just signs. We should be paid more for our services...it is fair... this job is a responsibility...we have to leave our own work to do this. We have asked for more payment but unfortunately the response (from the health authority) is always "if you want to get paid then go to university". (Woman, health promoter).</i>
Lack of competence in health professionals	<i>We visited Ms F (woman with RA) at her home and we found her sitting on her hammock in a lot of pain. Her daughter told us that they went to visit Dr. P and he told them the problem was that she was old and prescribed her glucosamine (a nutrition supplement). She had not found any pain relief from taking this product. (Field notes, physiatrist).</i>

Table 3 Quotations for the main theme: Accessing healthcare (continued)

Subtheme	Quotation
Impermanent health providers	<i>Honestly, it is a problem that they (medical students) change every year. If one doctor already knows how to manage a patient and then leaves, the new one will not know how to do this and what has happened with this patient. (Woman, health promoter).</i>
Language differences and lack of cultural sensibility	<i>It is a problem (that the health professionals do not speak Mayan). My wife does not speak Spanish, so it is complicated when she needs medical care. I always have to be there for her to listen what they tell her and what they prescribe to her. (Male, health promoter).</i> <i>There have been many complaints (from the users). They come to me and tell me that the doctor did not want to give them medicine or consultation. The problem is that the doctor does not understand what the family said and wants. (Woman, health promoter).</i>

Figure 1. Process of defining community needs concerning the problem of musculoskeletal diseases in Chankom

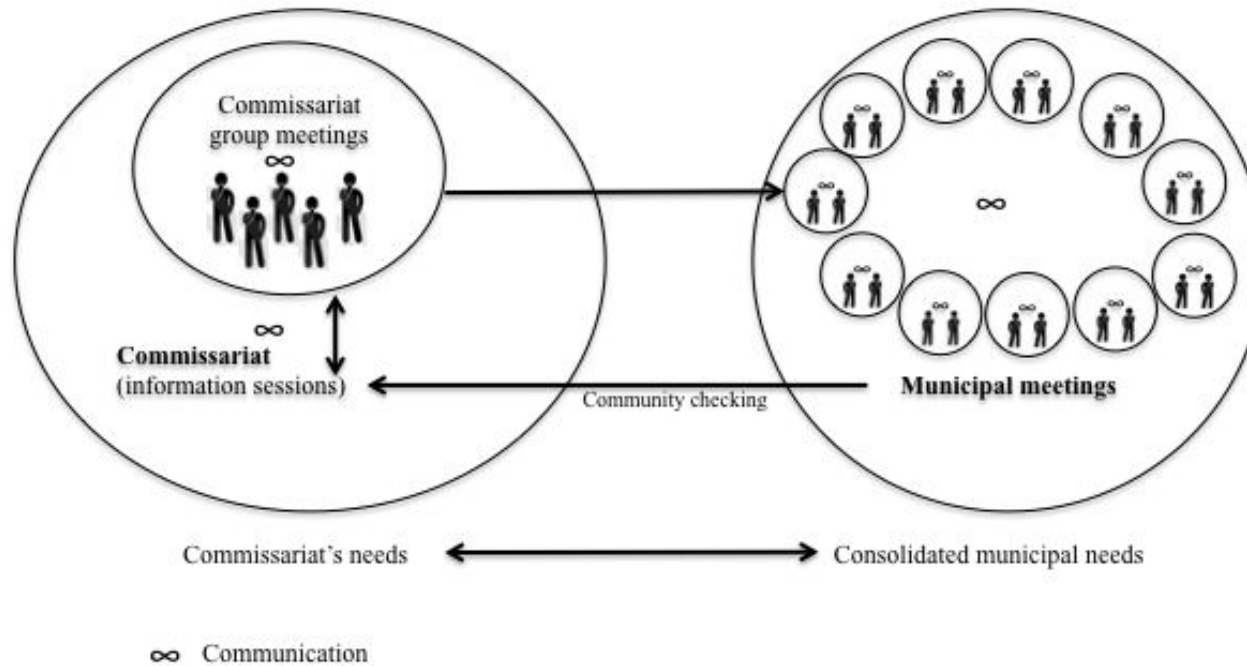


Figure 2. The disablement process of arthritis in Chankom and its impact on the health-related quality of life.

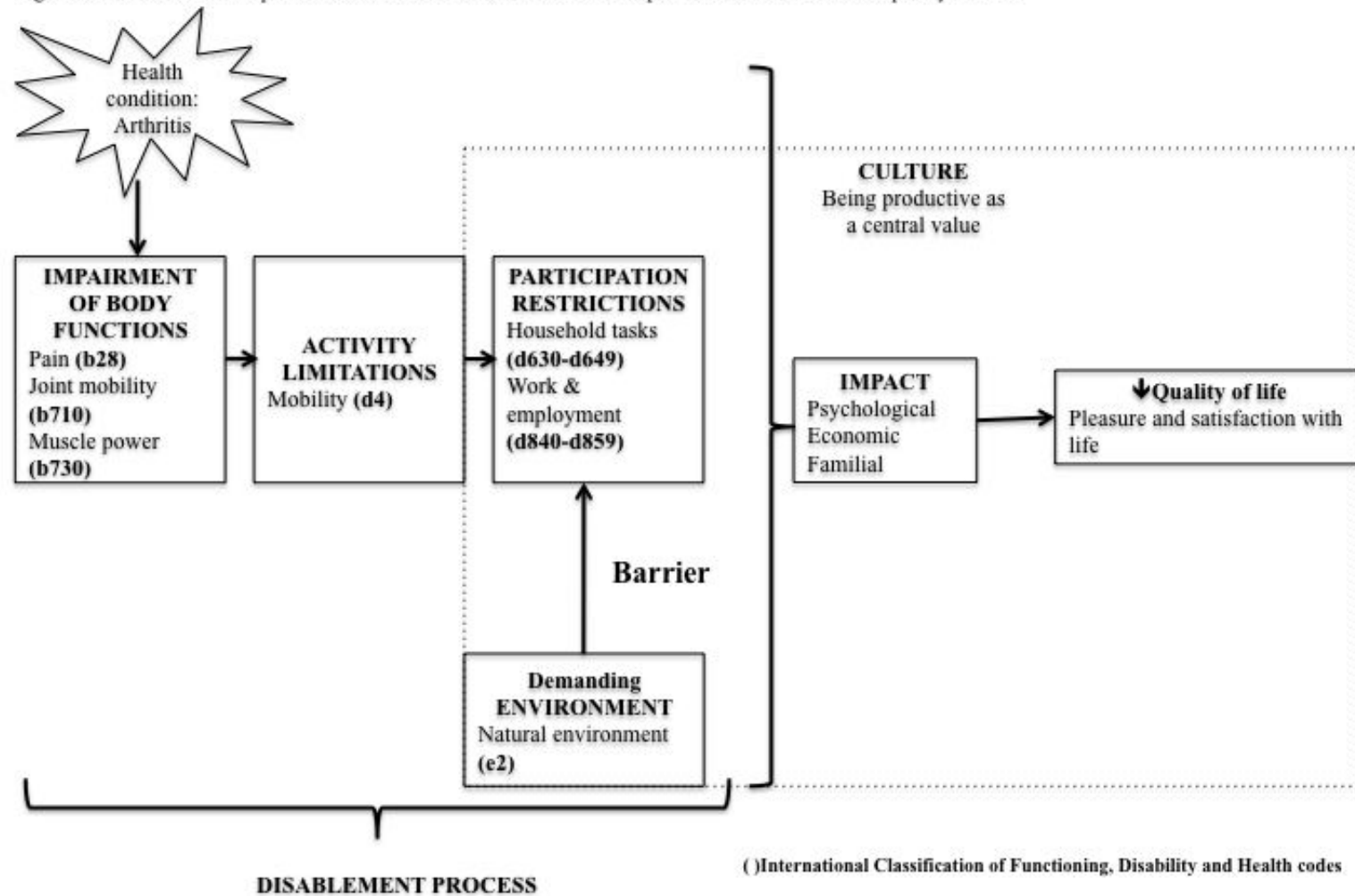
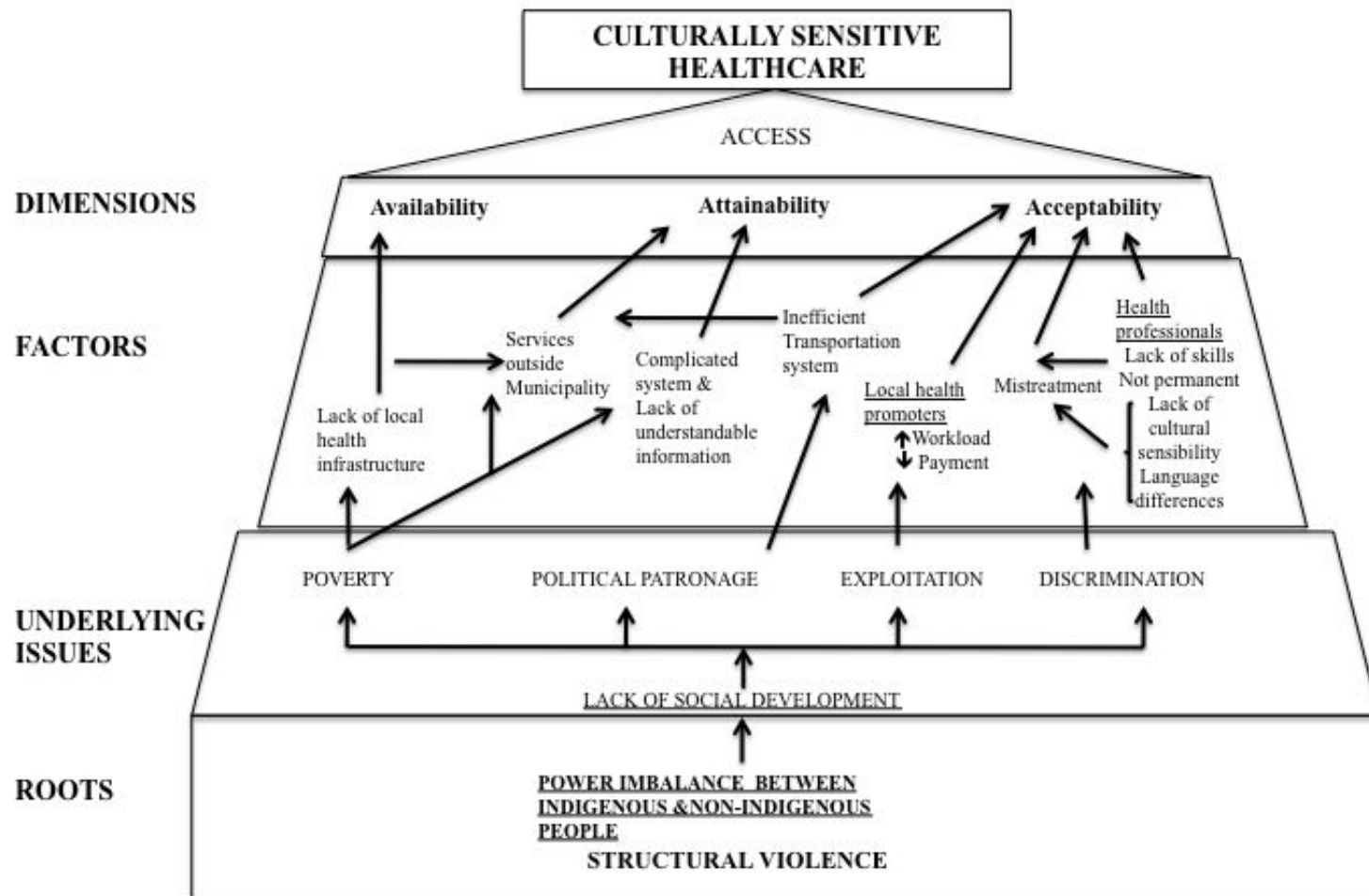


Figure 3. Barriers for accessing culturally sensitive healthcare for people living with arthritis in Chankom and their causes.



CHAPTER SIX

CONCLUSIONS

6.1 Main contributions

There are different disciplinary, methodological and substantive contributions made by the work of this thesis. This thesis contributes to the discipline of Rehabilitation Science, demonstrating the pronounced disabling effects of chronic diseases, such as arthritis, in rural marginalized communities where rehabilitation services are not available. This situation underlies the importance of developing community-based rehabilitation interventions within primary care in underserved communities. In addition, this work demonstrates the importance of providing communities with a voice to participate and collaborate in the construction of their own rehabilitation interventions, assuring their cultural sensitivity.

The methodological contributions of this thesis are related to the development of community-based rehabilitation programs, a strategy greatly promoted by the World Health Organization. This work shows how applying quantitative and qualitative methods, establishing a dialogue between them, helps to obtain a thorough understanding of the disability present in a community. This understanding is essential for identifying the components of community-based rehabilitation programs directed at decreasing disability through improving health systems and services. Moreover, this thesis shows that the relevance and cultural sensitivity of community-based rehabilitation programs

could be greatly enhanced by conducting transdisciplinary work involving the social sciences along with incorporating community members within a participatory-action research approach.

The substantive contributions from this thesis relate to an increased understanding of the disabling effects of arthritis within rural Mayan communities, a problem that has not been adequately explored to date. This work indicates that arthritis is a common disease in Chankom municipality (chapter three) and is associated with a disablement process that negatively affects the health-related quality of life of the people living in this Mayan community (chapters three and five). Moreover, the prevalence of arthritis is associated with lower levels of wealth and high body mass index (chapter three) and the subgroup of people diagnosed with osteoarthritis presented clinically significant problems in functioning associated with the presence of different social, physical, psychological and behavioral factors (chapter four). In addition, this thesis reveals that accessing culturally sensitive healthcare is the primary need perceived by the community for the people living with arthritis (chapter five). The barriers to accessing this culturally sensitive healthcare are related to the availability, accessibility and acceptability (chapter five) of services, and power imbalances between indigenous and non-indigenous people are the main reason for their existence (chapter five).

6.2 Lessons learned

The main lessons learned obtained by conducting the situational analysis and program development stages of the CONCORD project in Chankom relate to applying the principles of community-based participatory research and executing quantitative and qualitative methodologies. This learning will help with the further completion of the CONCORD project in this community and to conduct similar projects in other communities.

We were not able to involve the community from the beginning of the project, as there were no community-based organizations working or interested in improving the health of the municipality's inhabitants at the time. The absence of community organization around health was interpreted as a lack of unity amongst the community members. Consequently, we conducted the first stage of the project (situational analysis) without formalizing a partnership with the community, which is the first step of the community-based participatory research strategy (19). Nevertheless, we used the results of the situational analysis to commence a community organization process, which has continued since December 2013. This process has resulted in the formation of eleven community groups, each comprised of four to five leaders who are collaborating to address the problems associated with musculoskeletal diseases in the municipality. This experience has shown us that working with organized communities, is a pre-requisite to implementing the community-based participatory research approach proposed by Israel et al (2005)(15). In addition, implementing community-based participatory research in

communities where the community is not working as a cohesive group requires time to undertake community organisation before establishing formal partnerships.

Conducting a census strategy to screen and detect cases of musculoskeletal diseases within the entire adult population of the municipality was time consuming. First, the population of Chankom municipality is geographically diverse with many settlements or commissariats that are poorly connected. Therefore, moving an entire team of eight local interviewers and three physicians from commissariat to commissariat was logistically difficult. Second, local interviewers surveyed the communities going door to door, and were constantly interrupted to translate for physicians, who did not speak Mayan. Third, applying physical function evaluations in a community without adequate health facilities hampered their standardization. Consequently, investing in training human resources, efficient transportation, and adequate evaluation tools is important to ensure data quality in this type of epidemiologic study.

Language differences also hindered ethnographic fieldwork. First, most interviews as well as participant and non-participant observations required assistance from Mayan translators. Researchers consistently felt that the meaning of communication was lost in translation. Second, the analysis and interpretation of qualitative data was conducted exclusively in Spanish, which excluded the English-speaking members of the project from this process. Though all analytic decisions were recorded in English as an audit trail, English-speaking researchers could not entirely follow the analytic interpretations. It would be optimal if all members were competent though not necessarily fluent in all

languages within this type of research. Consequently, including language-skills training in international long-term projects is worth considering.

The experience of executing qualitative and quantitative methods to conduct a situational analysis towards the development of a community-based rehabilitation program confirmed that a mixed scientific research approach is fundamental for this endeavour (14). Using both research paradigms yielded results that justify the need for a community-based rehabilitation program in this Mayan community. Moreover, these results will help to define the strategies to complete the next stages of the CONCORD project in Chankom. For example, quantitative findings help us consider and address different modifiable factors associated with the manifestation and disabling effects of arthritis; while, qualitative findings help identify potential allies (e.g. the municipal president or the regional public health director) who can assist in developing a community-based rehabilitation program for Chankom. These potential allies will be invited to a stakeholder dialogue drawing on the approach used by the McMaster Health Forum (20) (see chapter two).

Finally, the situational analysis allowed me to reflect on my relationship with the Mayan community as a non-indigenous white, male physician and researcher within an environment where indigenous people are frequently patronized. This is a result of historically driven colonialist practices (21). I was aware and reflective of the constant power imbalances present during my interactions. This experience has made me more open to cultural differences and more respectful of the Mayan culture. This personal reflection was largely due to the interactions and transdisciplinary work with

anthropologists, whose perspectives broadened my thinking. Therefore, the last experience contributing to my learning is the importance of collaborating with social scientists through transdisciplinary efforts in projects of this nature.

6.3 Future actions

The findings described in this thesis support the need for action in reducing the prevalence and disabling effects of arthritis in Chankom, which justifies the continuation of the CONCORD project in this community. The next step towards the creation of a community-based rehabilitation program will be establishing a formal partnership between the community, academia and public health institutions (see chapter two). In addition, it will be important to consider the different laws and regulations identified during the qualitative analysis and advocate for the creation of local and regional policies to facilitate a community-based rehabilitation program. This will involve, adopting a “bottom-up” strategy working directly with the community, along with a “top-down strategy”, involving a dialogue with health authorities and policy makers.

It will be essential to involve the local municipal government in the development of the community-based rehabilitation program. As described in the introduction of this thesis and in chapter five, the municipal government involvement in the development of health services and infrastructure to date has been minimal. Nevertheless, Yucatan’s law mandates that municipal governments increase and operationalize programs to meet the health needs of indigenous populations (22). Therefore, it is important to involve

Chankom's municipal government in the creation of local public policies that facilitate the development of rehabilitation programs to improve the quality of life of its habitants. Supporting this, the United Nations considers that the development of local public policies within Mexican indigenous communities could be more effectively implemented and made less dependent on the federal government (23).

Our findings show that there has been a failure to consider the bio-psycho-social perspective endorsed by the World Health Organization in the implementation of health programs and policies within Yucatan's health system. The medical model dominates both public and private health sectors, which are more focused on the biomedical than the social dimensions of disease. In addition, the language of functioning, disability and rehabilitation from The International Classification of Functioning, Disability and Health (ICF, 2001) is almost absent within these health sectors. Consequently, it is imperative to incorporate the ICF framework and taxonomy into the health system of Yucatán, through health professionals' education and the creation of public and private rehabilitation services. These efforts must be supported by new policies based on the Mexican federal and Yucatan State legislation for the protection of people with disabilities (24,25).

In summary, the work presented in this thesis is the extensive examination of the problems associated with arthritis undertaken in collaboration with an indigenous community in Mexico, using both quantitative and qualitative methods. This work resulted in a situational analysis of the arthritis-related problems within this rural and underserved community. This situational analysis will support the development of a community-based rehabilitation program to promote social development and improve the

health-related quality of life of people living with arthritis in Chankom. In addition, the experience of conducting the situational analysis of the CONCORD project in Chankom will inform the methodology of projects in other communities.

REFERENCES

- (1) Bickenbach J, Degener T, Melvin J, Quinn G, Posarac A, Schulze M, et al. The World Report on Disability: Understanding Disability. World Health Organization (Malta). 2011.
- (2) Albrecht G, Bartolomeos K, Chatterji S, Diamond M, Emerson E, Fujiura G, et al. The World Report on Disability: Disability- a global picture. World Health Organization (Malta). 2011.
- (3) Murray ET, Hardy R, Strand BH, Cooper R, Guralnik JM, Kuh D. Gender and life course occupational social class differences in trajectories of functional limitations in midlife: Findings from the 1946 British birth cohort. *J Gerontol A Biol Sci Med Sci* 2011 Dec; 66(12): 1350-1359.
- (4) Bergman S. Public health perspective- How to improve the musculoskeletal health of the population. *Baillieres Best Pract Res Clin Rheumatol* 2007 Feb; 21(1): 191-204.
- (5) Helmick CG, Felson DT, Lawrence RC, Gabriel S, Hirsch R, Kwoh CK, et al. Estimates of the prevalence of arthritis and other rheumatic conditions in the United States. Part I. *Arthritis Rheum* 2008 Jan; 58(1): 15-25.
- (6) Reginster JY. The prevalence and burden of arthritis. *Rheumatology (Oxford, England)* 2002; 41(Suppl 1): 3-6.
- (7) Baldassari AR, Cleveland RJ, Callahan LF. Independent influences of current and childhood socioeconomic status on health outcomes in a North Carolina family practice sample of arthritis patients. *Arth Care Res* 2013 Aug; 65(8): 1334-1342.

- (8) Guzman, Juan Manuel S, Elva G. Disability and Rehabilitation in Mexico. *Am J Phys Med & Rehabil* 2014 Jan;93(1) (Supplement 1): S36-S38.
- (9) Pelaez-Ballestas I. Sanin LH. Moreno-Montoya J. Alvarez-Nemegyei J. Burgos-Vargas R. Garza-Elizondo M. Rodriguez-Amado J. Goycochea-Robles MV. Madariaga M. Zamudio J. Santana N. Cardiel MH. Grupo de Estudio Epidemiologico de Enfermedades Musculo Articulares (GEEMA). Epidemiology of the rheumatic diseases in Mexico. A study of 5 regions based on the COPCORD methodology. *J Rheumatol Suppl* 2011 Jan; 86: 3-8.
- (10) Rodriguez-Amado J, Moreno-Montoya J, Alvarez-Nemegyei J, Goycochea-Robles M, Sanin L, Burgos-Vargas R, et al. The Social Gap Index and the prevalence of osteoarthritis in the community: a cross-sectional multilevel study in Mexico. *Clin Rheumatol* [Internet]. 2014 Sep [cited November 16 2014]; 33(10)
- (11) Alvarez-Hernandez E, Pelaez-Ballestas I, Boonen A, Vazquez-Mellado J, Hernandez-Garduno A, Rivera FC, et al. Catastrophic health expenses and impoverishment of households of patients with rheumatoid arthritis. *Reumatol Clin* 2012 Jul-Aug; 8(4): 168-173.
- (12) Ackerman P, Asindua S, Blouin M, Cameron D, Clode K, Cockburn L, et al. The World Report on disability: Rehabilitation. World Health Organization. 2011.
- (13) Chung EY, Packer T, Yau M. When East meets West: Community-based rehabilitation in Chinese communities. *Disabil Rehabil* 2011; 33(8): 697-705.
- (14) Grandisson M, Hebert M, Thibeault R. A systematic review on how to conduct evaluations in community-based rehabilitation. *Disabil Rehabil* 2014; 36(4): 265-275.

- (15) Israel B, Eng E, Schulz A, Parker E. Chapter 1. Introduction to Methods in Community-Based Participatory Research for Health. In: Israel B, Eng E, Schulz A, Parker E, editors. *Methods in Community-Based Participatory Research for Health*. 1st ed. San Francisco, CA: Jossey-Bass A Wiley Imprint; 2005. p. 1-26.
- (16) Programa Nacional para el Desarrollo y la Inclusión de las Personas con Discapacidad 2014-2018. 2014; DOF: 30/04/2014.
- (17) Unidad de Microregiones. Catálogo de Localidades. Sistema de Apoyo para la Planeación del PDZP. Resumen Municipal. Municipio de Chankom. 2013.
- (18) Loyola Sanchez A, Richardson J, Pelaez-Ballestas I, Lavis JN, Wilkins S, Wilson MG, et al. Developing Community-Based Rehabilitation Programs for Musculoskeletal Diseases in Low-Income Areas of Mexico: The Community-Based Rehabilitation for Low-Income Communities Living With Rheumatic Diseases (CONCORD) Protocol. *JMIR Res Protoc* [Internet]. 2014 [cited Nov 21]; 3(4): e57.
- (19) Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health* 2010 Apr; 100(Suppl 1): S40-6.
- (20) McMaster Health Forum. 2014; Available at: <http://www.mcmasterhealthforum.org/>.
- (21) Maldonado-Torres N. XI. La topología del Ser y la geopolítica del saber. Modernidad, Imperio, Colonialidad. In: de Sousa Santos B, Meneses MP, editors. *Epistemologías del Sur (perspectivas)* Spain: Ediciones Akal, S.A.; 2014. p. 331-372.
- (22) Ley para la protección de los derechos de la comunidad Maya del Estado de Yucatan. 2011; Decreto 407 Diario Oficial del Gobierno del Estado de Yucatán.

(23) Programa de las Naciones Unidas para el desarrollo (PNUD). Informe sobre el desarrollo humano de los pueblos indígenas en México: El reto de las desigualdad de oportunidades. Mexico: Programa de las Naciones Unidas para el desarrollo; 2010.

(24) Ley general para la inclusión de las personas con discapacidad. 2011;Diario Oficial de la Federación 30/05/2011.

(25) Ley para la protección de los derechos de las personas con discapacidad del estado de Yucatán. 2011; Decreto 469.

APPENDIX A

Cross-culturally validated community-based survey

**PROYECTO DE PREVALENCIA Y ANTROPOLOGÍA DE LA MEDICINA DE
MALESTARES MUSCULOESQUELÉTICOS Y ENFERMEDADES REUMATICAS EN
PUEBLOS INDIGENAS MAYAS Y MIXTECOS [Prevalence and medical
anthropology of musculoskeletal symptoms and rheumatic diseases within
Maya and Mixtec indigenous people]
Sector Región Maya [Maya Region]**

Place: _____	Date: ____ / ____ / ____
Start time: _____ hrs. _____ mins.	Case number: _____

GENERAL INFORMATION:

Name: _____
First Last name Second Last name Name
Address: Street _____ Number: _____ between _____ and _____.
Community: _____
Municipality: _____ State: _____
Weight: _____ Kg. Height: _____ BMI: _____ Kg/cm²

SECTION A: INFORMATION ABOUT THE STUDY

Rheumatic diseases affect an important number of people within the general population. The objective of this study is to obtain information about the frequency of rheumatic diseases in adults older than 18 years within our region. This will help us to understand how rheumatic diseases affect on the daily activities of persons and the type of care that can improve their quality of life. This questionnaire is designed to obtain information about your personal history, work history, presence of pain, functional capacity and treatment received. All information will be kept confidential. Your participation is voluntary and you can ask all the questions you like. You can withdraw from the study whenever you like. In case that you may have a rheumatic disease you will receive orientation about the medical care you should receive.

SECCION A1. COMORBILIDAD.

- ☐ Diabetes
- ☐ High blood pressure
- ☐ Heart disease
- ☐ Alcoholism
- ☐ Anxiety
- ☐ Depression
- ☐ Smoking
- ☐ Gastritis

- ☐ Obesity
- ☐ Cholesterolemia
- ☐ Venous insufficiency
- ☐ Adiction to drugs
- ☐ Joint injury
- ☐ Other, specify _____

SECCIÓN B. BACKGROUND

B1. ¿How old are you? _____

Gender

- ☐ Male
- ☐ Female

B2. Marital status.

- ☐ Not married
- ☐ Married
- ☐ Common law
- ☐ Widow
- ☐ Divorced
- ☐ Other

B3. ¿Where did you born? _____

SECCIÓN C. WORK HISTORY

C1. Do you work at this moment?

- ☐ Yes
- ☐ No

C2. What do you do?

Tell me if you do other things at your home even if you do not get paid for them, su as studying, housework, etc. _____

C3. ¿What did you do before? _____

Have you have other long term jobs?.

- ☐ Yes
- ☐ No

Specify _____

C4. If you do not work: Why is this?

- ☐ Disease
- ☐ Can not find a job
- ☐ Other, specify: _____

SECCIÓN D. PAIN, SWELLING OR STIFFNESS.
--

D1. Do your parents, brothers and/or offspring have or had have rheumatism?

- ☐ Yes

- ☐ No

D2. Have you have pain, swelling, or stiffness in your body during the last 7 days?

- ☐ Yes
- ☐ No (Go to section D6)

D3. Mark with an X where is your pain and for how long?



D4. Why do you feel this pain? Did you have any blow, sprain or fall?

- ☐ Yes
- ☐ No
- ☐ I do not know

IF YES, WHAT WAS THE CAUSE:

- ☐ Fracture
- ☐ Sprain
- ☐ Dislocation
- ☐ Other, specify: _____

D5. How much pain have you have due to your disease **DURING THE LAST 7 DAYS.**

- ☐ Intense
- ☐ Strong
- ☐ No very strong

- Little
- Nothing

D6. Have you have pain, swelling or stiffness **DURING ALL YOUR LIFE?** (show figure)

- Yes
- No

If D2 is yes and D6 is no go to section E.

If D2 and D6 are NO go to section H.

D7. Mark with an X where did you have the pain and for how long.



D8. Was this pain caused by a blow, sprain or fall?

- Yes
- No
- I do not know

If yes, what was the cause?

- Fracture
- Sprain
- Dislocation

- Other, specify: _____

D9. How much pain do you have felt due to this disease?

- Intense
- Strong
- Not very strong
- Little
- Nothing

SECCIÓN E. LABORAL INCAPACITY

E1. Are there things that you stopped doing due to your disease?

- YES
- No

If yes, How long?

_____ Days
_____ Weeks
_____ Months
_____ Years

- Not today, but before yes.

How long?

_____ Days
_____ Weeks
_____ Months
_____ Years

SECCIÓN F. TREATMENT

F1. Who have you consulted to relief your rheumatism?

- A doctor
- Other (naturopath, bone setter, shaman, other: specify _____)

F2. Are you using or have used medications for you pain?

- Yes
- No (go to question F4)

F3. What is the name of the medicine you are using or have used?

Drug name	Prescribed by a physician?	Self-prescribed?	¿Other people gave it to you?	Does it help?	Why you chose this?
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	
	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	

F4. Other treatments.

Physical therapy and rehabilitation.

- ☐ Yes
- ☐ No

Did it help?

- ☐ Yes
- ☐ No
- ☐ I am not sure

Why did you choose this? : _____

Surgery.

- ☐ Yes
- ☐ No

Did it help?

- ☐ Yes
- ☐ No
- ☐ I am not sure

Why did you choose this? : _____

SECCIÓN G. INFORMATION ABOUT YOUR DISEASE

G1. Did a physician tell you the name of your disease?

- ☐ Yes
- ☐ No

G2. If yes, what is the name of your disease?

- ☐ Arthritis

- Gout
- Ankylosing spondilitis
- Osteoporosis
- Arthrosis
- Rheumatoid arthritis
- Fibromyalgia
- Lupus
- Other, specify : _____

G3. How much pain have you felt due to your disease?

- Intense
- Strong
- Not very strong
- Little
- Nothing

G4. How are you doing with your disease?

- Very well
- Well
- Not very well
- I do not feel well

SECCION H. DIFFICULTY TO EXECUTE SPECIFIC ACTIVITIES
Say how much difficulty have you have during <u>THE LAST 7 DAYS</u>

	I had no trouble	A little bit of trouble	A lot of trouble	I could not do it
DRESSING/ CHANGING CLOTHES: How difficult it was to				
Dress yourself, put on your shoes, buttoning clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wash you hair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
STANDING: How difficult it was to				
Standing from sitting in a chair without using your hands	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lay down or get up from your bed or hammock.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EATING: How difficult it was to				
Cut to pieces	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grab a cup or full glass	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Open a soda	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

bottle				
WALKING: How difficult it was to				
Walk around the house on a flat surface	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Go up 5 stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you need any help for doing these activities of dressing, standing, eating or moving?

<input type="checkbox"/> Cane	<input type="checkbox"/> Walker	<input type="checkbox"/> Crutches	<input type="checkbox"/> Wheel chair
<input type="checkbox"/> Fixed chair	<input type="checkbox"/> Adapted stove	<input type="checkbox"/> Something to put on your shoe	
<input type="checkbox"/> Other, such as			

Say how much difficulty have you have doing the following during the LAST 7 DAYS

	I had no trouble	A little bit of trouble	A lot of trouble	I could not do it
BATHING: How difficult it was to				
Bathe and dry you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to the bathroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
REACHING: How difficult it was to				
Holding and get something weighting a little over a kilo from above your head	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bending and grabbing things from the ground	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GRABBING: How difficult it was to				
Open a car door	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Open a jar	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Open and close the faucet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
THINGS THAT YOU DO: How difficult it was to				
Go shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get in and out of a car	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing housework, washing dishes, doing laundry, prepare meals, mowing field	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Embroider or sew on a sewing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

machine				
---------	--	--	--	--

Do you need any help for doing these activities of bathing, drying, grabbing or doing housework?

<input type="checkbox"/> Special chair to go to the bathroom	<input type="checkbox"/> Special chair for bathing	<input type="checkbox"/> Something to open a jar	<input type="checkbox"/> Something to grab on in the bathroom
<input type="checkbox"/> Something to reach to things	<input type="checkbox"/> Something long for reaching while bathing	<input type="checkbox"/> Other, such as.	

Do you need help from other people to the following?

<input type="checkbox"/> Bathing, drying, go to the bathroom.	<input type="checkbox"/> Reaching things	<input type="checkbox"/> Grabbing things	<input type="checkbox"/> Washing dishes, prepare meals, moving field
---	--	--	--

How much pain do you have due to your rheumatism during **THE LAST 7 DAYS**

- Very strong
- Strong
- Not very strong
- Just a little
- Nothing

SECCION I.BIOMECHANICAL LOAD

What is the job that you have performed most often during your life?

_____:

Does this job imply doing the following?

Jolting hand movements	<input type="radio"/> Yes	<input type="checkbox"/> No
Carry things heavier than 20 kg	<input type="radio"/> Yes	<input type="checkbox"/> No
Pushing things heavier than 20 kg	<input type="radio"/> Yes	<input type="checkbox"/> No
Going up and down stairs frequently	<input type="radio"/> Yes	<input type="checkbox"/> No
Standing for more than 30 minutes	<input type="radio"/> Yes	<input type="checkbox"/> No
Being crouched for more than 30 minutes	<input type="radio"/> Yes	<input type="checkbox"/> No
Walking for more than 30 minutes	<input type="radio"/> Yes	<input type="checkbox"/> No
Standing and sitting frequently	<input type="radio"/> Yes	<input type="checkbox"/> No

In addition to this work do you do other things for recreation or do you have other job?

- ☐ Yes
- ☐ No

Specify: _____

Does this job imply doing the following?

Jolting hand movements	<input type="radio"/> Yes	<input type="checkbox"/> No
Carry things heavier than 20 kg	<input type="radio"/> Yes	<input type="checkbox"/> No
Pushing things heavier than 20 kg	<input type="radio"/> Yes	<input type="checkbox"/> No
Going up and down stairs frequently	<input type="radio"/> Yes	<input type="checkbox"/> No
Standing for more than 30 minutes	<input type="radio"/> Yes	<input type="checkbox"/> No
Being crouched for more than 30 minutes	<input type="radio"/> Yes	<input type="checkbox"/> No
Walking for more than 30 minutes	<input type="radio"/> Yes	<input type="checkbox"/> No
Standing and sitting frequently	<input type="radio"/> Yes	<input type="checkbox"/> No

SECCIÓN J. EVALUATION

J1. Did you understand everything that was asked?

- ☐ Yes
- ☐ No

J2. Do you have any suggestions to improve these questions?

- ☐ Yes
- ☐ No

Specify: _____

End time: ____ hrs. ____ mins.

Name of interviewer: _____

Diagnosis and comments

CUESTIONARIO SOCIOECONÓMICO [Socioeconomic questionnaire]

PERSONAL INFORMATION			
<p>Name: _____</p> <div style="display: flex; justify-content: space-around; margin-top: 5px;"> First last name Second last name Name </div> <p>Community: _____</p> <p>Municipality: _____ State: _____</p>			
<p style="text-align: center;">Where do you receive health care?</p> <div style="display: flex; justify-content: space-between;"> Salubridad (SS) <input type="checkbox"/> IMSS <input type="checkbox"/> ISSSTE <input type="checkbox"/> Seguro Popular <input type="checkbox"/> Private <input type="checkbox"/> </div> <p style="text-align: center;">None <input type="checkbox"/></p>			

EDUCATIONAL AND OCCUPATIONAL CHARACTERISTICS:

What is your level of education and how many completed grades do you have?
 _____(years)

INCOME

What is your total monthly income (in Mexican pesos)? (If unemployed does not apply)

Up to 2 minimum wedges or < 2,598	<input type="checkbox"/>
Between 2 to 4 minimum wedges or 2,598 to 5,196	<input type="checkbox"/>
Between 4 to 8 minimum wedges or 5,196 to 10,392	<input type="checkbox"/>
Between 8 to 14 minimum wedges or 10,392 to 18,186	<input type="checkbox"/>
More than 14 minimum wedges or > 18, 186	<input type="checkbox"/>

HOME CHARACTERISTICS AND HOME EQUIPMENT

The house were you live is:

Own	<input type="checkbox"/>	Renter	<input type="checkbox"/>
Borrowed	<input type="checkbox"/>	Other (specify)_____	<input type="checkbox"/>

c) Do you have a room for cooking?

Yes ☐ No ☐

d) Do you use this room for sleeping? (Does not apply if previous answer is No)

Yes ☐ No ☐

e) How many rooms there are in your house not counting hallways, bathroom and kitchen?

Yes ☐ No ☐

f) How many rooms in your house are used to sleep?

Yes ☐ No ☐

g) Do the occupants of your home use...? (Read the options and mark with an X)

Bathroom with sink	<input type="checkbox"/>	Hole	<input type="checkbox"/>
Bathroom without sink	<input type="checkbox"/>	Other: (specify) _____	<input type="checkbox"/>
They go in the yard or toilet	<input type="checkbox"/>		<input type="checkbox"/>

h) Does your home have...? (Read the options and mark with an X)

Radio or tape recorder	<input type="checkbox"/>	Computer	<input type="checkbox"/>	Boiler	<input type="checkbox"/>
TV	<input type="checkbox"/>	Bicycle	<input type="checkbox"/>	Motorcycle	<input type="checkbox"/>
Sewing machine	<input type="checkbox"/>	Fridge	<input type="checkbox"/>	Automobile	<input type="checkbox"/>
DVD	<input type="checkbox"/>	Washing machine	<input type="checkbox"/>	Van	<input type="checkbox"/>
Telephone	<input type="checkbox"/>	Stove	<input type="checkbox"/>	Microwave oven	<input type="checkbox"/>
Cable	<input type="checkbox"/>	Cell phone	<input type="checkbox"/>	Tricycle	<input type="checkbox"/>

This ends the questionnaire, thank you for answering these questions.

APPENDIX B

Initial Hamilton Integrated Research Ethics Board Approval 2013-2014



Hamilton Integrated Research Ethics Board (HIREB)
293 Wellington St. N., Suite 102, Hamilton, ON L8L 8E7
Telephone: 905-521-2100, Ext. 42013
Fax: 905-577-8378

June 24, 2013

PROJECT NUMBER: 12-544

PROJECT TITLE: Development of a culturally sensitive community-based rehabilitation program for people living with osteoarthritis in the Mayan community of Chankom, Yucatán, México

PRINCIPAL INVESTIGATOR: Dr. Adalberto Loyola-Sanchez

LOCAL PI: Dr. Julie Richardson

This will acknowledge receipt of your letter dated June 10, 2013 which enclosed revised copies of the Information/Consent Forms for the above-named study. These issues were raised by the Research Ethics Board at their meeting held on September 18, 2012. Based on this additional information, we wish to advise your study has been given **final** approval from the full REB.

The following documents have been approved on both ethical and scientific grounds:

- The submission
- Study Protocol version 10 dated August 9, 2012
- Information/Consent Form – Study Two – Epidemiological Assessment version dated June 2013
- Information/Consent Form – Study Three – Ethnography Assessment version dated June 2013
- Information/Consent Form – Study Four – Summary of Evidence version dated June 2013
- Information/Consent Form – Study Five – Program Construction version dated June 2013
- Information/Consent Form – Study Six – Program Piloting, Quantitative Mixed Methods Study version dated June 2013
- Information/Consent Form – Study Seven – Program Implementation and Evaluation, Pure-Mixed Methods Study version dated June 2013
- In-Depth Interviews for People who live with Osteoarthritis
- Interview Guide for Focus Group
- Overview of Reviews: Abstract Screening Phase form
- Overview of Reviews: Data Extraction Form
- COPCORD Survey Questionnaire
- Socioeconomic Questionnaire
- Medical Assessment for Participants with Suspicion of Hand, Hip or Knee Osteoarthritis
- Epidemiological Assessment Regression Model

Please note attached you will find the Information/Consent Forms with the HIREB approval affixed; all consent forms used in this study must be copies of the attached materials.

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; for studies conducted at St. Joseph's Hospital, HIREB complies with the health ethics guide of the Catholic Alliance of Canada

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review and renewal of HIREB approval. Any changes or revisions to the original submission must be submitted on an HIREB amendment form for review and approval by the Hamilton Integrated Research Ethics Board.

PLEASE QUOTE THE ABOVE-REFERENCE PROJECT NUMBER ON
ALL FUTURE CORRESPONDENCE

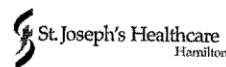
Sincerely,

A handwritten signature in black ink, appearing to read 'S. Salama', with a stylized flourish at the end.

Suzette Salama PhD.,
Chair, Hamilton Integrated Research Ethics Board

REB #: 12-544

Renewal Approval 2014-2015



Hamilton Integrated Research Ethics Board
RENEWAL FORM
Review of an Active Study (to be completed by HIREB Chair only)

REB Project #: 12-544

Principal Investigator: Dr. Julie Richardson

Project Title: Development of a Culturally Sensitive Community Based Rehabilitation Program for People Living with Osteoarthritis in the Mayan Community of Chankom, Yucatan, Mexico

☒ **Approved for Continuation**

☐ **Approved conditional on changes noted in "Conditions" section below**

Type of Approval:

☒ **Full Research Ethics Board**

☐ **Research Ethics Board Executive**

REB Approval Period: Approval period covers June 24th 2014 to June 24th 2015

☐ **New Enrolment Suspended**

☐ **Suspended pending further review**

Conditions:

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; for studies conducted at St. Joseph's Hospital, HIREB complies with the health ethics guide of the Catholic Alliance of Canada.

Suzette Salama PhD., Chair
Raelene Rathbone, MB BS, MD, PhD, Chair

6/17/2014
Date of REB Meeting

All Correspondence should be addressed to the HIREB Chair(s) and forwarded to:
HIREB Coordinator
293 Wellington St. N, Suite 102, Hamilton ON L8L 8E7
Tel. 905-521-2100 Ext. 42013 Fax: 905-577-8378

Mexico's General Hospital Research Ethics Approval



DI/03/324/14

México, D. F., a 24 de julio de 2014

DRA. INGRIS PELAEZ BALLESTAS

Servicio de Reumatología
Presente.

Por este conducto hago de su conocimiento que la última versión del protocolo titulado: "DESARROLLO, IMPLEMENTACIÓN Y EVALUACIÓN DE LA EFECTIVIDAD DE UN PROGRAMA DE REHABILITACIÓN CULTURALMENTE SENSIBLE PARA PERSONAS QUE VIVEN CON ENFERMEDADES MUSCULOESQUELÉTICAS EN LA COMUNIDAD MAYA-YUCATECA DE CHANKOM", con clave de registro DI/14/404D/05/050, así como el Consentimiento Informado, fueron presentados a los Comités de Ética e Investigación quienes dictaminaron su **A P R O B A C I O N**. Por lo tanto, puede dar inicio a su investigación.

"A la Vanguardia en el Cuidado de la Vida"

Atentamente
Director de Investigación


DR. JUAN CARLOS LOPEZ ALVARENGA

Nota este proyecto será aprobado por el CONACYT

c.c.p. Profe. Carlota Elza Herrera Alanilla Unidad Contable de Proyectos

JCLA/GMM/cvc*

DIRECCIÓN DE
INVESTIGACIÓN

Dr. Balmis 148
Colonia Doctores

T +52 (55) 5004 3842
Can +52 (55) 7789 7000

APPENDIX C

Medical Assessment for participants with suspicion of hand, hip or knee osteoarthritis

Note: All participants referred for medical assessment will be evaluated once the radiographic images are completed and available.

Name:

ID number:

Gender:

Age (years):

Referred with suspicion of osteoarthritis in:

Hand ☐

Hip ☐

Knee ☐

SECTION A. OSTEOARTHRITIS CONFIRMATION

1. Hand

1. Hand pain, aching, or stiffness for most days or prior months Yes ☐

No ☐

2. Hard tissue enlargement of ≥ 2 of 10 selected joints [*] Yes ☐

No ☐

3. Metacarpophalangeal joint swelling in ≥ 2 joints Yes ☐

No ☐

4. Hard tissue enlargement of ≥ 2 distal interphalangeal joints Yes ☐

No ☐

5. Deformity of ≥ 2 of 10 selected hand joints [*] Yes ☐

No ☐

Diagnostic confirmation if **Yes** in 1, 2, 3, 4 or 1, 2, 3, 5



*10 Selected hand joints
Bilateral (both hands):
a) Second and third distal interphalangeal joints.
b) Second and third proximal interphalangeal joints.
c) First carpometacarpal joint.

2. Hip

1. Hip pain for most days or prior months Yes ☐ No ☐
2. Femoral or acetabular osteophytes on radiographs Yes ☐
No ☐
3. Hip joint space narrowing on radiographs Yes ☐
No ☐

Diagnostic confirmation if **Yes** in 1, 2, and 3.

3. Knee

1. Knee pain for most days or prior months Yes ☐
No ☐
2. Osteophytes at joint margins on radiographs Yes ☐
No ☐

3. Age ≥ 40 years Yes ☐

No ☐

4. Crepitus on active joint motion Yes ☐

No ☐

5. Morning stiffness lasting ≤ 30 min Yes ☐

No ☐

Diagnostic confirmation if **Yes** in 1, 2 or 1, 3, 4, 5

SECTION B. HISTORY

1. Co morbidities. Do you have any of the following diseases, which were diagnosed by a health provider?

Diabetes ☐

Stroke ☐

Hypertension ☐

Heart disease ☐

Lung disease ☐

Cognitive disease ☐

Visual disease ☐











Other ☐ specify _____

2. Rapid assessment of physical activity

Physical Activities are activities where you move and increase your heart rate above its resting rate, whether you do them for pleasure, work, or transportation.

The following questions ask about the amount and intensity of physical activity you usually do. The intensity of the activity is related to the amount of energy you use to do these activities.

Examples of physical activity intensity levels:

Light activities <ul style="list-style-type: none"> • your heart beats slightly faster than normal • you can talk and sing 	 Walking Leisurely  Stretching  Vacuuming or Light Yard Work
Moderate activities <ul style="list-style-type: none"> • your heart beats faster than normal • you can talk but not sing 	 Fast Walking  Aerobics Class  Strength Training  Swimming Gently
Vigorous activities <ul style="list-style-type: none"> • your heart rate increases a lot • you can't talk or your talking is broken up by large breaths 	 Stair Machine  Jogging or Running  Tennis, Racquetball, Pickleball or Badminton

How physically active are you? *(Check one answer on each line)*

		Does this accurately describe you?		
		Yes	No	
RAPA 1	1	I rarely or never do any physical activities.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	2	I do some light or moderate physical activities, but not every week.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	3	I do some light physical activity every week.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	4	I do moderate physical activities every week, but less than 30 minutes a day or 5 days a week.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	5	I do vigorous physical activities every week, but less than 20 minutes a day or 3 days a week.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	6	I do 30 minutes or more a day of moderate physical activities, 5 or more days a week.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	7	I do 20 minutes or more a day of vigorous physical activities, 3 or more days a week.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
RAPA 2 3 = Both 1 & 2	1	I do activities to increase muscle strength , such as lifting weights or calisthenics, once a week or more.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
	2	I do activities to improve flexibility , such as stretching or yoga, once a week or more.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

3. Principal activities [activities that are part of the participants' socio cultural context and are desired and/or necessary for their well-being]

a) What would you say is/are your main **household and personal care**^{*} activity (ies)?

b) What would you say is/are your main **work**[†] activity (ies)?

c) What would you say is/are your main **leisure** activity (ies)?

* household activities= instrumental activities of daily independent living and no major activities (shopping, light housework, prepare own meals, manage own money, use telephone, etc.); personal care activities= basic activities of daily living (eat, toilet, transfer, dressing, bathe, etc.)

[†] work activities= activities implied in person's major role, could be job or housework

4. Present functioning status (enacted).

a) At this moment are you performing all your usual **household and personal care** activities?

Yes ☐ No ☐

If **Yes**, Have you modified the way or reduced the frequency with which you do these activities?

Yes ☐ No ☐

b) At this moment are you performing all your usual **work** activities?

Yes ☐ No ☐

If **Yes**, Have you modified the way or reduced the frequency with which you do these activities?

Yes ☐ No ☐

c) At this moment are you performing all your usual **leisure** activities?

Yes ☐ No ☐

If **Yes**, Have you modified the way or reduced the frequency with which you do these activities?

Yes ☐ No ☐

5. Level of self-efficacy to perform usual activities.

a) How much confidence you feel to execute your usual **household and personal care** activities? None to little Sufficient to very much

b) How much confidence you feel to execute your usual **work** activities?

None to little Sufficient to very much

c) How much confidence you feel to execute your usual **leisure** activities?

None to little Sufficient to very much

6. Evaluation of Pain, Stiffness and Physical function (hypothetical). Always check that the HAQ-DI applied during the census is complete at this moment.

a) WOMAC questionnaire (only for Hip and Knee involvement)

WOMAC OSTEOARTHRITIS INDEX

1. The following questions concern the amount of pain you are currently experiencing in your knees. For each situation, please enter the amount of pain you have experienced in the past 48 hours.

	None	mild	moderate	severe	extreme
A. Walking on a flat surface	A. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Going up or down stairs	B. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. At night while in bed	C. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Sitting or lying	D. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. Standing upright	E. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Please describe the level of pain you have experienced in the past 48 hours for each one of your knees.

	None	mild	moderate	severe	extreme
A. Right knee	A. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Left knee	B. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. How severe is your stiffness after first awakening in the morning?

None	mild	moderate	severe	extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. How severe is your stiffness after sitting, lying, or resting later in the day?

None	mild	moderate	severe	extreme
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. The following questions concern your physical function. By this we mean your ability to move around and to look after yourself. For each of the following activities, please indicate the degree of difficulty you have experienced in the last 48 hours, in your knees.

What degree of difficulty do you have with:

	None	mild	moderate	severe	extreme
A. Descending (going down) stairs	A. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Ascending (going up) stairs	B. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. Rising from sitting	C. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. Standing	D. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. Bending to floor	E. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F. Walking on a flat surface	F. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G. Getting in/out of car	G. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H. Going shopping	H. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I. Putting on socks/stockings	I. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J. Rising from bed	J. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K. Taking off socks/stockings	K. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L. Lying in bed	L. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
M. Getting in/out of bath	M. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
N. Sitting	N. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O. Getting on/off toilet	O. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
P. Heavy domestic duties (mowing the lawn, lifting heavy grocery bags)	P. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q. Light domestic duties (such as tidying a room, dusting, cooking)	Q. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION C. PHYSICAL EXAMINATION

1. Height (cm): _____ Weight (kg): _____ BMI: _____

2. Affected joints:

	Right	Left
Hand	Fingers	
Distal interphalangeal	2 3 4 5	2 3 4 5
Proximal interphalangeal	1 2 3 4 5	1 2 3 4 5
Metacarpophalangeal	1 2 3 4 5	1 2 3 4 5
Carpal metacarpal		
Hip		
Knee		
Total		

3. Heberden nodules present: Yes ☐ No ☐

4. Bouchard nodules present: Yes ☐ No ☐

5. Hyper mobility. Is it possible to touch the ventral face of forearm with thumb?

Yes ☐ No ☐

6. Functional Range of Movement.

Movement	Right		Left	
Finger flexion (100°)	Yes	No	Yes	No
Finger extension (0°)	Yes	No	Yes	No
Hip internal rotation (15°)	Yes	No	Yes	No
Hip external rotation (30°)	Yes	No	Yes	No
Hip abduction (15°)	Yes	No	Yes	No
Hip adduction (20°)	Yes	No	Yes	No
Hip flexion (100°)	Yes	No	Yes	No
Hip extension (5°)	Yes	No	Yes	No
Knee flexion (110°)	Yes	No	Yes	No

Knee extension (-5°)	Yes	No	Yes	No
----------------------	-----	----	-----	----

7. Muscle Strength.

a) Grip strength (kg): Trial 1: Trial 2: Trial 3:

Average (kg):

b) Manual Muscle Test

Movement	Trial 1	Trial 2	Trial 3	Average
	(Kg)	(Kg)	(Kg)	(Kg)
Right hip flexion				
Left hip flexion				
Right knee extension				
Left knee extension				

8. Physical Functioning (experimental)

a) Mobility: 6 minute walk test (6MWT): _____(meters).

Resting Heart rate (RHR): _____beats per minute.

Heart rate during the first minute of 6MWT completion: _____beats per minute.

[Instructions: have a 30 m flat corridor measured and marked with cones. The trajectory that participants are meant to be needs to be clear. Instruct the patient to walk at a comfortable pace. The patient should wear their usual clothes. Encourage the participant by saying “ you are doing very well, please keep going” every 30 seconds (3 in total).]

b) Manual Dexterity: Functional dexterity test (FDT)

Hand	Dominant (Yes/No)	OA (Yes/No)	Initial score	Penalty for touching board (5 s)	Penalty for supinating (5 s)	Penalty for dropping peg (10s)	Total score	Functional level	Observations
Right									
Left									

APPENDIX D

Initial interview guide for people living with arthritis

In depth interviews for people who live with osteoarthritis

Objective

The objective of the following interview is to understand the “explanatory models” about osteoarthritis (OA) within the popular health system, represented by people who live with osteoarthritis in Chankom.

Definitions

The popular health system includes all health practices based on individual and familiar beliefs. In this study people with osteoarthritis will represent the popular system.

The explanatory model of an illness is defined as the group of beliefs and interpretations of an individual related to the causes, progress, consequences and treatment of a disease.

The principal assumption in this project is that the perspectives from the people living with OA in Chankom are meaningful, knowable and can be made explicit.

Interview Guide

Previous to the interview

The interviewer should make sure that the participant has completely understood the informed consent form and has accepted to participate in the interview by signing this form. It is important that the interviewer check that the audio recording equipment is working and ready by the beginning of the interview.

Themes Guide

SOCIODEMOGRAPHIC DATA

Gender

Age

Study level

Marital Status

Number of years with OA diagnosis

First theme to explore: Reconstruction of life history in relation with osteoarthritis.

The objective of this theme is to obtain a narrative about the disease trajectory during the participant's life. This narrative should include descriptions about the definition, causes, body manifestations, and impact of the disease on the personal and social life of the person.

*It is suggested to start with this request: **Tell me the story of your joint illness since it started until now.***

Subthemes

Beginning and definition of the disease [We want to obtain the conceptualization and meaning of OA.]

When did you notice that something was wrong with your joints?

What did you do about it?

What were the conclusions of this?

What does it mean to you to have this disease?

Disease development and its expression in the body [We want to know the participant's perspective on the how OA manifests in the body and why (causal meanings and biologic processes).]

How has your body changed since you have the disease?

Why do you think these changes happen? Or what is the disease doing to your

Body?

Disease impact on the biologic, psychology, and social spheres [We want to know the consequences and impact of the disease. In addition we want to know which is the area or areas of life most affected.]

How has the disease affected your daily life?

Basic activities of self-care, feeding, dressing, hygiene

Social activities (family, friends, groups, etc.)

Work activities

Body image

Self-confidence

Emotional state (loneliness, stigma, sense of loss, lost of control, dependence) [It is important to look for emotions like anger, anxiety, despair, fear, concern, uncertainty. For example: What are your concerns about this disease, what do you fear from this disease?]

Economy

Which part of your life has been more affected by the disease?

Experiences with other people with osteoarthritis [We want to know how the person perceives him or herself with respect to other people with OA. We want to

obtain descriptions of the perceived similarities and differences with other persons with OA along with the reasons of these.]

Do you know other people that suffer from this disease?

How are you in relation to other people that suffer from this disease?

Similarities

Differences

Second theme to explore: Therapeutic framework

The objective of this theme is that the participant provides a detailed history about all the treatments that he/she has tried to improve his/her disease.

*It is suggested to begin with this request: **Describe all the treatments that you have use to treat your disease from the beginning until today.*** [We suggest the construction of a time line including the following subthemes with each time point.]

Subthemes

Treatments' characteristics [We want a detailed description of ALL the treatments received until TODAY following a time line.]

What treatments have you received until today?

Treatments' origins [We want to clarify the origins of each of the treatments used until today.]

Who recommended you these treatments? [It is fundamental to clarify to the participant that we are interested in ALL treatments provided by ALL type of health providers (popular, folk or professional)]

Treatments' impact [We want a description about the efficacy (biomedical or symbolic) of each treatment used until today.]

What treatments have worked and why?

What treatments have not worked and why?

Attitudes toward treatments [It is important to know about fears on possible side effects of treatments in relation to the concept of adherence.]

What do you think about the treatments you have told me about?

What do you think about the possible adverse effects of these treatments?

What do you think about the possible harms posed by these treatments?

How does these ideas influence on your adherence to these treatments?

Third theme: perspectives about the “must be” of OA management. [It is pretended to obtain an idea about management expectations through the construction of the “should or must be”]

The objective of this theme is to obtain the participant's perspective about the ideal management of the disease in relation with his/her personal history and the history of other people with OA.

*It is suggested to begin with the following request: **Imagine for a moment that we live in an ideal world and everything we need is reachable, now describe me what would you advice to do to a person that is beginning with the disease.***

Subthemes

Self-management [We want to know the participant's perspective about how a person with OA should ideally manage his/her disease. Self-management is defined as: every task that a person with a chronic disease should do in order to live well.]

What life changes should a person with OA must do to live well?

Traditional management [We want to know what types of traditional treatments are perceived as ideal. It is also important to know why this is perceived.]

What do you think about the help that a witch doctor, homeopathist, bone-setter

etc. can offer?

Biomedical management [We want to know the level of health care (primary, secondary, tertiary) that is considered ideal for the biomedical management of OA. We also want to know which type of health professional is considered to be ideal for the biomedical management of OA.]

What do you think about the help that the health system can provide?

Do you think that treatment should be provided in a clinic or in a hospital and

why?

Who do you think is the best health professional for the management of this

disease: general physician, nurse, orthopedic surgeon, rheumatologist, physical

Therapist, etc. and why?

Ideal management combination [We want to know the participant's perspective about the ideal combination of treatments (self-management, traditional, biomedical) for the management of OA.]

What is the ideal combination of treatments for the disease?

Barriers to get ideal management combination [We want to know about what is that obstructs the “should be” of the management. It is important to ask about cultural, social, political, and economical factors.]

Social Barriers (i.e. stigma)

Cultural Barriers (what is related to the culture)

Economical Barriers (related to resources)

Political Barriers (related to the State structure)

Plan for the second wave of ethnographic activities

Registro Etnográfico Fase 2

A continuación se describirán las decisiones con respecto a las acciones realizadas y por realizar del plan propuesto durante la primera etapa de la etnografía. Este registro se realizará de forma cronológica.

Febrero 22 2013

Tomando en cuenta lo discutido con Julie acerca de las necesidades a explorar para entender el posible papel del “self-management” en el programa a crear, durante su visita al campo (diario de campo p. 189), se decide: a) indagar acerca del rol de género en las actividades grupales; y b) incorporar a las entrevistas en profundidad el tema de estrategias para control y o manejo de la enfermedad. El primer punto ya se encuentra incluido en los temas a explorar en los pacientes durante las entrevistas en profundidad y se encuentra contemplado para las observaciones no participantes de las actividades grupales de salud como lo son los grupos de ejercicio. Por otro lado, el segundo punto se incorporará a las entrevistas en profundidad dentro de los modelos explicativos/ tratamiento de la enfermedad incluyendo la pregunta directa acerca de las posiciones forzadas en flexión que se han detectado hasta ahora en las observaciones participante y no participante.

Por otra parte, de la visita de Julie (diario de campo p. 189) surge la idea de tomar uno o dos casos representativos y seguirlos de manera mas exhaustiva con respecto a una actividad o grupo de actividades en especial, esto con el fin de contrastar la función

representada con la hipotética y reconocer también las estructuras de acogida y adaptación de demanda del ambiente. Esto se comentará con Ingris.

Febrero 23, 2013

De una plática con Julie registrada en el diario de campo (p. 176) se recuerda la idea de explorar la carrera de Rehabilitación en la UADY ya que se tiene el entendido de que tiene un enfoque comunitario. Se incluirá la visita a este departamento dentro de la exploración de las estructuras de trabajo social.

Por otro lado se encuentra en diario de campo (p. 191) una experiencia con representantes de la secretaría estatal de desarrollo social por lo que se plantea una visita de exploración a esta organización gubernamental.

Se encuentra relato en diario de campo de visita al CDI (p. 194) y se conoció al director Miguel Angel Santos Coronado quien nos sugirió hacer un oficio de invitación y contactar a los directores de los albergues en Chankom y a los integrantes del comité de padres de familia de estos. Se incluirá a estas personas en entrevistas en profundidad.

También, nos sugirió investigar en el Municipio la existencia de las ONG que se encuentran operando en el municipio (p.195). Por lo tanto se agregará esto como actividad programada en el plan.

En diario de campo se encuentra entrevista informal realizada a Jose Alfredo Pool titular de area operativa de Oportunidades (p.196) quien nos sugiere asistir a SEDESOL federal a buscar otras oportunidades de financiamiento para infraestructura del programa. En base a esto se plantea una visita a esta secretaría. Asi mismo se encuentra un consejo (p. 195)

de involucrar en la alianza a vocales de Oportunidades por lo que se incorporarán para entrevistas en profundidad.

Marzo 11, 2013

Después de iniciar las acciones programadas para la etapa dos del trabajo etnográfico y haber recibido retroalimentación de Ingris, se decidió que vamos a darle prioridad de aquí a abril a obtener entrevistas en profundidad para personas con OA y AR y a entrevistar a potenciales miembros de la alianza por realizar. También a sugerencia de Ingris solo vamos a seguir 3 criterios de diferenciación para la muestra con variabilidad máxima de las personas con OA: localización, género y discapacidad (muchos o pocos) por lo que queda una muestra propositiva de 12 sujetos. Con respecto a personas con AR nos enfocaremos en personas con severidad en cuanto a manifestaciones clínicas. Del diario de campo se recoge que es importante obtener más riqueza en algunos casos representativos de OA y de AR por lo que se plantea hacer 3 historias de vida: al Sr. Gualberto de Chankom, a la pareja Don Jose Concepción y su esposa Gregoria de Muchucuxcah, y a Los hermanos Diego y Macario de X-coptel. Estas historias requerirán de observaciones participantes y no participantes así como de más entrevistas formales e informales. Con respecto a lo demás planeado se decide que le vamos a dar prioridad también a entrevistas a personas que se negaron a participar en el estudio, y a la familia de pacientes en este caso de 2 casos: de Don Jose Reyes de Xkalakdzonot y de Don Alberto Tun de X-cocail. Por otro lado, las entrevistas a proveedores tradicionales quedarán como secundarias y solo se obtendrá una o dos máximo dando prioridad a Don Maximo de Muchucuxcah por tener fama en esto. Así mismo, las entrevistas faltantes a

médicos pasantes y enfermero de clinicas de salud (Xkalakdzopnot, X copteil, y Ticimul) quedarán con prioridad secundaria y solo se realizarán de haber tiempo y oportunidad. Las tareas rápidas ya programadas junto con la exploración informal de las estructuras de desarrollos social gubernamentales (SSA, IMSS oportunidades, Seguro Popular, CDI) y no gubernamentales (Medicina privada, Hombre sobre la tierra, etc...) y la observación no participante o participante de grupos GAM se continuarán como previsto, solo que disminuirémos la observación de los grupos GAM al mínimo. En cuanto a tareas por hacer observación no participante con video y participante queda la de quemar, leñar y alguna de recreación como baile aprovechando las actividades de la festividad próxima de X-copteil. Se realizará un nuevo esquema de planeación por comunidad para tener bien claras las actividades pendientes en cada comunidad y poder trabajar de forma más eficiente.

Themes for the in-depth interviews conducted during the second wave of ethnographic activities.

List of topics for in-depth interviews

Community Leaders

- 1 - Possibility that community health workers could be executors within the Community based rehabilitation (CBR) program.
- 2 - Expectations of income for the executors of the CBR
- 3 - Collaboration with the development of the CBR
- 4 - Ideas on collaboration and participation

- 5 - Perception of the concept of health
- 6 - Control of income through Opportunities welfare program
- 7 - Value given to professionals' ideas.
- 8 - Politics and health programs.

Traditional Health Providers

- 1 - Explanatory models of rheumatic disease
 - a. Definition
 - b. Cause and process
 - c. Consequences and impact
 - d. Treatment
 - e. Prognosis
 - f. Prevention
- 2 - Ideas for collaboration and participation (emphasis on collaboration in program design)
- 3 - Interactions with other traditional healers.
- 4 - Politics and its influence on the health of the community

People who suffer from OA or RA

- 1 - Physical activity and exercise
- 2 - Climate and geographical conditions
- 3 - Ideas on collaboration and participation (exchange of goods)
- 4 - Concept of health
- 5 - Foreign language and quality of health care
- 6 - Family as facilitator or barrier
- 7 - Religion and suffering (facilitator or barrier)
- 8 - Location as a facilitator or barrier

9 – Welfare programs such as “Oportunidades”

10 - Perception of private medicine

11 – Vicarious experiences

12 - The ideal and real being

13 - Gender and socialization

14 - Quality of health care provider [service promptness, effectiveness of treatments and language]

15 - value of professional opinion

16 - Explanatory models:

a. Definition and illness process

b. Cause

c. Diagnosis

d. Impact

i. Functionality, Functional Capacity and Functional Reserve

ii. Preclinical Disability

iii. Pain as a mediator

iv. Family and household economy

v. Catastrophic Expenses

w. Fear of being a burden

e. Treatment and control, management strategies [self-medication, prescription popular and traditional treatments, the reason for uncomfortable positions]

f. Forecast (path unpredictability)

g. Prevention

17 - Centrality of work (physical demand source, such as definition of being in the world)

18 - Perception of aid use (cane because of shame)

19 - Perception of poverty (in general and with respect to illness)

20 - Policy and its impact on health.

Professional Health Providers

- 1 - Ideas of collaboration and participation
- 2 - Concept of health
- 3 - Foreign language
- 4 – Patellofemoral involvement
- 5 - Importance of human functioning
- 6 - Competence in the management of rheumatic patients
- 7 - Changes in temperature as RA or OA causality rheumatism
- 8 - Differences in language
- 9 - Explanatory models of OA and RA
 - a. Definition
 - b. Cause and process
 - c. Diagnosis
 - d. Consequences and impact
 - e. Treatment (role of steroids)
 - f. Prognosis
 - g. Prevention
- 10 - Policy and its impact on health