Co-design of a Community Based Rehabilitation Program to decrease Musculoskeletal Disabilities in a Mayan-Yucateco Municipality

Edgar Villarreal-Jimenez, Jose Antonio Lores-Peniche, Ingris Pelaez-Ballestas, Gabriela Cruz-Martín, Daniela Flores-Aguilar, Hazel García, Arturo Velazco Gutiérrez, Hugo Ayora-Manzano, Kenia López, Adalberto Loyola-Sanchez

AUTHORS:

Edgar Villarreal-Jimenez. Credentials: Physical Therapist Affiliation: Universidad Marista de Mérida. E-mail: <u>villarreal.edgar1501@gmail.com</u>

Jose Antonio Lores-Peniche. Credentials: Physical Therapist Affiliation: Universidad Marista de Mérida . E-mail: <u>jalores26@gmail.com</u>

Ingris Pelaez-Ballestas. Credentials: MD, MSc, PhD Affiliation: Rheumatology Unit. Hospital General de México "Dr. Eduardo Liceaga", Mexico City. E-mail: <u>pelaezin@gmail.com</u>

Gabriela Cruz-Martín. Credentials Social Anthropologist MSc, PhD student: Affiliation: Universidad Nacional Autónoma de Mexico E-mail: agcuma@hotmail.com

Daniela Flores-Aguilar. Credentials: Social Anthropologist Affiliation: Universidad Autónoma de Yucatán. E-mail: <u>dmaya.joplin@gmail.com</u>

Hazel García. Credentials: Rheumatologist Affiliation: Hospital Amerimed, Cancún México. Email: <u>drahazelgarcia@hotmail.com</u>

Arturo Velazco Gutiérrez. Credentials: Internal Medicine Affiliation: Hospital Amerimed, Cancún, México. E-mail: <u>tutivelasco@hotmail.com</u>

Hugo Ayora-Manzano. Credentials: PT Affiliation: Universidad Autónoma de Yucatán . E-mail: hugo.ayora@gmail.com

Villarreal-Jimenez, E., Lores-Peniche, J.A., Pelaez-Ballestas, I., Cruz-Martín, G., Flores-Aguilar, D., García, H., Velazco Gutiérrez, A., Ayora-Manzano, H., López, K., Loyola-Sanchez. A. (2022) Co-design of a Community Based Rehabilitation Program to decrease Musculoskeletal Disabilities in a Mayan-Yucateco Municipality. *Progress in Community Health Partnerships*. (Forthcoming.) 6 September 2022.

Kenia López. Credentials: Community Member Affiliation: Chankom Municipality E-mail: naykelohe@gmail.com

Adalberto Loyola-Sanchez. Credentials: MD, MSc, PhD. Affiliation: Assistant Professor, Division of Physical Medicine and Rehabilitation, Faculty of Medicine and Dentistry, University of Alberta, Department of Clinical Neurosciences, Alberta Health Services E-mail: <u>adalbert@ualberta.ca</u> (corresponding author).

Submitted 30 November 2021, revised 4 July 2022, accepted 18 July 2022.

ABSTRACT:

Background: Chronic musculoskeletal (MSK) diseases are an important cause of disability in the Mayan community of Chankom in Yucatán, Mexico.

Objective: To understand a community-based participatory research (CBPR) strategy implemented in Chankom to design a community-based rehabilitation (CBR) program for people living with MSK diseases.

Methods: Qualitative descriptive thematic analysis from an ethnographic work conducted in Chankom, during the implementation of a CBPR strategy from 2014 to 2017.

Results: Four main themes describe the main processes that formed our CBPR strategy: 1) forming and maintaining an alliance between academic and community members, 2) prioritizing community needs, 3) integrating local and global knowledge and 4) shared-decision making. This CBPR strategy allowed the design of a Community-based rehabilitation program formed by six main interventions: 1) health services coordination, 2) personal support, 3) community venous blood sampling services, 4) community specialized services, 5) health promotion and 6) health transportation services.

Conclusions: Co-designing a CBR program for people living with chronic MSK diseases in Chankom was possible through an extensive community engagement work structured around four main processes, including the essential principles of CBPR. The designed CBR program includes culturally sensitive interventions aimed at improving the quality, availability, accessibility, and acceptability of healthcare services. Moreover, the program mainly addressed the "Health" component of the World Health Organization-CBR matrix, suggesting a need for a new CBPR cycle after it is implemented and evaluated in the future.

KEYWORDS: Community-Based Participatory Research, Rehabilitation, Health Services,

Indigenous, Musculoskeletal Diseases

Introduction

Musculoskeletal (MSK) diseases are one of the principal causes of disability worldwide (1, 2). The disabling effects of MSK diseases are increased in contexts of inequity related to poverty and social exclusion (3). Indigenous Peoples worldwide have a high prevalence of MSK diseases (4, 5). Consequently, Indigenous peoples show higher levels of MSK disease severity (6, 7) along with higher levels of disability (6, 8) in comparison with their non-Indigenous counterparts. A multi-level epidemiological study in Mexico demonstrated that speaking an Indigenous language is associated with an increased prevalence of rheumatoid arthritis, one of the most disabling MSK diseases (9).

In the Mayan Municipality of Chankom, Yucatan, Mexico, MSK diseases are highly prevalent (10) and strongly associated with disability (11). People living with osteoarthritis (OA) in this rural community have limitations in their ability to complete work-related activities (12). Similarly, having a MSK disease in Chankom is associated with a reduced quality of life, due to a combination of disability and barriers to access appropriate healthcare (13). Consequently, this population needs culturally sensitive healthcare services.

The community-based rehabilitation (CBR) strategy proposed by the World Health Organization (WHO-CBR) after the Alma-Ata declaration in 1978 has evolved over the last 30 years to become a multi sectoral strategy aimed at reducing disability (14). This strategy aims to promote community development that allows people with disabilities to successfully integrate in Society through the implementation of interventions in five main sectors: health, education, livelihood,

social life, and empowerment. The evidence supporting the effectiveness of CBR is not solid, urging the need to implement research strategies that improve its evaluation (15).

The CBR strategy has usually been implemented in rural underserved areas of low and middle income countries for a wide variety of populations with disabilities with good results (16). Implementing a CBR program to improve the function and quality of life of people living with MSK diseases in Chankom seems to be appropriate. International experiences in the implementation of CBR show the importance of including community members and stakeholders in the design of CBR components, with the intention to avoid cultural inappropriateness (17), suggesting a need for research approaches that effectively include the voices of community members.

Community-based participatory research (CBPR) is an effective way to include community members and stakeholders in partnership with academic researchers (18). CBPR is a collaborative approach to research that equitably involves community partners in the research process, allowing the creation of knowledge and social actions to increase health equity (19). This research strategy has been successful to produce positive health changes at community level (20) including Indigenous contexts (21).

Our group implemented a CBPR strategy to define the elements of a community-based rehabilitation program to decrease disability and improve quality of life of people living with MSK diseases in Chankom. The objective of this manuscript is to understand the CBPR strategy implemented to design this community-based rehabilitation program.

Methods

Setting

Chankom is a Mayan-Yucateco Municipality situated in Yucatan, Mexico. This Municipality has a total population of 4464 habitants distributed along 11 hamlets or "comisarías". Municipal leadership is represented by one Municipal President and 11 "comisarios" or hamlet representatives. More than 80% of the population live below the poverty line (22). The main economic activities in this community are agriculture and crafting. Ninety seven percent of Chankom's population receive public health services from "Seguro Popular" (23).

Design

Qualitative study part of a larger mixed methods project to design, implement and evaluate a CBR program for musculoskeletal diseases in Mexican underserved communities (24).

Data collection and analysis

We conducted a descriptive thematic analysis (25) of an ethnographic work (26) conducted by two anthropologists (GCM and DFA) in different Chankom's locations (i.e., clinics, government facilities, one community-project's office, public spaces and people's homes) from 2014 to 2017. These ethnographies were formed from non-participant observations of community meetings,

meetings with local and regional government representatives, community education sessions, clinical visits, and research team fieldwork. They also included non-structured interviews with academic and community leaders after their participation in engagement activities. The objective of the ethnographic work was to understand and integrate the diverse perspectives from community members, government decision makers, researchers and health providers for the design of community interventions to improve the lives of people with MSK diseases.

The ethnographic reports were consolidated chronologically in a single word document and two researchers (EVJ and JLP) conducted a line-by-line coding to identify major themes that describe the components of the CBPR strategy implemented, using a descriptive thematic analysis approach as reported by Taylor, et al (27). Periodical meetings were conducted to triangulate findings and guide the interpretations. Considering the descriptive and non-theoretical nature of our study we did not formally document any thematic saturation.

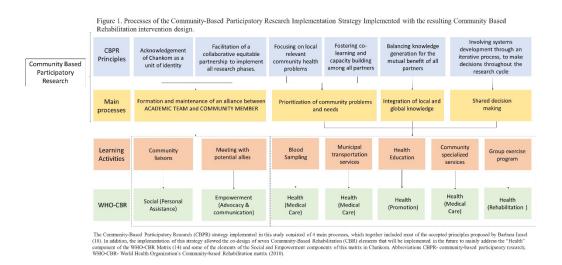
Ethical considerations

This study was approved by the Research Ethics Board of the Hospital General de México, Dr. Eduardo Liceaga (approval number DI/14/404D/05/050). All participants provided verbal and/or written consent after the details of the project were explained by the community workers.

Results

We identified four main themes that describe the CBPR strategy implemented: 1) Formation and Maintenance of an Alliance between Academia and Community Members; 2) <u>Prioritization of</u>

<u>Community Problems and Needs; 3) Integration of Local and Global Knowledge: Community</u> <u>Learning Activities; and 4) Shared Decision-Making</u>, which includes six central principles as defined by Israel et al (28) (see Figure 1). This strategy was successful in defining the elements of a CBR program, which consider some of the WHO-CBR main components (see Figure 1). *Community Based Participatory Research strategy*.



Our thematic analysis showed that our CBPR strategy could be described by the following processes:

1.Formation and Maintenance of an Alliance between Academia and Community Members: This process was further structured by three main activities:

a) Community engagement

The alliance between our academic team and members of Chankom's community started during the dissemination of results from a mixed methods study conducted in the Municipality of Chankom, Yucatan, Mexico between 2011 and 2012. Bi-lingual community members, who were previously trained in MSK quantitative and qualitative research during our previous community work, were hired as "community workers" to facilitate this dissemination. We used a narrative-

based strategy, presenting paradigmatic stories created from synthesizing our results with community images, to increase awareness on the impact of MSK diseases.

This narrative-based strategy was implemented through 40 community meetings, open to all habitants of each hamlet during 2013. Once this strategy was concluded, each hamlet selected three representatives, who showed interest in improving the negative impact of MSK conditions in Chankom. Around two meetings with representatives of each hamlet were held between 2013 and 2014.

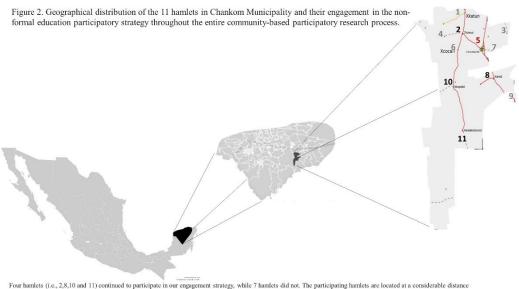
All meetings were facilitated by the community workers, who were trained in group facilitation techniques to: 1) promote knowledge exchange in the topics of health and well-being in the community, 2) initiate and solidify a trust-based relationship between community members and research team, and 3) define priority needs to decrease the negative impact of MSK diseases.

b) Creation of a municipal representative group

Forty- eight meetings were held between May 2014 and December 2015, including 39 with representatives of the different hamlets, eight with representatives of all the municipalities (i.e., each hamlet sent one representative) and one with patients with arthritis living across all hamlets. These meetings aimed to increase capacity for the identification of health issues related with MSK diseases and the utilization of dialogue as a process to generate a group identity and sense of belonging around the mission of improving the health of people living with MSK diseases in Chankom. This effort relied on the implementation of a non-formal education process, or education that takes place outside the formal school-based system (24). All meetings were

scheduled in advance and the community workers communicated dates and times in person with one week in advance.

Only representatives from four of the 11 hamlets continued to actively engage in this participatory process (see Figure 2). Representatives from the other hamlets stopped participating in the meetings and when asked why, they reported time constraints, lack of interest and perception that the process was only talk and no action. Consequently, since 2016 we made the decision to only work with four hamlets. Representatives of the 4 hamlets agreed to work on behalf of the entire Municipality and they named this municipal group "Much Meyaj To o'olal", which in the Maya-Yucateco language means "working together for our health". We continued updating our progress to community members of the non-participating hamlets at least twice a year in person.



from the Municipal Head (i.e., #5), which could have influenced their interest to participate, as they typically do not receive as much attention as the Municipal Head.

Twenty-six meetings with the "Much Meyaj to o'lal" group were held between 2016 and 2017 including the following content: 1) community work motivation, 2) follow up to agreements and tasks assigned, 3) training and sensibilization on MSK diseases and their impact on individual lives and the health care system, 4) identification of community health problems and possible solutions, and 5) continuous goal setting. All these meetings included participation from members of our research team, which formalized an alliance between community representatives and our academic group.

We implemented strategies to increase capacity within the "Much Meyaj to o'lal" group and our research team members on effective knowledge exchange and mutual understanding. Discussions were centered on Indigenous peoples' rights, people with disability rights and community-based rehabilitation and were facilitated by the community workers. The frequency and timing of these meetings varied according to the times and needs of each of the hamlets.

We continuously engaged in open and clear communication in between meetings to maintain the partnership between the "Much Meyaj to o'lal" group and our academic group through tele communication media using internet and cell phone networks. The community workers were the principal bridge for communication.

c) Engagement with local and regional authorities

We conducted a series of meetings with Municipal and State authorities, involving community and research team representatives. These meetings aimed to establish a dialogue towards fostering agreement on the implementation of sustainable solutions to the priority needs and problems identified by the community. This dialogue helped increase the communication skills of community members to effectively advocate for their community needs with local and regional authorities.

Meetings with authorities included the "Jurisdicción sanitaria 2" of Yucatan's Health Ministry, which covers the public health care system of Chankom and the "Hospital de Valladolid", the regional general hospital that serves this population. These meetings aimed to coordinate efforts to improve the health services provided to people living with rheumatic diseases in Chankom, enhance the distribution of medications and discuss future quality improvement projects. Meetings with the Municipal president were also done to coordinate support for the transportation for health purposes.

2. Prioritization of Community Problems and Needs

This process focused on local relevant community health problems and was implemented through dialogue-deliberation techniques or group activities that allowed each participant to reflect and formulate opinions about the root causes of the problems faced by individuals living with MSK diseases in Chankom in a respectful and orderly manner. These techniques were applied in a series of education sessions, including knowledge generated by our academic group, and Indigenous Peoples rights (29, 30). Sessions were implemented throughout the course of one year and were facilitated by the community workers, who continuously visited each hamlet before for each programmed meeting with the "Much Meyaj to o'lal" group.

Community representatives initially identified sixteen main problems that affected the lives of people living with MSK diseases, which were further synthesized in five main groups (see Table 1). The roots of these five problems were discussed to order them according to their priority in relation with potential impact and feasibility to address them in the short term.

3. Integration of Local and Global Knowledge: Community Learning Activities

Once community needs were identified, we implemented a process to integrate available scientific evidence reported in the literature to effectively address the recognized needs (i.e., global evidence) with the regional and cultural norms in Chankom. Global evidence was obtained and assessed through the review of published systematic reviews on: a) effectiveness of community-health workers for improving population's health (31, 32); b) implementation and effectiveness of culturally sensitive community programs on community health (33-35); c) design and improvement of health care systems for vulnerable communities (36-38); d) effectiveness of specialized services on rural communities health (39); e) barriers and facilitators

for health interventions implementation in Indigenous populations with chronic diseases (40); and f) strategies to increase participation and retention of health professionals in rural and underserved communities (41-45).

The content from these reviews was carefully reviewed and their main points were translated to lay terms to facilitate sharing with community members. This knowledge exchange strategy allowed the members of Much Meyaj to o'lal group to clearly communicate to our academic team which alternatives were appropriate to explore and helped all partners to define specific learning activities. These learning activities consisted of implementing the following actions in the community, which produced important learning lessons including identification of challenges to implementation (see Table 2): a) community blood sampling; b) community specialist consultations; c) municipal transportation services d) group exercise program; e) health education; f) community liaisons; and g) meetings with potential allies.

4. Shared Decision-Making

The decision-making structure within our collaboration with the "Much Meyaj to'olal" group was the result of a continuous dialogue process with community members, aimed to identify the differences among our views and priorities, and to agree on the best way to integrate them through a coherent process. Our shared decision-making process consisted in the orderly implementation of the following steps: 1) community workers met bi-weekly with the academic team to define what decisions were to be discussed in the coming meeting with "Much Meyaj to 'olal" group; 2) community workers met with Much "Meyaj to 'olal" group to discuss upcoming decisions-to-be-made, identifying alternatives; and 3) the academic and the "Much Meyaj to

'olal" group met on a bi monthly basis to agree and finalize pending decisions. This way, we tried to promote the empowerment of the Much Meyaj to'olal group to make their own decisions and focus the academic team input to the technical implications of this group's decisions.

Community Based Rehabilitation Elements

The implementation of our CBPR strategy allowed the definition of six main components to decrease disability and increase the quality of life of people living with MSK diseases in Chankom: 1) Health services coordination; 2) Culturally sensitive personal support; 3) Community venous blood sampling services; 4) Community specialized services; 5) Health promotion; and 6) Health transportation. These components were defined from the lessons learned obtained during the learning activities described above (see Table 2). The six components have specific objectives, activities and expected outcomes (see Table 3) and are expected to be implemented as a CBR program in the future.

Health services coordination, Community venous blood sampling services and Health transportation directly address service accessibility. Culturally sensitive personal support is directed to improve acceptability of services. Community specialized services aim to increase service availability. Finally, Health promotion aims to improve individual and community chronic illness management.

The future implementation of these components will depend on the coordinated work of the following roles (see Table 3): 1) internal community liaison- hired community member trained in system navigation, monitoring and management of chronic disease; 2) external community liaison- hired community member trained in system navigation and effective communication

skills in transcultural settings to support people with MSK diseases when they receive care outside the community; 3) liaison coordinator- hired community member trained in program management, community development and communication skills to oversee the appropriate integration of all components; 4) technical supervisor- hired rehabilitation professional to train and support community liaisons, and communicate with clinicians outside Chankom; and 5) Rheumatologist and Physiatrist trained in Chankom's cultural norms.

Discussion

Our CBPR strategy was formed by four processes, which together allowed the co-design of a community-based rehabilitation program. These processes consider most of the main CBPR principles reported in the literature (28) (see Figure 1). The six components of the co-designed CBR program mainly addressed the "Health component" of the WHO-CBR matrix (46), but also included some aspects of the "Social" and "Empowerment" components of this matrix.

The community engagement process required an extensive effort to increase community awareness on the disabling effects of chronic musculoskeletal conditions in Chankom. Defining the elements of the CBR program was not straightforward and required numerous meetings to reflect and agree on priority needs, as well as adapting solutions reported in the scientific literature. The use of learning activities to test implementation strategies helped us integrate global and local knowledge and define tangible strategies that respond to the unique context of Chankom. The use of learning activities as pilots has been reported in the development of innovations within participation efforts involving academics and community members from socially adverse scenarios (47).

Our shared decision-making processes underline the importance of investing in continuous efforts to increase understanding between academics and community members, allowing for the modification of pre-existing beliefs to accommodate diverse cultural realities. It is important to notice that the learning processes investigated in this study did not flow hierarchically, but it was a transversal knowledge exchange that helped the group to move forward and design a complex healthcare intervention. Knowledge exchange strategies are at the core of community based participatory research and have been recommended as an optimal way to assure meaningful participation from community members (48).

Part of the success of our community participatory work was assured by hiring and training community workers. The financial remuneration of these persons was essential to assure they could dedicate appropriate time to the project and could be held accountable. The community workers expressed that if we were asking them to dedicate working hours to do project's work, then they needed to get the money they were not making. In contrast, community members from the Much Meyaj to 'olal group volunteered their time only when they were off working hours. Consequently, we think having a transparent definition of who is going to be financially retributed for their work is essential for the success of participatory research projects and remuneration of community workers is essential to maintain participation, as has been suggested in the literature (49).

The six CBR program components co-designed mainly address the WHO-CBR "Health Component"(46) (see Figure 1). The components of health services coordination, culturally sensitive personal support, specialized services, venous blood sampling and health promotion

designed in this project mainly cover WHO-CBR elements of medical care, health and rehabilitation (46). Considering this program was co-designed with community representatives, this strong emphasis on health could mean community members are mostly aligned with a biomedical view of disease.

Alternatively, the strong focus of the CBR program on the WHO-CBR "Health Component" could be related with power imbalances during decision making, as vision and priorities of academics could have been more represented. These imbalances could have come from community members' perception that academic members had superior knowledge and with the pressures faced by the academic team to conduct and finish the project according to funding agency expectations. Power imbalances disfavoring community members in CBPR have been reported, being associated with a lack of community members' experience in the dominant research culture (50). We need to assure further dialogue between community and academic members to define the value of everyone's contributions and be transparent about funding agency pressures before engaging in collaborative decision making.

The co-designed CBR program components related with health services coordination, culturally sensitive personal support and health transportation also address some elements from the WHO-CBR "Social Component" and "Empowerment Component", as these include strategies to increase personal assistance and advocacy. The fact we did not address all WHO-CBR Components in our program reflects the fact that building a comprehensive CBR program as defined by the WHO-CBR strategy requires multiple cycles of community engagement, as it was originally proposed (51).

The roles of community liaisons within the co-designed CBR program, underline the value of hiring and training community members to improve the quality and cultural sensitivity of health interventions. Building community capacity to provide health care services has been proven to improve the quality of care provided to vulnerable populations (33). There is also evidence that trained community members improve communication with health professionals (35), decrease healthcare access gaps (32) and assure the relevance and cultural appropriateness of the health services (33). Consequently, it is expected that implementing these roles will contribute to the successful implementation of the CBR program.

Implementing specialized services will likely improve the quality of care received by people living with chronic musculoskeletal conditions in Chankom, as this has been demonstrated in other settings (37, 38). The provision of these specialized services will have a positive effect on families' economic burden, as has been reported in the literature (39, 52). The WHO suggests that bringing specialized services closer to communities could be facilitated by community visits or telehealth (45), wo we will need to further define the best format to implement this component in Chankom.

Limitations

The selection of the ethnographic reports considered for this analysis could have omitted important events or community engagement activities, decreasing the trustworthiness in the themes identified for fully representing the CBPR strategy. It is also important to recognize this

analysis did not significantly include perspectives of community members who are part of the partnership created, also limiting our findings trustworthiness.

Conclusions

Co-designing a Community-Based Rehabilitation program for people living with chronic MSK diseases in a Mayan community was possible through implementing a CBPR strategy formed by four main processes. The co-designed CBR program mainly included a complex integration of culturally sensitive interventions aimed at improving the quality, availability, accessibility, and acceptability of healthcare services. This program mostly addressed the "Health" component of the WHO-CBR matrix, suggesting a need to repeat another CBPR cycle after it is implemented to consider including other components.

Community Policy Brief

What is the purpose of this study?

• This manuscript describes the process of a community-based participatory research strategy implemented in a Mayan community to design a community-based rehabilitation program for people living with chronic musculoskeletal diseases.

What is the Problem?

• Many people living in the Mayan community of Chankom have a musculoskeletal disease that limits their function and participation in community life. Therefore, there is a need to develop a rehabilitation program that decreases the disabling effects of these conditions, considering their specific sociocultural needs.

What are the Findings?

- The Community-based participatory research (CBPR) strategy was formed by 4 main processes: 1) forming and maintaining an alliance between academia and community representatives, 2) clarifying community needs, 3) integrating local and global knowledge, and 4) conducting shared-decision making efforts, all of which include the basic principles of CBPR.
- We co-designed a community-based rehabilitation program formed by 6 main
 components: 1) coordination of services, 2) provision of personal support, 3)
 provision of blood sampling services, 4) provision of specialized rheumatology and
 rehabilitation services, 5) implementation of health promotion strategies and 6)
 provision of transportation, which mainly address the Health Component of the
 World Health Organization-CBR matrix.

Who Should Care Most?

 This study is relevant for anyone trying to design a community-based rehabilitation program in Indigenous and other underserved communities with full engagement and participation of community members.

Recommendations for Action

- Community-based rehabilitation programs aimed at improving functioning of people living with disabilities in Indigenous contexts should be co-designed with the community, following a community-based participatory research strategy.
- Community members who contribute with working hours to the participatory effort should be adequately financially compensated for their time.

The future implementation of the 6 components of the co-design CBR program will likely improve the quality of services provided to this Mayan community and hence the function and quality of life of people living with chronic musculoskeletal diseases in this Indigenous community.

Figure Legends

Figure 1. Processes of the Community-Based Participatory Research Implementation Strategy Implemented with the resulting Community Based Rehabilitation intervention design. CBPRcommunity-based participatory research; Legend (to be placed at the bottom of the figure)- The Community-Based Participatory Research (CBPR) strategy implemented in this study consisted of 4 main processes, which together included most of the accepted principles proposed by Barbara Israel (18). In addition, the implementation of this strategy allowed the co-design of seven Community-Based Rehabilitation (CBR) elements that will be implemented in the future to mainly address the "Health" component of the WHO-CBR Matrix (14) and some of the elements of the Social and Empowerment components of this matrix in Chankom. Abbreviations: WHO-CBR- World Health Organization's Community-based Rehabilitation matrix (2010)

Figure 2. Geographical distribution of the 11 hamlets in Chankom Municipality and their engagement in the non-formal education participatory strategy throughout the entire community-based participatory research process. Legend (to be placed at the bottom of the figure)- Four hamlets (i.e., # 2,8,10 and 11) continued to participate in our engagement strategy, while 7 hamlets did not. The participating hamlets are located at a considerable distance from the

Municipal Head (i.e., # 5), which could have influenced their interest to participate as they typically do not receive as much attention as the Municipal Head.

Acknowledgements

This project was funded by a Consejo Nacional de Ciencia y Tecnología (CONACYT) Mexico, grant (FONDOS SECTORIAL DE INVESTIGACION EN SALUD Y SEGURIDAD SOCIAL SSA/IMSS/ISSSTE CONACYT.CONVOCATORIA. 233777-2015-2018) and by an International League against Rheumatism Research Grant (2014).

Adalberto Loyola-Sanchez received a Canadian Institutes of Health Banting Scholarship for completing part of this work as a postdoctoral fellow.

References

1. Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M, et al. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2163-96.

2. Brooks PM. The burden of musculoskeletal disease--a global perspective. Clin Rheumatol. 2006;25(6):778-81.

3. Palmer M. Disability and Poverty: A Conceptual Review. Los Angeles, CA: SAGE Publications; 2011. p. 210-8.

4. McDougall C, Hurd K, Barnabe C. Systematic review of rheumatic disease epidemiology in the indigenous populations of Canada, the United States, Australia, and New Zealand. Semin Arthritis Rheum. 2017;46(5):675-86.

 Pelaez-Ballestas I, Pons-Estel BA, Burgos-Vargas R. Epidemiology of rheumatic diseases in indigenous populations in Latin-Americans. Clin Rheumatol. 2016;35 Suppl 1:1-3.

6. Alarcon AM, Munoz S, Kaufman JS, Martinez C, Riedemann P, Kaliski S. Contribution of ethnic group and socioeconomic status to degree of disability in rheumatoid arthritis in Chilean patients. Rheumatol Int. 2015;35(4):685-9.

 Hurd K, Barnabe C. Systematic review of rheumatic disease phenotypes and outcomes in the Indigenous populations of Canada, the USA, Australia and New Zealand. Rheumatol Int. 2017;37(4):503-21.

8. Massardo L, Pons-Estel BA, Wojdyla D, Cardiel MH, Galarza-Maldonado CM, Sacnun MP, et al. Early rheumatoid arthritis in Latin America: low socioeconomic status related to high disease activity at baseline. Arthritis Care Res (Hoboken). 2012;64(8):1135-43.

9. Moreno-Montoya J, Alvarez-Nemegyei J, Sanin LH, Perez-Barbosa L, Trejo-Valdivia B, Santana N, et al. Association of regional and cultural factors with the prevalence of rheumatoid arthritis in the Mexican population: a multilevel analysis. JCR: Journal of Clinical Rheumatology. 2015;21(2):57-62.

 Peláez-Ballestas I, Alvarez-Nemegyei J, Loyola-Sánchez A, Escudero ML. Prevalence and factors associated with musculoskeletal disorders and rheumatic diseases in indigenous Maya-Yucateco people: a cross-sectional community-based study. Clinical Rheumatology. 2016;35(S1):15-23.

Loyola-Sanchez A, Richardson J, Pelaez-Ballestas I, Alvarez-Nemegyei J, Lavis JN,
 Wilson MG, et al. 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.
 Clinical Rheumatology. 2016;35(S1):25-34.

Loyola-Sanchez A, Richardson J, Pelaez-Ballestas I, Alvarez-Nemegyei J, Lavis JN,
 Wilson MG, et al. Physical Function Assessment of a Mayan Population Living With

Osteoarthritis: The Importance of Considering Different Aspects of Functioning. Rehabilitation Process and Outcome. 2017;6.

13. Loyola-Sanchez A, Richardson J, Wilkins S, Lavis JN, Wilson MG, Alvarez-Nemegyei J, et al. Barriers to accessing the culturally sensitive healthcare that could decrease the disabling effects of arthritis in a rural Mayan community: a qualitative inquiry. Clin Rheumatol.

2016;35(5):1287-98.

14. Organization WH. Community-Based Rehabilitation: CBR Guidelines. Non-formal Education Geneva: World Health Organization; 2010. Available from:

https://www.ncbi.nlm.nih.gov/books/NBK310920/.

15. Cornielje H, Velema JP, Finkenflugel H. Community based rehabilitation programmes: monitoring and evaluation in order to measure results. Lepr Rev. 2008;79(1):36-49.

16. M'Kumbuzi V R, Myezwa H. Adaptation of the global frameworks for community based rehabilitation in southern Africa: a proof of concept. Rural and remote health. 2017;17(3):3717.

17. Chung EY, Packer T, Yau M. When East meets Wests: community-based rehabilitation in Chinese communities. Disability & Rehabilitation. 2011;33(8):697-705.

 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. 1. San Francisco, CA: Jossey-Bass A Wiley Imprint; 2005. p. 1-26.

19. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. American Journal of Public Health. 2010;100(Suppl 1):S40-6.

20. De las Nueces D, Hacker K, DiGirolamo A, Hicks LS. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. Health services research. 2012;47(3 Pt 2):1363-86.

21. Laveaux D, Christopher S. Contextualizing CBPR: Key Principles of CBPR meet the Indigenous research context. Pimatisiwin. 2009;7(1):1.

22. Consejo Nacional de Evaluación de la Política de Desarrollo S. Informe Anual sobre la Situación de Pobreza y Rezago Social. Chankom, Yucatán. [Annual inform on the Poverty and Social Lag Situation. Chankom, Yucatán]. Mexico: SEDESOL; 2014. Contract No.: Report.

Frenk J, Gonzalez-Pier E, Gomez-Dantes O, Lezana MA, Knaul FM. [Comprehensive reform to improve health system performance in Mexico]. Salud Publica de Mexico.
 2007;49(Suppl 1):S23-36.

24. 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 research protocols. 2014;3(4):e57.

25. Taylor SJ, Bogdan R, Piatigorsky J. Introducción a los métodos cualitativos de investigación. La búsqueda de significados. Editorial Paidós Básica. 1987.

26. Guber R. La etnografía: método, campo y reflexividad: Siglo XXI editores; 2019.

27. Taylor S, Bogdan R. El trabajo con los datos. Análisis de los datos en la investigación cualitativa. Introducción a los métodos cualitativos de investigación. 1987:152-76.

28. Israel BA, Coombe CM, McGranaghan RJ. Community-Based Participatory Research: A Partnership Approach for Public Health. Michigan USA: Michigan Public Health Training Center; 2009.

29. Ley para la protección de los derechos de la comunidad Maya del Estado de Yucatán,(2017).

30. Yucatán GdEd. Ley para la protección de los derechos de las personas con discapacidad del Estado de Yucatán. In: Humanos CNdID, editor. Yucatan, Mexico2011.

31. Carr S, Lhussier M, Forster N, Geddes L, Deane, K, Pennington M, et al. An evidence synthesis of qualitative and quantitative research on component intervention techniques, effectiveness, cost-effectiveness, equity and acceptability of different versions of health-related lifestyle advisor role in improving health. Health Technology Assessment. 2011;15(09).

32. Mercer C, Byrth J, Jordan Z, Stern C. The Experiences of Aboriginal Health Workers and Non Aboriginal Health Professionals Working Collaboratively in the Delivery of Health Care to Aboriginal Australians: a systematic review of qualitative evidence. JBI Database of Systematic Reviews and Implementation Reports. 2012;10(Supplement):1-12.

33. Clifford AC, Doran CM, Tsey K. A systematic review of suicide prevention interventions targeting indigenous peoples in Australia, United States, Canada and New Zealand. BMC Public Health. 2013;13(1):463.

34. Haozous EA, Neher C. Best Practices for Effective Clinical Partnerships with Indigenous Populations of North America (American Indian, Alaska Native, First Nations, Métis, and Inuit). Nursing Clinics of North America. 2015;50(3):499-508.

35. Hou S-I, Roberson K. A Systematic Review on US-Based Community Health Navigator (CHN) Interventions for Cancer Screening Promotion—Comparing Community- Versus Clinic-Based Navigator Models. Journal of Cancer Education. 2015;30(1):173-86.

36. Devarakonda S. Hub and spoke model: making rural healthcare in India affordable, available and accessible. Rural and remote health. 2016.

37. Gaede B. Doctors as street-level bureaucrats in a rural hospital in South Africa. Rural and remote health. 2016.

38. Vaughan K, Kok MC, Witter S, Dieleman M. Costs and cost-effectiveness of community health workers: evidence from a literature review. Human Resources for Health. 2015;13(1).

39. Gruen R, Weeramanthri T, Knight S, Bailie R. Specialist outreach clinics in primary care and rural hospital settings (Cochrane Review). Community Eye Health. 2006;19(58):31.

40. Gibson O, Lisy K, Davy C, Aromataris E, Kite E, Lockwood C, et al. Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review. Implementation Science. 2015;10(1).

41. Dolea C, Stormont L, Braichet J-M. Evaluated strategies to increase attraction and retention of health workers in remote and rural areas. Bulletin of the World Health Organization.
2010;88(5):379-85.

42. Grobler L, Marais BJ, Mabunda S. Interventions for increasing the proportion of health professionals practising in rural and other underserved areas. Cochrane Database of Systematic Reviews. 2015.

43. Lehmann U, Dieleman M, Martineau T. Staffing remote rural areas in middle- and lowincome countries: A literature review of attraction and retention. BMC Health Services Research. 2008;8(1):19.

44. Loevinsohn BH, IGO. Contracting for the Delivery of Community Health Services : A Review of Global Experience. Health, Nutrition and Population (HNP) discussion paper.
Washington D.C.; 2004. Contract No.: License: CC BY 3.0 IGO.

45. Roodenbeke ED, Lucas S, Rouzaut A, Bana F. WHO Guidelines Approved by the Guidelines Review Committee. Outreach Services as a Strategy to Increase Access to Health Workers in Remote and Rural Areas: Increasing Access to Health Workers in Rural and Remote Areas. Geneva: World Health Organization

Copyright © World Health Organization 2011.; 2011.

46. World Health O. Community-based rehabilitation: CBR guidelines. Geneva: World Health Organization; 2010.

47. Schindler HS, Fisher PA, Shonkoff JP. From Innovation to Impact at Scale: Lessons
Learned From a Cluster of Research-Community Partnerships. Child Development.
2017;88(5):1435-46.

48. Wilson MG, Lavis JN, Travers R, Rourke SB. Community-based knowledge transfer and exchange: Helping community-based organizations link research to action. Implementation Science. 2010;5(1):33.

49. Bhattacharyya K, Winch P, LeBan K, Tien M. Community health worker incentives and disincentives. Virginia: USAID-BASICS II. 2001.

50. Plumb M, Price W, Kavanaugh-Lynch M. Funding community-based participatory research: lessons learned. Journal of Interprofessional Care. 2004;18(4):428-39.

51. Khasnabis C, Motsch KH, Achu K, Al Jubah K, Brodtkorb S, Chervin P, et al. About the CBR guidelines. Community-Based Rehabilitation: CBR Guidelines: World Health Organization; 2010.

52. Wakerman J, Humphreys JS, Wells R, Kuipers P, Entwistle P, Jones J. Primary health care delivery models in rural and remote Australia – a systematic review. BMC Health Services Research. 2008;8(1):276.

Table 1. Five main problems identified by community representatives

There are no specialized and culturally appropriate medical and rehabilitation services in the community for people with musculoskeletal diseases.

There are no venous blood sampling services in the community, which causes important time and financial loss for community members who need to get this done outside the community.

Municipal Health transportation services is of very low quality.

Community members have a hard time understanding healthcare providers and perceive they are mistreated.

Community members find it difficult to navigate the local and regional healthcare system.

Table 2. Description of the community learning activities implemented in Chankom and their contribution to the final elements of the Community-based Rehabilitation Program.

Learning Activity	Description	Lessons Learned	CBR element(s) defined
Community Blood sampling	Training of community volunteers on venous blood sampling process according to best practice standards with the support of local and regional public institutions.	Trained community volunteers were able to take samples safely and efficiently. Samples were transported for processing to nearest hospital in coordination between Municipal and Regional health services. Results were available for primary and specialist visits. Documented important reduction in out-of-pocket expenses and overall burden for community members. Challenges- the opportunities to practice were limited and sometimes obtaining the phlebotomy supplies to run these sessions smoothly was difficult to find.	Community venous blood sampling services

sp	ommunity ecialist onsultations	Implementing culturally sensitive monthly rheumatology, physiatry, internal medicine, physical therapy, and occupational therapy visits in the community. This involved the participation of regional, national and international healthcare providers who were trained on the cultural aspects of Chankom through pairing with trained community members while delivering their services.	Improved disease education to people with chronic illnesses and their families. Observed improvement in disease control, disease knowledge and pharmacological management of chronic illnesses, including a reduction in inappropriate self-medication. Improvement of activity limitations and participation restrictions for community members. Improvement on the knowledge of specialists on cultural safety, cultural sensibility and cultural humility. Challenges- bringing such a large number of specialists to the community was quite costly. Sometimes, community members did not understand the value of such visits and they thought these were "second class" assessment, while in reality these services are not available anywhere in this Mexican State.	Community specialized services
tra	unicipal insportation rvices	Providing transportation services by Municipal government, coordinated by a designated community member to facilitate access to medical services located outside the community.	Despite some issues related with the quality of transportation services provided by the Municipality in terms of coordination, availability of vehicles and punctuality, the effect of providing this service was very positive for the personal/familial economy of community members. Challenges- many times the transportation was late and there were political strains between community participants and the Municipal government, which required the intervention of the research team to assure all community members had access to these services.	Health transportation

Group exercise program	Implementing a group-based exercise program in the community delivered by a trained community member, which included self-management education and the principles of neuromuscular exercise. This intervention was designed by an international Physiatrist.	All participants in the exercise program (n=16) reported an improvement in their joint symptoms (e.g., pain and stiffness) as well as in their main functional activities. Challenges- Not every community member was comfortable with doing exercise in a group format. The concepts of self-management utilized were not always applicable to this community.	Community specialized services and Personal support
Health education	Providing several community education sessions led by health professionals and facilitated by hired community members on the definition, cause, prevention and management of MSK diseases. Health professionals represented regional, national and international expertise and were guided by community members to ensure clear communication.	Interviews with community members who attended the education sessions (n=12) revealed that these sessions helped them to better understand their illnesses, which allowed them to take a better care of their health. Challenges- for some participants the language utilized was confusing, which created mis interpretations in the community. For example, one woman understood that the medical team aimed to "cut the legs" of people with MSK and she started disseminated this idea in the community.	Health promotion

Community liaisons

Training of community members on health systems, socio-economic-cultural determinants of health, Indigenous and People with Disability human rights and communication skills to facilitate encounters with health professionals. The support and facilitation of communication for community members during numerous encounters with health professionals was reported by community members as highly effective for understanding the nature of the encounter as well as management recommendations and care plans. Challenges- the concepts were not always clear and facilitators had to spend extra time with the academic team trying to clarify them first, before being able to teach the rest of community members. Culturally adapting these concepts was clearly a challenge in the project.

Culturally sensitive personal support

Meetings with potential allies	Meetings with several Municipal, regional and education institutional representatives to establish relationships with community & academic representatives to ensure support from existing resources and foster interventions' sustainability.	As a result of the meetings, a clear process was designed and implemented for the obtention and distribution of medications in the community. This increased access to appropriate pharmacological treatment as well as decreased out of pocket expenses for the members of the community living with chronic MSK conditions. Challenges- on many occasions the authorities did not show up, as this small Mayan community is not always the priority for their political agendas. In addition, time allocated for these encounters was always limited, which decreased the opportunities for all community members involved to exercise their voices and learn how to communicate with Municipal and regional authorities.	Health services coordination
-----------------------------------	--	--	---------------------------------

Table 3. Description of the six elements that form the Community-based Rehabilitation program designed to decrease the disabling effects of musculoskeletal conditions in Chankom.

Element	Objective(s)	Expected outcome	Team member(s) involved
Health services coordination	To improve timely access to required services, which are necessary to improve health and quality of life of people with MSK in Chankom.	Increase in the availability, accessibility and affordability of appropriate services. Improvement in the relational continuity of care. Improvement in perceived quality of life Improvement in disease control Decrease in individual out of pocket catastrophic expenses.	Liaison coordinator, internal and external community liaisons.
Culturally sensitive personal support	To improve community members' experiences using existing healthcare services, improving the communication between them, their family members and health providers, decreasing discrimination.	Improvement in the relational, management and informational continuity of care. Increase satisfaction with health care services. Improvement in chronic disease self- management, increasing disease control.	Liaison coordinator, internal and external community liaisons and technical
	To improve individuals' control of their chronic illnesses through appropriate self- management strategies.	Improvement of functioning. Improvement on quality of life.	supervisor.

Community venous blood sampling services	To decrease the need for community members to go through the hardship of going out of their communities to get venous blood work completed.	Decrease in individual out of pocket catastrophic expenses. Improve satisfaction with health care services Increase availability and accessibility to blood analyses services.	Liaison coordinator, internal and external community liaisons and technical supervisor.
Community specialized services	To improve the functioning of people living with chronic musculoskeletal diseases in Chankom.	Increase in community participation. Decrease activity limitations. Decrease impairment severity Improve quality of life.	Rheumatologist, Physiatrist, Liaison coordinator, internal and external community liaisons and technical supervisor.
Health promotion	To increase opportunities for people with musculoskeletal diseased in Chankom to achieve better health.	Increased skills for people with musculoskeletal diseases to better manage and control their chronic illnesses. Increased sense of community among those living with musculoskeletal chronic illnesses in Chankom through the creation of peer support groups. Increased family members and overall community awareness on the impact,	Liaison coordinator, internal and external community liaisons and technical supervisor.

management and prevention of disability related to chronic musculoskeletal diseases.

Improved perception of transportation users about the quality of health Municipal transportation services.

Increased availability of transportation services for non-urgent healthcare purposes.

Decreased out of pocket expenses related with transportation to obtain healthcare services.

Liaison coordinator, external community liaisons and Municipal drivers.

To provide efficient and appropriate

Municipal transportation services for people

Health

transportation

with chronic musculoskeletal conditions to access necessary healthcare services.