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Piña Palmera is a place for learning

A qualitative study of experiences from the Piña Palmera Community
Based Rehabilitation program for people with disabilities in Oaxaca,
Mexico

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Abstract

Introduction Persons with disabilities are among the most vulnerable groups in every society and the World Health Organisation (WHO) has introduced Community Based Rehabilitation (CBR) with the intention of decreasing this vulnerability. In Oaxaca, Mexico, the Piña Palmera CBR program is working with persons with disabilities from rural communities to improve their quality of life.

Objective The objectives of this qualitative study were to explore what motivates people to engage in the Piña Palmera CBR program, the expected and perceived benefits of participation, and future hopes and ideas for the program among program participants and their family members.

Method Data was collected in the state of Oaxaca in southern Mexico during November-December 2014, in the form of 8 semi-structured interviews. Analysis of the data collected in the interviews was done by using thematic analysis.

Findings The analysis of the data resulted in four themes regarding motivations for and perceived benefits of participation: Piña Palmera is a place for learning, You feel part of a group in Piña Palmera, Piña Palmera is improving the situation for persons with disabilities, and No other place works like Piña Palmera.

Conclusion That Piña Palmera is a place where you get opportunities to learn, that one feels a part of a group, and that the program is different from other options in the way they work can make them an important resource for persons with disabilities in Oaxaca, decreasing problems with unemployment, discrimination, and lacking governmental support for persons with disabilities.

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Abbreviations

C.A.I Piña Palmera A.C - Piña Palmera Centro de Atención Infantil Asociación Civil

CBR - Community Based Rehabilitation

CONADIS - National Counsel for the Development and Inclusion of Persons with Disabilities (Consejo Nacional para el Desarrollo y la Inclusión de las Personas con Discapacidad)

CREE - Centre for Rehabilitation and Special Education (Centro de Rehabilitación y Educación Especial)

ICF - The International Classification of Functioning, Disability and Health

IMSS - Mexican Institute of Social Security (Instituto Mexicano del Seguro Social)

INEGI - National Institute of Statistics and Geography (Instituto Nacional de Estadística y Geografía)

NGO – Non-Governmental Organisation

SHIA - Swedish Organisations' of Disabled Persons International Aid Association

Sida - Swedish International Development Cooperation Agency

Sistema DIF - System for Family Development (Sistema para el Desarrollo Integral de la Familia del estado de Oaxaca)

UNCRPD - United Nations Convention on the Rights of People with Disabilities

WHO - World Health Organisation

Introduction

This is a qualitative study exploring the experiences among participants and family members of participants in a Community Based Rehabilitation (CBR) program in the state of Oaxaca in southern Mexico. Persons with disability are among the most vulnerable groups in any society and CBR programs are aimed at improving their quality of life, access to education, employment, and inclusion in society (1). To ensure that CBR programs do what they are aimed at it is important to evaluate them and in the evaluation consider the opinions and experiences among the people involved in the program (1-3). By exploring what motivates persons with disabilities and parents of children with disabilities to engage in CBR programs, the expected and perceived benefits of participation, and future hopes and ideas for the program this study will hopefully be useful in the future development of the Piña Palmera CBR program in Oaxaca, Mexico.

Disability

Disability is a complex term to define and several different definitions exist. One recent and commonly used definition is stated in The International Classification of Functioning, Disability and Health (ICF) (4): “Disability serves as an umbrella term for impairments, activity limitations or participation restrictions. It denotes the negative aspects of the interaction between an individual, with a health condition, and that individual’s contextual factors, environmental and personal factors (4, p 213).” I chose this definition since it was stated by the World Health Organisation (WHO) in the ICF and it is commonly used by them (4). This definition is also useful since it doesn’t focus solely on the medical aspects of disability; instead it also highlights the importance of the surrounding context when defining disability (4). There is a wide variety of disabilities and people are affected and experience their disabilities in different ways. People can be born with a disability or acquire it during their lifetime; it can range from being born with cerebral palsy, losing your leg in an accident or losing your vision due to diabetes or old age (1).

Historically persons with disabilities have largely been segregated from society and the help they have received have been in institutions and special schools (5). Since the 1970’s a change has been seen where people are beginning to look at disability as a

human rights issue, while policy is shifting towards inclusion in the community and education, mainly driven by self-organization of persons with disabilities (6). The shift in policy can be seen in the United Nations Convention on the Rights of People with Disabilities (UNCRPD) that was adopted on December 13th 2006, where the equal rights of persons with disabilities are stated (7).

However, persons with disabilities are still among the most vulnerable and poverty stricken groups in societies and they are less likely to have access to health services and are often excluded from education and employment (8). These inequalities are even more evident in low- or middle income countries and the prevalence of persons with disabilities is also higher in low-income countries (8). Recent estimates put the number of persons in the world living with some kind of disability somewhere around 1 billion, 10-15% of the world's population, and that number is increasing due to population ageing and the increasing prevalence of chronic diseases (8). Here it is worth noting that measuring disability is complicated and estimates from different countries vary greatly depending on the definition of disability and method of data collection (9, 10). According to The World Report on Disability from 2011 the most common causes of disability are loss of hearing, visual impairments, depression and unintentional injuries (8). The existing inequalities for persons with disabilities and the increasing number of persons with disabilities highlight the importance of taking action to realize the rights of persons with disabilities stated in the UNCRPD (7).

Community Based Rehabilitation

The WHO introduced CBR after the Declaration of Alma-Ata in 1978 with the intention of improving access to health service and thereby enhancing the quality of life for persons with disabilities (1). During the years CBR has developed and the CBR guidelines were developed after recommendations made in 2003 at the International Consultation to Review Community-based Rehabilitation in Helsinki and presented in 2010 (1). The guidelines are based on the principles of the UNCRPD (7) with two added principles; empowerment and sustainability, and according to the guidelines these principles should guide every CBR program (1). All CBR programs are supposed to focus on rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all persons with disabilities through the combined efforts of the persons with disabilities, their families, organizations and communities, and the relevant

governmental and non-governmental health, education, vocational and social services (1). CBR programs can consist of five key components; health, education, livelihood, social life and empowerment, and each component have five sub-elements which can be seen in the CBR Matrix (Annex 1) (1). CBR programs are not expected to implement every component and element of the CBR matrix; instead they are encouraged to select the options which best meet their local needs, priorities and resources (1). Currently CBR is implemented in over 90 countries and it is continuously endorsed by the WHO, seen here in this statement on disability by the World Health Assembly in 2013 (11): “WHO urges member states to promote and strengthen integrated community-based support and services as a multisectoral strategy that empowers all persons with disabilities to access, benefit from, and participate fully in inclusive education, employment, and health and social services (11, p 3)”.

The Mexican context

Mexico is the second largest economy in Latin America and is considered an upper middle income country according to the World Bank (12). Mexico has seen economic growth and a decline in economic inequality since the mid 1990´s (13); however large economic inequalities remain with data from 2012 showing that about 53.3 million people (45.5%) of the Mexican population live in poverty and 11.5 million people (9.8%) in extreme poverty (14). When it comes to persons with disability the percentages are even higher with 51.2% living in poverty and 12.7% in extreme poverty (14), confirming the fact that persons with disability are among the most vulnerable groups in society (8).

A survey in 2012 by the National Institute of Statistics and Geography, Instituto Nacional de Estadística y Geografía (INEGI), estimated the percentage of persons living with a disability in Mexico to be 6.6% (15). The most common types of disabilities were problems walking, visual impairments, and hearing impairments (15). It is worth remembering that these numbers are from a self-reported survey, which increases the risk that the number of persons with disability was underestimated (15, 16).

Laws and policies for the inclusion and rights of persons with disabilities exist in Mexico and are coordinated and promoted by the National Council for the Development and Inclusion of Persons with Disabilities, Consejo Nacional para el Desarrollo y la Inclusión de las Personas con Discapacidad (CONADIS) (17). The different laws indicate that the government needs to ensure the full enjoyment of human rights for persons with disabilities, including inclusion and equal opportunities to participate in all areas of society (18). The Mexican Institute of Social Security, Instituto Mexicano del Seguro Social (IMSS), is considered the most important provider of rehabilitative services in Mexico (18). The IMSS runs 164 different health institutions around Mexico and 46 of them are integrated rehabilitative care units (18). In addition to these institutions run by IMSS there are several different private initiatives, like the Teletón company (19) and different community based options (20, 21). Despite the existence of laws and services provided by the IMSS and private provider little is known about the actual implementation of the laws around the country and how well the needs of persons with disabilities are met (18).

Disability in Oaxaca

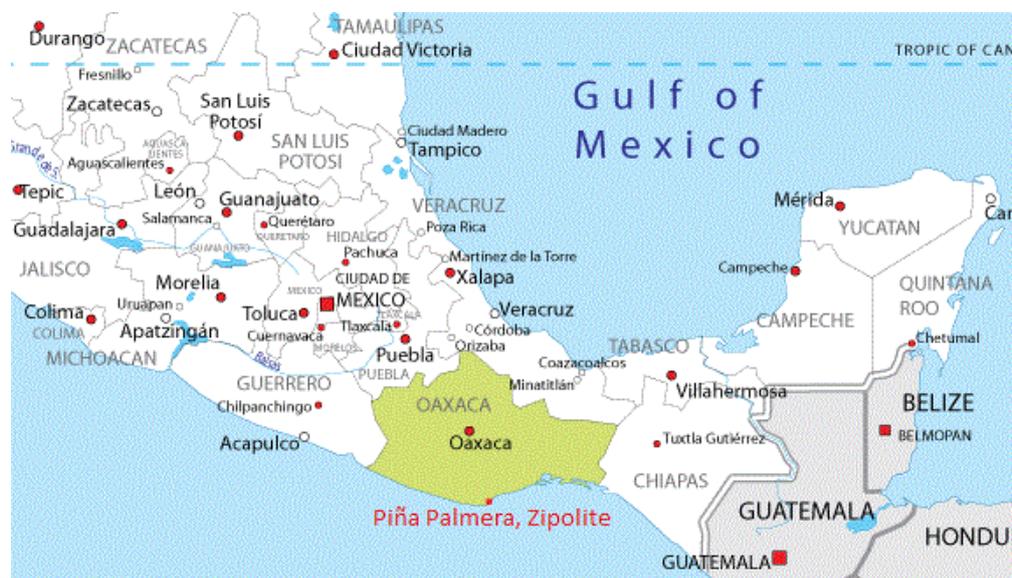
Oaxaca is a state located in the south of Mexico (see map on page 10) and it is among the poorest in Mexico with 2.4 million (61.9%) of the population living under the poverty line (14). The state also has some of the most unfavourable indicators in health, education and marginalization in the country (15, 22, 23).

An estimate from 2012 puts the percentage of persons living with a disability in Oaxaca at 10.7%, the second highest in all of Mexico (15). Once again it needs to be noted that these statistics are from self-reported surveys, which increases the risk of the number of persons with disability being underestimated (15, 16). In agreement with the rest of Mexico the most common types of disabilities were problems to walk, visual impairments, and hearing impairments, followed by difficulty to talk or mental disabilities (15). According to a survey in 2010 the most significant problems in society for persons with disability in Oaxaca are lack of employment, discrimination and not being self-sufficient (24).

In Oaxaca the state-run System for family development, Sistema para el Desarrollo Integral de la Familia del estado de Oaxaca (Sistema DIF) promote and protect the rights and inclusion of persons with disabilities (25). The Sistema DIF provides free rehabilitation for persons with disabilities at the Centre for Rehabilitation and Special education, Centro de Rehabilitación y Educación Especial Oaxaca (CREE), located in the state capital, Oaxaca City (25). The help from the Sistema DIF also consists of the program for wellbeing and support of persons with disabilities, “*MIR Programa Bienestar de Apoyo a Personas con Discapacidad*”, that give monetary support to persons with disabilities every two months (25). However, only 55% of the persons with disabilities in Oaxaca have a health insurance that makes them entitled to health service (23) and the rehabilitation centre located in Oaxaca City is hard to reach for people in other parts of the state.

Few other options exist, but on the southern coast of Oaxaca, in the small town Zipolite (see map on page 10), a CBR program has been set up by the non-governmental organisation (NGO) Piña Palmera Centro de Atención Infantil, Asociación Civil (C.A.I Piña Palmera A.C), that is working with persons with disabilities from rural communities (20). The Piña Palmera centre work according to the CBR guidelines and offer a wide range of different services to persons with disabilities (20). This study is a qualitative evaluation of the Piña Palmera CBR program, exploring the experiences among participants in the program and their family members.

Map of Mexico with Oaxaca and Zipolite marked.



Evaluating CBR programs

The CBR guidelines do not give any defined instructions on how to conduct evaluations of CBR programs; instead they suggest a wide variety of aspects to study and methods to use in data collection (1). The guidelines do say that evaluations of CBR programs are important and it has been suggested by several authors that it can help to promote the sustainability of programs, lead to improvements of existing programs and help in the development of new programs (1-3). In the guidelines the aspects suggested for evaluations are; relevance, efficiency, effectiveness, impact and sustainability of the program (1). Regarding methods the guidelines give suggestions of both qualitative and quantitative methods, without recommending any specific method (1). The guidelines do give the recommendation that the persons with disabilities participating in the program should be involved in the evaluation (1), something that was also highlighted by Sharma (26) in 2003 and Grandisson et al. (2) in 2013, and it goes well with the inclusive idea of CBR programs. It is also emphasized how important it is to report and share the findings from evaluations and use what you learn from the evaluation in the development of the CBR program (1).

No other guidelines or frameworks for evaluations of CBR programs could be found when conducting a thorough literature review; however several studies reviewing methods used in the evaluation of CBR programs exist; Sharma (26) in 2003, Grandisson et al. (2) in 2013 and Lukersmith et al. (3) in 2013. They all find that there is a wide variety of methods being used and both Grandisson et al. (2) and Lukersmith et al. (3) suggest creating resources such as guidelines, frameworks, common processes and checklists for monitoring and evaluation of CBR. Sharma (26) and Grandisson et al. (2) suggests that a combination of viable qualitative and quantitative methods should be used; however none of the three reviews give any clear suggestion what exact methods should be used.

The CBR matrix (Annex 1) has been suggested by several authors to be a possible and useful framework to use in evaluations; however there exists no widespread and agreed upon way of how it should be used (2, 3, 27). Thomas (27) suggest that the desirable outcomes for each component of the CBR matrix are used to create outcome indicators, while Grandisson et al. (2) make their own framework by integrating the CBR matrix with other suggested frameworks.

Several previous evaluations of CBR programs have found positive experiences regarding CBR programs among the persons with disabilities and their family members (28-30). When looking at what the persons with disabilities and their family members find positive and beneficial about being a part of a CBR program, things like the relationship with the workers in the CBR program was mentioned (28, 31, 32), and also that the program increased their participation in the community (33-35) and helped them manage their disability (35, 36). Among parents the benefits expressed in previous studies were that CBR programs help them to care for and understand their children better (37-39).

Despite the existence of several previous evaluations of CBR programs the need for further evaluations of CBR programs in order to strengthen the evidence base has been recognized by several authors (1, 2, 40-42).

Objectives

This qualitative study is exploring the experiences of the Piña Palmera CBR program among program participants and family members of program participants.

The main objective of the study is to answer the question: What motivates people to engage in a CBR program and what are the expected and perceived benefits of participation among participants and family members of participants involved in the Piña Palmera CBR program in Oaxaca, Mexico. A secondary objective is to explore the future hopes and ideas regarding the development of the program among participants and family members of participants.

The purpose is that the findings of the study will be useful in the further development and improvement of the Piña Palmera CBR program and other CBR programs.

Theoretical framework

The CBR matrix (Annex 1) can be seen as a common framework for most CBR programs and it contains five main components; Health, Education, Livelihood, Social and Empowerment (1).

The health component of the matrix has five key elements; Health promotion, Prevention, Medical care, Rehabilitation and Assistive devices (1). The goal for CBR programs should be to work within all these elements in order for persons with disabilities to achieve their highest possible standard of health (1).

The educational component of the matrix is aimed at facilitating access to education for persons with disabilities, improving their chance to fulfil their potential and to participate in society (1). The component contains the five elements; Early childhood care and education, Primary education, Secondary and higher education, Non-formal education and Lifelong learning (1).

The goal for the livelihood component is that persons with disabilities have access to social protection and are able to earn an income large enough to lead dignified lives and contribute economically to their families and communities (1). Skills development, Self-employment, Wage-employment, Financial services, and Social protection are the elements that make up the building blocks of the Livelihood component (1).

For the social component the goal is for persons with disabilities to be treated like equal members of society and have meaningful social roles and responsibilities in their families and communities (1). The elements making up this component are; Personal assistance, Relationships, marriage and family, Culture and arts, Recreation, leisure and sport, and Justice (1).

The final component of the CBR matrix is empowerment and it is supposed to cut across all the other components and help improve the quality of life for persons with disabilities (1). The goal for the component is to see that persons with disabilities and their family members can make their own decisions and take responsibility for changing their lives and improving their communities (1). The elements of the component are; Advocacy and communication, Community mobilization, Political participation, Self-help groups, and Disabled people's organizations (1).

The CBR matrix should guide all CBR programs (1) and several authors (2, 3, 27) have suggested that it might be used in the evaluation of CBR programs. In this study the CBR matrix has supported the design of the study and it will be used as a framework and support for analysis, comparison and discussion of the findings.

Methods

Study design

This study uses a qualitative design with semi-structured interviews (43) and thematic analysis (44). A qualitative design was seen as appropriate since the study is aimed at understanding and exploring the experiences of the CBR program from the perspective of the program participants and their family members aiming at exploring and understanding the experiences and perceptions of people involved in the CBR program (45).

Setting

The study was done in cooperation with C.A.I Piña Palmera A.C, a NGO, which for 30 years has been working with persons with disabilities from rural communities on the southern coast of Oaxaca, Mexico (20). The organisation states no political or religious interest, and it is financed through donations and income from a store belonging to the organisation (20).

The Piña Palmera centre, located in Zipolite (see map on page 10), was founded in 1984 and between the years 1984 and 1990 it functioned as a shelter for children with disabilities and who had been abandoned; providing food, medical attention and education (46). In 1990 they began working in the communities, with basic rehabilitation and home visits for children and youths with disabilities (46). In 1994 the centre officially started the work according to the CBR manual (47) and a program was setup in three communities (46). The program has continually developed during the years and added new activities like; teaching sign language to deaf children, summer camps for children with or without disabilities, giving economical support for persons with disability to study and including more communities in the CBR program (1).

Today the centre includes a medical and rehabilitation clinic where the team that make community visits works, a special care area for persons with severe disabilities, areas for wooden handicrafts and paper recycling, a store and a garden (48). The work is centred on rehabilitation, social integration, information and prevention of any kind of disability (physical, intellectual, learning difficulties, psycho-social,

epilepsy, Down's syndrome or hearing and visual impairments), regardless of the grade of disability, ability to pay or ethnicity (20). Currently there are 750 persons with disabilities participating in the program, 20% children, 35% youth, 35% adults and 10% elderly (20).

The centre offers therapy according to the need of the person with disability, examples of this can be physical therapy for children that have problems walking, teaching sign language to persons with hearing problems, learning to read Braille and walking with a cane for blind people and language therapy for children with a speech impediment (48). The therapy takes place at the centre or in the communities when the therapy team from Piña Palmera makes their community visits every two weeks (48). The amount of rehabilitation given varies greatly according to need of the person with disability; it can be daily sessions where the person with disability comes and stays at the centre or every two weeks during the community visits (48).

The workshops for wooden handicrafts and paper recycling are a way for the centre to be self-sustainable by selling the products produced in their store. In addition the workshops are used to teach persons with disabilities skills that can help them find employment and have a more independent life (48). In the community the centre works to raise awareness about the rights of persons with disability by being in contact with local authorities, schools and by organising forums and workshops aimed at raising awareness (48).

The objectives of Piña Palmera are (20):

- To help people with disabilities to accept themselves and to integrate themselves into their families, communities and daily lives.
- To assist disabled people to be as independent as possible.
- To promote the development of the abilities of people with disabilities to the fullest.
- To generate social acceptance in the region towards people with disabilities.

Participants

Participants for the study were selected purposively with the help of a contact person involved in the program in order to find participants with experience from the program and who are currently engaged in the program. The participants were chosen to get an even division between program participants and family members of participants. The contact person has been working at the centre for the last 10 years and has a good insight in to the Piña Palmera centre and the surrounding communities. The plan was to do between 8 and 12 interviews and in the end 8 semi-structured interviews were conducted as points of saturation were noticed after 6-7 interviews.

Four interviews were with program participants (3 male and 1 female) and four with parents of children currently participating in the CBR program (3 females and 1 male). The program participants are persons who have gone through a rehabilitative process at the centre or got help from the centre as children, and who are currently employed by and an important part of the centre and the CBR program, working with community visits, workshops, and training and empowerment of persons with disabilities. The parents that were interviewed all have children who are enrolled in the Piña Palmera CBR program, and they all help Piña Palmera organise community visits and workshops in their communities. Among the parents the occupations were; mechanic, architect, entrepreneur and housewife.

All the program participants had the same educational level, secondary school, while the parents had a large variation in the level, from primary school up to a university degree. The age of the study participants ranged from 19 to 40 years old and the average age was 31 years old, no major difference was seen between the program participants and the parents. The types of disabilities represented among the program participants and children of the parents participating were different visual impairments, speech impediments, physical disabilities, and learning difficulties. The program participants had been enrolled in the Piña Palmera program between 2 to 30 years, with an average of 14 years. The children of the parents had been enrolled for between 1 up to 7 years, with an average of 4 years in contact.

The interviews

Data was collected in the form of semi-structured interviews during a period of 30 days in November-December 2014. Semi-structured interviews were chosen since it gives an opportunity to explore the experiences of people in detail, and find new and unexpected areas or ideas that were not anticipated when starting the research (43). During data collection a journal with field notes was kept in order to record important observations and events during the data collection.

The semi-structured interviews followed an interview guide (Annex 2) and were aimed at exploring the participants' perceptions of the CBR program. The topics explored were; what motivates the participants to participate, what are the benefits or results of participation, what are their hopes or ideas for the future of the CBR program and if there are any problems or something that decreases their motivation.

The interviews were conducted in Spanish by the student researcher using a Spanish speaking interpreter with a good understanding of the local context and who was well informed about the study. The interpreter also functioned as the contact person for the student researcher, and has been living in Mexico for 10 years and is working as a physiotherapist at the Piña Palmera centre. The interpreter had a previous connection with all the participants from the work as a physiotherapist at the Piña Palmera centre.

All the interviews were recorded and the length of them ranged between 36 minutes to 81 minutes, adding up to 7 hours and 36 minutes of recorded data. All the interviews were conducted individually in a private and comfortable location at the Piña Palmera centre or in the participant's communities. On three occasions the children of the participants were present during the interview; otherwise only the student researcher, the interpreter and the participant were present.

Thematic Analysis

The recorded data was transcribed by the student researcher in both Spanish and English, since the answers from the participants were in Spanish and the translation from the interpreter was in English. The answers in Spanish given by the participants were compared to the English translation from the interpreter to ensure that the translation was correct and no information was lost in translation. One transcript was cross-checked by the contact person to ensure that it was correctly transcribed in both Spanish and English.

Analysis of the data collected in the interviews was done by using thematic analysis as defined by Braun and Clarke (44) in 2006. Thematic analysis was considered suitable for the study since it is flexible, not bound to a certain theory, useful for summarising key features of large amounts of data and it can highlight similarities and differences across the data (44). Thematic analysis was also chosen because the student researcher is an inexperienced qualitative researcher and thematic analysis is seen as easy to learn and use for researchers with little experience of qualitative research (44). The student researcher had previously not conducted any qualitative research, but during his studies, he completed a course in advanced qualitative research, where thematic analysis was introduced and tried.

The process of thematic analysis can be divided into six steps; familiarising yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing the report (44). A code is used to identify a basic element of the data that seems important and interesting and helps organise the data into meaningful groups (44). The codes are grouped under themes, that are like a label for segments of data that are about the same topic and captures something important about the data in relation to the research question (44, 45).

In thematic analysis themes or patterns can be identified in two different ways; inductive or theoretical/deductive (44). This study will mainly use an inductive way of identifying themes; meaning that the themes will be strongly linked to and driven by the data, not by an underlying theory (44). However since it is very hard for any researcher to free themselves from the theory underlying the research and identify themes in a purely inductive way (44), the student researcher acknowledges the fact

that the analysis was influenced by the underlying framework, the CBR matrix (Annex 1) (1). An example of a theme and code derived from the data answering the research question (RQ) can be seen below in table 1.

Table 1: An example of the thematic analysis process from text to theme.

| | |
|----------|--|
| RQ | What are the perceived benefits of participation in a CBR program? |
| Quote | <i>"...an important thing is the inclusion of children with disabilities in the regular schools"</i> |
| Code | Inclusive education |
| Subtheme | Gaining access to education |
| Theme | Piña Palmera is a place for learning |

Ethical considerations

To ensure that the study was feasible and given approval, the Director and the board of C.A.I Piña Palmera A.C. were informed about the study and gave their consent prior to the study.

The following steps were taken in order to ensure that the participants of the study felt comfortable in sharing their experiences knowing that it would not affect the care they receive from the centre and to ensure that their answers are confidential.

To protect individual confidentiality during data analysis, no participants’ names were used and each transcript collected has been coded. The interviews were tape-recorded and then stored securely in password-protected files by the student researcher; transcripts and other data connected to the thesis were stored securely in the same manner. All raw data collected during the study was only accessible to the student researcher and the contact person that checked one of the transcripts.

Participants were notified of their right to refuse to participate, without giving a reason, at any time during the research process. Participants were informed that participation or withdrawal from the project would not affect their care or rehabilitation. Written informed consent (Annex 3, 4) was gained from all participants before undertaking any data collection. The information sheet (Annex 3) and consent form (Annex 4) was developed by the student researcher during a course in field research in the spring of 2014. Information regarding the objectives of the

study, confidentiality and potential risks and benefits and the consent form was provided to the participants in Spanish, translated by the contact person.

No economical or other compensation was provided to the participants of the project to ensure that their participation was voluntary and not due to the promise of any compensation.

Reflexivity

I am a male Swedish licensed Physiotherapist with seven years of working experience in a Swedish Public Health centre and I am currently pursuing a Master's degree in International Health. During my Master studies I came across and became interested in the concept of CBR, seeing it as a different and positive way to work with and for persons with disabilities. My interest in CBR led me to look for a possibility to write my Master's thesis about this subject. I had no previous experience working with CBR programs, however prior to undertaking the study I conducted a thorough literature review on the topic and when arriving in Mexico I spent 3 weeks working as a volunteer at the Piña Palmera centre to get to know the work they do. The time spent at the Piña Palmera enabled me to meet the participants prior to the interviews and take part in workshops, community visits and other activities arranged by the Piña Palmera organisation. My experiences at the centre were positive and I found that the work they do has a positive impact on the surrounding communities and in the life of persons with disabilities. I believe that the time I spent at the centre gave me a better understanding of the work they do and also helped me build a trusting relationship with the participants. Possible risks with my pre-understanding of CBR and experiences from the centre are that my positive view and experiences could influence the data analysis. Also my prior connection with the participants and me working at the centre could make it harder for them to speak freely and for me to ask critical questions during the interviews.

Findings

Thematic analysis of the data resulted in 4 themes and 14 subthemes regarding experiences of participation in a CBR program, specifically motivational and beneficial factors, and future hopes and ideas regarding the development of the program among program participants and family members of program participant and these are presented below in Table 2.

The themes were derived with the above mentioned objectives in mind, but are not specific to the different parts of my objective as it was found that there is a large crossover between what motivates people to participate and the benefits of participation. Regarding the secondary objective about the future hopes of Piña Palmera this is also included in some of the themes as is any negative factors that were brought up in the interviews.

Table 2: Themes and subthemes regarding participant’s perceptions of motivations for and benefits of participation in the Piña Palmera CBR program.

| Themes | Piña Palmera is a place for learning | You feel part of a group in Piña Palmera | Piña Palmera is improving the situation for persons with disabilities | No other place works like Piña Palmera |
|------------------|---|---|--|---|
| Subthemes | Learning to be independent | You work collectively | Piña Palmera raise awareness about the issue of disability | Everybody is equal in Piña Palmera |
| | Gaining access to education | Being inspired by other participants | Piña Palmera empowers persons with disabilities | They see your abilities not your disabilities |
| | You gain more knowledge | You can help other persons with disabilities | How they can improve the situation for persons with disabilities in the future | It is easy to get help from Piña Palmera |
| | Learning to socialise with others | Motivation decreases when people do not attend | | |

Piña Palmera is a place for learning

That Piña Palmera is a place for learning was perceived as an important benefit and it included different ways of learning like the rehabilitation and practical training one gets from Piña Palmera, formal education from school and courses, and also more informal learning from one's peers. What one gets to learn was also varied and included things like learning how to do daily activities, to cooperate with other people, and gaining a deeper knowledge about different topics. Being a part of the Piña Palmera program was perceived as a constant learning experience, that everything one does with Piña Palmera teaches you something new.

“It is for me a constant learning, I have been learning all the time since I got here...” (Female, participant)

This theme includes the four subthemes; learning to be independent, gaining access to education, you gain more knowledge, and learning to socialise with others, which will be presented below.

Learning to be independent

To become independent was perceived as an important benefit of being in contact with Piña Palmera by both parents and program participants, and described as containing two different ways of learning; rehabilitation and practical training. Rehabilitation was described as an expected benefit and something that motivated both the parents and the program participants to contact Piña Palmera.

“Well it was because of the arm of my child, that he needed therapy because of his arm that was weak, and that is why I came to Piña Palmera” (Female, parent)

To be receiving rehabilitation and improving was a significant motivational factor for program participants and for parents it was the fact that their child was receiving rehabilitation and improving that motivated them. Parents also perceived the fact that Piña Palmera teaches them how to do exercises and give rehabilitation to their child as a benefit. Rehabilitation could encompass activities like learning to walk with a cane, using one's paralysed arm better, moving around in a wheelchair, or other

parts of the rehabilitation process that will help one live more independently and see that one can do things.

“They told me I can do things and I got to understand that I can actually do things and then in one moment I got to get here by myself from my house...”
(Male, participant)

To be independent also includes learning to perform daily activities and this is where the practical training comes in to play. The practical training was perceived as an important benefit and motivation for continued participation. The training contained different activities like cooking food and washing one’s clothes, but also skills that one gets from the different workshops at Piña Palmera working with handicrafts or recycling paper in order to be able to make a living and live independently.

“Here in Piña Palmera, first, I got trained in how to sand and make handicrafts, wooden handicrafts, and then after that paper recycling products and that's where I am now.” (Male, participant)

Gaining access to education

Gaining access to education was described as a benefit and motivational factor and something that could help one learn. Different levels of education were mentioned from kindergarten or pre-school up to secondary school. Access to education included both being able to start studying again and being given the support needed to continue one’s studies.

“...it motivates me that I have been able to retake my studies, to start studying again, and that Piña Palmera is helping me with this, that I can manage to do that.” (Male, participant)

Inclusive education was also perceived as a benefit when it comes to gaining access to education and something that motivated parents and program participants alike. Inclusive education means that children with disabilities are included in regular schools together with children without disabilities or learning difficulties, instead of special schools which only children with disabilities or learning difficulties attend. This is something that Piña Palmera is promoting and it is perceived to help the

children learn more, since the education in regular schools is perceived to be better than the one in special schools.

“...it was really good to include him in this school and teachers say that to...”
(Male, parent)

You gain more knowledge

Gaining more knowledge is perceived as both a benefit and a something that motivates people to keep participating in the Piña Palmera program. It was perceived as a benefit and motivational factor that one could gain more knowledge and come to learn about subjects that one would never have known if one was not in contact with Piña Palmera. The parents described that both they and their children were getting more knowledge and that this was an important motivational factor for them. Some examples of subjects that people describe getting more knowledge about were, the environment, how to take care of your child, and the rights of persons with disabilities. Something the parents specifically described as a benefit and motivational factor for them was how Piña Palmera has given them more knowledge about how to take care of and understand their children.

“I as a father I have learnt how to manage the situation with (name of child) and not see him as a child with a disability, just to see more that he is a child like any other child” (Male, parent)

The learning was described as happening during the activities that Piña Palmera organises; like workshops, educational forums and community visits. It was described that the activities give increased knowledge and that an important form of receiving knowledge was to meet other persons with disabilities that could share their experiences and knowledge.

“...so well one important or the most important part is to get to know the experience of others with disabilities and how they have done things.” (Male, participant)

Learning to socialise with others

Getting the opportunity to learn how to be more social and cooperate with others was also expressed as an important benefit of participating in the Piña Palmera program. The fact that one always work together with the staff from Piña Palmera and the other people from the community in a collective way was considered as very helpful for one to become more social and learn to cooperate with others.

“My family has never been very united it has been very conflictive, has had internal conflicts and has been fighting allot, and I was the same way, always fighting with everyone, but this to be in Piña has taught me allot and it has helped me, helped me to not be like that anymore.” (Male, participant)

This was expressed by the program participants and also by the parents who could see that both they themselves and their children were learning to be more social, not only when they attend the meetings with Piña Palmera, but also in their daily lives.

“So to talk to different people, talk to all people, that is what I mean with socialisation and because we didn't do that me and my child, we didn't talk. We were very scared, and the living together or being together with Piña Palmera, that took this fear away” (Female, parent)

You feel part of a group in Piña Palmera

The feeling of being part of a group and getting to socialise with others at Piña Palmera was another important motivational factor and benefit. This feeling of being part of a group comes from being given the chance to work together with others, to help other persons with disabilities, and get inspired by other persons with disabilities. However, here was also mentioned one of the factors that can decrease one´s motivation, when people do not attend the meetings with Piña Palmera. These are the four subthemes under this theme; you work collectively, being inspired by other participants, you can help other persons with disabilities, and motivation decreases when people do not attend, which will be presented below.

You work collectively

To always be working together like a collective was perceived to be a benefit and something that makes one feel part of a group. In the collective work it is not just the program participants and family members that take part, the workers from Piña Palmera are also considered as an essential part of the collective work. This was described by program participants and parents alike, how everyone is striving towards the same goal and that working together makes the participants feel stronger.

“So this is something important, that we are united together, that we work all the time for the same thing...” (Female, parent)

Being inspired by other participants

How other participants can inspire one in different ways was described as an important benefit and motivational factor of being in a group. When they talk about being inspired they describe how one would see other persons with disabilities in the Piña Palmera program living independent and happy lives, and how this would give them hope for themselves or their children. It was also describe how other people with disabilities having gone through a process of rehabilitation would share their experiences and teach them how to overcome obstacles in their own or their children’s process of rehabilitation.

“...and how his process of, how he learned how to get around in a wheelchair, and how to value himself, and to become independent, and his process, and this really motivates me.” (Male, participant)

You can help other persons with disabilities

To be able to help others was perceived as a motivating factor by program participants and parents alike.

“...so we can help others because we have learned so much in these years”
(Female, parent)

It was described how being a part of the Piña Palmera program, and the group of participants and parents gives one a chance to help other persons with disabilities by using what one have learnt in the program and it was seen as a way to give back and show gratitude for the help they had received from Piña Palmera.

Motivation decreases when people do not attend

Something that was perceived as a factor that would decrease the motivation among parents was when people do not show up to the community visits or attends other activities that Piña Palmera organises. The perceived reasons for why people do not attend the meetings with Piña Palmera are that they might be ill, they don't care enough for their children or they expect faster results than Piña Palmera can offer. When other parents and persons with disabilities do not attend the meetings the motivation of the parents decreases because they feel that the others are not taking their responsibility and doing what they promised which makes it harder for them to feel like they are all part of a group and to perform the planned activities.

“Well up to this date it has been when persons with disabilities don't come to the program, because then I'm asking myself. What are we doing wrong, why is it that people don't follow up their process?” (Female, parent)

Piña Palmera is improving the situation for persons with disabilities

That Piña Palmera is improving the situation for persons with disabilities in different ways was perceived as both a benefit and a motivational factor for continued participation. The different ways that Piña Palmera is improving the situation for persons with disabilities relate to how they are raising awareness about the issue of disability and empowering persons with disabilities. Also more practical things were brought up and suggestions or hopes for how Piña Palmera can improve the situation in the future were made. The subthemes for this theme are; Piña Palmera is raising awareness about the issue of disability, Piña Palmera empowers persons with disabilities, and how they can improve the situation for persons with disabilities in the future.

Piña Palmera is raising awareness about the issue of disability

That Piña Palmera raises awareness about persons with disability, and the issue of disability in general, was seen as a motivational factor for participation in the Piña Palmera program. Both the program participants and the parents described how this was something that being part of the Piña Palmera program had given them on a personal level, that they have become more aware of issues regarding disability.

“The workshops for awareness they help allot, for me and for other people to understand.” (Male, parent)

It was also described that a lack of awareness in society was a great problem and something that can make it harder for Piña Palmera to do their work. However it was also described how Piña Palmera was working to change this and that they can raise awareness in the society by participating in different forums and giving out information in the community. This was seen as a way that Piña Palmera was working for and improving the situation for persons with disabilities now and in the future.

“Yes, Piña Palmera is like a prevention for the future, and also gives information about the reality today and how to treat persons with disabilities today.” (Female, parent)

Piña Palmera empowers persons with disabilities

The way that Piña Palmera works to empower persons with disabilities was seen as both a motivational factor and a benefit of being a participant in the program. It was described how Piña Palmera gives practical help and support to people in the communities when they are in contact with schools and other authorities to solve problems or improve the situation for persons with disabilities in the community.

“...and another thing that Piña does is that is important for me is that they empower persons with disabilities, empower them to fight for their human rights and I can't see this anywhere else.” (Female, participant)

Being a part of the program was also seen as something that could teach the parents and participants to speak up and express their opinions in the contact with authorities and in general in the community.

How they can improve the situation for persons with disabilities in the future

When talking about how Piña Palmera can improve the situation for persons with disabilities in the future a general hope was that Piña Palmera could continue in the way that they were working and in that way help more persons with disabilities.

“...what I want Piña to do, I hope that Piña will continue many, many, many years to work...” (Male, participant)

There were also some practical suggestions brought up on how Piña Palmera can improve the situation for persons with disabilities in the future. These suggestions were made by parents that wished that there would be a constant place in their communities where persons with disabilities could come every day and get rehabilitation, do exercise and be more active. This was seen as a way that Piña Palmera could improve the situation for persons with disabilities and also a way in which the awareness in the communities would be raised.

“Well one dream I have is that there would be a permanent space where Piña Palmera could be every day and where persons with disabilities could come and learn things...” (Female, parent)

No other place works like Piña Palmera

That Piña Palmera is different from all other places for rehabilitation in the state and country in the way they work was brought up as an important benefit of being a participant in the Piña Palmera program. One factor that was perceived as something that sets Piña Palmera apart from and makes them better than other rehabilitation options, is that everybody is equal and has their say when decisions are made in Piña Palmera. Another part that was described as not existing in any other place for rehabilitation in the state is how Piña Palmera works to see the abilities in people and not the problems and disabilities. When describing Piña Palmera as something

different it was mainly compared to the rehabilitation that could be offered by the government or other institutions and here it was emphasized that it is easier to get help from Piña Palmera. The subthemes are; everybody is equal in Piña Palmera, they see your abilities not your disabilities, and it is easy to get help from Piña Palmera.

Everybody is equal in Piña Palmera

That everybody is equal was described as a benefit and motivational factor when participating in the Piña Palmera program and as something completely different from any other place of rehabilitation in the state or the country. The equality between persons with or without disability was described in terms of people working side by side at the Piña Palmera centre and everybody having their say when decisions are made in Piña Palmera. This was also described as that there is no discrimination in Piña Palmera and that no hierarchy exists between persons with or without disabilities or between people in different roles in the program.

“...if we will call it team work and we participate both persons with disabilities and persons without disabilities and this is very difficult to find anywhere else” (Male, participant)

They see your abilities not your disabilities

The way that Piña Palmera looks at disability was also seen a crucial benefit and something that sets them apart from the rest of the society and the government. The benefit and what makes the Piña Palmera program different was described as the fact that they try to see what a person can do and teach you that you are able to do things. In contrast it was described that the rest of the community often see persons with disability as “pobrecitos” (literally “poor little ones” in English) that need help and that all other rehabilitation in the state is focused on a passive assistive way of helping persons with disability.

“Here we don't see the disability we see the abilities and this helped me.”
(Male, participant)

It is easy to get help from Piña Palmera

That it was easy to get help from Piña Palmera was perceived as an important benefit and something that sets them apart from other providers of rehabilitation. It was described that the government and local authorities don't do enough for persons with disabilities and that many times what is offered from the government or other providers would require that people travel long distances in order for them to participate in rehabilitation. Both the travelling to get rehabilitation and also fees for rehabilitation were seen as great barriers to rehabilitation. In contrast the fact that Piña Palmera makes community visits and doesn't charge anything was seen as much better and something that made it easier to get help from them compared to other places.

“Well I do it because what the authorities, the local authorities and the state authorities and the government, or the authority of the republic they don't do anything. They don't see these people and they don't do anything for people with disabilities, and in Piña Palmera we have everything, there is everything and they don't even charge a peso.” (Male, parent)

Discussion

Discussion of findings

The findings indicate that Piña Palmera is a place for learning, that one feels part of a group there, and that the way they work to empower persons with disabilities, seeing their abilities, not disabilities, is different from other rehabilitation options in the state. These findings were considered the most important motivational factors for and benefits of participation in the Piña Palmera CBR program. These findings will be discussed in this section by taking previous research on the topic, the Mexican context and the CBR guidelines (1) in to consideration.

Piña Palmera is a place for learning

Learning and getting access to education was perceived as both a motivational factor and benefit of being a part of the Piña Palmera program. The learning described in this study encompasses several different kinds of learning, from learning to do certain activities to getting a deeper understanding about different topics. When looking at previous studies of CBR programs learning and gaining more knowledge has been found to be positive parts of the programs (29, 35-39, 49). Learning to handle your disability and becoming independent was described as something positive in several of the previous studies (29, 35, 36) and also found to be an important part of learning in this study. The parents in this study mentioned how they have learnt how to take care of and understand their child, which has also been seen as important in several previous studies (37-39). Some studies mainly focus on measuring changes in knowledge or skills, taking for granted that learning is a benefit of the CBR program (37, 49). That learning is considered a benefit, in this and previous studies of CBR programs, is not surprising as rehabilitation is in many ways a kind of learning.

When exploring what has been found regarding access to education in previous evaluations of CBR programs several studies have found similar results as this study (33, 34, 50, 51). In one of the previous studies on CBR, conducted by the WHO and the Swedish Organisations' of Disabled Persons International Aid Association (SHIA), similar results were found where the majority of people interviewed expressed that education is important. However, the perceptions of education vary and some parents of children with disabilities did not consider access to education as

an essential part and benefit of CBR programs (51). Still most do find that education is important and Sharma et al. (33) in 2001 and Mol et al. (34) in 2014 both found that access to education and inclusion into schools are important strengths of CBR programs.

The fact that education is seen as a benefit of the Piña Palmera CBR program can be seen in the light of the fact that the state of Oaxaca has a lower level of education and access to education than the rest of the country (15). This problem is even more evident among persons with disability (15) and if the Piña Palmera program can help decrease this difference it is not surprising that it is perceived a benefit and motivational factor.

I believe that the learning that people can do in Piña Palmera and by gaining access to education can decrease some of the problems that persons with disabilities in Oaxaca experience, lack of employment and not being self-sufficient (24). To be educated and learning the skills you get at the Piña Palmera centre might help persons with disabilities to find employment and thereby be more self-sufficient and not dependant on support from the government or Piña Palmera.

A recommendation for the future, in the light of this lack of access to education, would be that the Piña Palmera CBR programs continues supporting and promoting access to inclusive education and giving the participants opportunities to learn, since this is something that is perceived as an essential benefit of this and other CBR programs.

You feel part of a group in Piña Palmera

That people find it a motivation and important benefit to be a part of a group when they participate in a CBR program is something that has been seen in previous studies as well (32, 38). Chapell et al. (32) in 2009 found that as a result of being part of a group, many CBR program participants reported the benefits of peer support and being able to share their experiences with others in similar circumstances. The support from others and sharing experiences with eachother were also mentioned as benefits of being a part of a group in this study. Sharing your experiences can be seen as a way of helping others, but other than that no previous study has been found mentioning anything about wanting to help others as a benefit or motivational factor among CBR program participants.

That the opportunity to help others came up as an important benefit and motivational factor could be related to the selection of participants in this study. All the participants are actively involved with Piña Palmera program in different ways; thereby they are a part of the support that Piña Palmera offers to persons with disabilities and have made an active choice to help others.

Another part of feeling a part of a group that was mentioned is to have a good and trusting relationship with the CBR workers. This has been seen in previous studies (28, 31, 32), and in a study by Thorburn (28) in 1992 it was found that contact with CBR workers was seen as positive, especially home visits by the workers.

Something that could explain that the participants find being part of a group a benefit is the problems with discrimination of persons with disability seen around the world (8) and specifically in the state of Oaxaca it was considered the second most important problem in society among persons with disabilities (24). Considering this it is understandable that the feeling of being part of a group and treated as an equal will be perceived as something positive.

Regarding the finding that people feel a decrease in motivation when others do not attend the meetings that Piña Palmera organises it is not something that has been specifically seen in previous studies. The finding is not surprising since people not attending the meetings can decrease the feeling of being a group.

These findings make it important for Piña Palmera to work towards a high attendance in order to keep motivation as high as possible. Suggestions how they can do this might be to make sure that the meetings always happen at the same times and weekdays, and if they have to change the date make sure that the information is distributed to the people in the community. The student researcher has personal experience from volunteering at Piña Palmera and experienced that the amount of people showing up for the meetings decreased significantly when the date for the meeting was changed.

It is also important that Piña Palmera look into what it is that makes people not attend the meetings, some reasons were suggested in the interviews like, they might be ill, they don't care enough for their children or they expect faster results. Looking into this might make it possible to decrease the number of people not attending by, for instance, making sure that people understand that it might take a long time to get

results from rehabilitation. Another way of decreasing the negative effect of people not attending is to set up a system of reporting if you will attend or not, which might make the people who do show up more able to understand the reasons for not attending the meetings.

The recommendation given by the study participants, concerning creating a place for persons with disability in the communities where they can come every day to be active and see staff from the Piña Palmera centre, can also be considered here. This might not be easy to do, but it could possibly improve the feeling of being in a group and decrease the risk of people not showing up, seeing as it would be easier to access, compared to going to the Piña Palmera centre or the community visits once every second week.

No other place works like Piña Palmera

Regarding the finding that Piña Palmera is perceived as something different and better than other options when it comes to rehabilitation, this makes one want to look at what the other options in the area looks like. This perception could have many reasons, it could be that the other options do not actually exist and that the government isn't doing enough for persons with disabilities, or it could be that quality of other options is not good enough. Another reason that needs to be considered is that the knowledge about other options might be low. Something that backs up the opinion that the quality and access to other options is low is how several participants describe having tried other options, but then choosing Piña Palmera as the better and more accessible option. The problems described with other options were that the participants were forced to travel long distances, pay user fees, and that the rehabilitation offered was not sufficient.

When looking at Mexico as a whole several similar community based projects exists and are working to support persons with disability (21), but not on the southern coast of Oaxaca where Piña Palmera work (20). The governmentally or stately run rehabilitation option, CREE, in the state of Oaxaca is mainly focused in the state capital, Oaxaca City (25), which is far from the southern coastal area where Piña Palmera works. The issue of access and having to travel to rehabilitation becomes clear when you look at the geography of the area where Piña Palmera works (see map on page 10), it is a rural and mountainous region with little or no collective transport,

which mean that travelling to Oaxaca or even other cities closer for rehabilitation will be both expensive and time consuming. Considering this it is understandable that Piña Palmera, who offers community visits and home visits, is seen as a better alternative.

A stately run program for persons with disabilities does exist in the state of Oaxaca, the “*MIR Programa Bienestar de Apoyo a Personas con Discapacidad*” that is aimed at the wellbeing of persons with disability (25). The problem with this program is that it only provides monetary support for persons with disabilities and no actual rehabilitation, which can be seen as a traditional passive way of helping persons with disability (5). This was also described by the participants, that the state focuses on a passive assistive way of helping persons with disability. This type of passive help, where you see the person with disability as someone who just needs help, should be compared to the support the participants described getting from Piña Palmera that strives to see the abilities of the persons with disabilities and treating them as equals. This more active way of supporting persons with disabilities can be seen as a more up-to-date kind of rehabilitation (8) and it is the way that is recommended in the CBR guidelines (1). The appreciation of this kind of active rehabilitation is also understandable when considering the problems with unemployment, discrimination and not being self-sufficient among persons with disabilities (24). Only receiving monetary support from the government will not make it easier for persons with disabilities to find employment, be more self-sufficient or experience less discrimination. In contrast persons with disabilities that get support to be more active and see what they are able to do will in my opinion have a greater possibility to find employment and thereby be more self-sufficient. Also to be treated as equals may decrease feelings of discrimination.

Seen in the light of lacking support and access to rehabilitation from the government in the rural areas of Oaxaca the appreciation of the Piña Palmera program is not surprising and something that should inspire the Piña Palmera program to keep working to provide access to rehabilitation to the persons with disabilities in the rural areas of southern Oaxaca.

Comparison with the CBR Matrix

The CBR matrix should guide all CBR programs; hence a comparison between the findings and the CBR matrix can indicate whether Piña Palmera is working according to the CBR guidelines (1). When comparing the findings of the study with the CBR matrix (Annex 1) it is clear that some part of all the five main components is represented (1). The fact that the beneficial and motivational factors found in this study coincide with the components in the CBR matrix strengthens the claim made in other studies that the CBR matrix can be a useful framework for evaluations of CBR programs (2, 3, 27).

Under the health component, rehabilitation and assistive devices are mentioned as part of the expected and perceived benefits, even if it is described more as a part of learning in this study. The study participants described learning to do daily activities independently as a part of rehabilitation and walking with a cane or using a wheelchair as a part of using assistive devices. The fact that promotion, prevention and medical care are not directly mentioned among the benefits could be because it is not a major concentration of Piña Palmera's work. Piña Palmera do offer medical care and the work that Piña Palmera does to raise awareness and empower persons with disability to be able to get the medical care they need can be seen as health promotion. However, since the participants did not mention that this was something they lacked it is hard to draw any conclusions about whether it is something that needs to be strengthened.

The educational component of the CBR matrix (1) focuses on access to inclusive education, where persons with disabilities are included in regular schools instead of special schools, from early childhood to higher education. The findings of this study correlate well with the focus of the CBR matrix, with access to education on all levels being an important part of the learning Piña Palmera offers, described as a benefit of participating in a CBR program. Apart from formal education, in school, the participants also described a different kind of learning from the meetings and courses given by Piña Palmera which can be considered a kind of non-formal education and life-long learning, which are part of the CBR matrix (1). When the participants describe the experience of being in contact with Piña Palmera as "*a constant learning*" it also goes well with the ideas of non-formal and life-long learning. This

indicates that Piña Palmera is doing well in achieving the goals of the educational component, to give persons with disabilities access to education.

The parts of the livelihood component mentioned as benefits and motivational factors in this study are skills development, as a part of the learning offered by Piña Palmera, which might lead to self-employment and wage employment (1). It was described that Piña Palmera help persons with disabilities become more independent and a large part of that was learning different skills that could help you find some kind of employment in or outside Piña Palmera. Financial services or social protection were not mentioned as any kinds of benefits or motivational factors, rather the financial support offered by state was seen as something negative and a passive way of supporting persons with disabilities.

The social component has the aim to enable persons with disability to be treated like equal members of society and have meaningful social roles and responsibilities (1). That Piña Palmera works for persons with disabilities is something that was evident in the data and it was described how they work to raise awareness in the communities to help persons with disability take part and be treated like equals. Under this component one can also see the learning to socialise with others that was described, which might support the person with disability to take part in society. The learning to socialise was also specifically described as something that helped participants get along better with their family, which can be seen as a part of the relationships, marriage and family element of this component. It is described how Piña Palmera does support persons with disabilities in contacts with authorities, something that can improve access to justice. When it comes to the other elements; Personal assistance, Culture and arts, and Recreation, leisure and sport, they are not evident in the data. However, what is described is the hope that in the future there might be a place in the communities where persons with disabilities can be active, in sports or culture.

The empowerment component of the CBR matrix is supposed to be cutting across the other components empowering persons with disabilities in accessing healthcare, education, employment and society in general (1). The CBR guidelines describe empowerment as being listened to, having control or gaining further control, being independent, and capable of fighting for one's rights (1). That Piña Palmera

empowers persons with disabilities was perceived as a benefit and it was described how they help them express their opinions in contact with authorities. Getting help in contact with authorities is something that is included in the element political participation, under the empowerment component. Advocacy and communication, and community mobilization are two other elements and here we can see Piña Palmera's work to raise awareness of the issue of disability in the communities. Self-help groups and disabled people's organizations are the final two elements of the component and these can be connected to the described feeling of being part of a group and C.A.I Piña Palmera A.C is in itself an organisation for persons with disabilities.

As mentioned previously every component of the CBR matrix is represented in the findings, indicating that Piña Palmera is working according to the CBR guidelines (1). However, some of the findings fall under several different components, which can relate to the fact there is a crossover between the different components of the CBR matrix. This crossover is not surprising considering the ICF's (4) definition of function, where you divide the effect a health condition has on a person into different levels, the bodily function, effect on activity and effect on their participation in society. This translates to the different components of the CBR matrix, where bodily function and activity is handled under the health component and participation in society comes into the educational, social and livelihood components (1, 4). However, here one needs to see that these are all interlinked, since a limitation in activity, like not being able to walk independently might hinder access to education, which in turn might hinder social participation and the chance of employment. The fact that the findings of the study many times can be linked to several different components of the CBR matrix is in my opinion proof that Piña Palmera is recognising the complexity of disability and that one needs to work on different levels to decrease the effect a health condition has on a person.

Methodological discussion

In qualitative research issues regarding credibility, confirmability, dependability, and transferability are used to evaluate the trustworthiness of the research and needs to be considered and discussed (52).

Credibility

In qualitative research credibility means how well the findings are consistent with reality and it is considered one of the most important factors in establishing trustworthiness (52).

Including both program participants and parents of program participants gives a wider variety of experiences and backgrounds among the study participants, which increase the credibility of the study. Since the focus of the study was perceptions on benefits of and motivations for participation all the study participants were purposively chosen because they are active participants in the CBR program or have children participating in the CBR program.

The distribution between male and female was not considered when selecting participants, instead their experiences of the CBR program and an equal distribution between parents and program participants were the deciding factors. The study has an equal distribution between female and male participants; however there is only one father and one female program participant in the study. This unequal distribution within the different groups in the study might be seen as a limitation and it is something that needs to be considered when determining the credibility of the results. However, when looking at the data no clear difference can be seen between the answers from male and female study participants, instead the differences that can be seen are between program participants and parents.

The four program participants in the study are also currently employed by Piña Palmera as a part of the working force that runs the centre. The fact that they are currently employed by Piña Palmera and in that way somewhat dependant of the centre could of course impact the results of the study in a way that they might feel obliged to give positive answers about the centre they are a part of. The same can be said about the parents in the study who are the people in their communities who most actively engage with Piña Palmera, but also in a way dependant on the Piña

Palmera centre in order for their child to receive rehabilitation. However, since the study was focused on exploring what motivates people to participate and the benefits of participation it was natural and I would argue necessary to recruit participants who are actively participating in the activities at Piña Palmera. Also information was given to all participants that any negative answers would not affect them and I feel that the interviews were held in an open and relaxed manner.

The interviews were conducted with the help of an interpreter since I, the student researcher, did not feel confident enough to conduct the interviews in Spanish, despite being able to speak and understand the language. Conducting interviews with the help of an interpreter does give the risk of information being lost in translation, however the fact that I know some Spanish and could understand parts of what was said by the interviewees should decrease the risk of this. Furthermore, both the Spanish answers and English translation was transcribed by me and when comparing them it was found that some information was lost in the translation. In the cases where this occurred the Spanish answer was translated and used in the analysis.

The interpreter that helped out during the interviews also functioned as my contact person and was a part of designing the study and selecting participants. My contact person has been a part of and working at the Piña Palmera centre for around 10 years and has a good knowledge about the area. I would argue that the knowledge of the interpreter was valuable during the interviews, since it made it easier understand what the participants were talking about. However, it needs to be acknowledged that the prior connection with the participants from being a part of the rehabilitation team in Piña Palmera may have affected the findings in the study, the participants may feel pressured to participate and give positive answers due to this, however information was given to all participants about the voluntary nature of their participation and that refusal or negative answers would not affect the care they receive. I experienced that every participant was happy and willing to participate, and that the interviews were held in an open and relaxed manner where the participants were able to express their opinions freely.

The choice to use thematic analysis strengthens the credibility seeing as it is a well-established and widely used method of analysis within qualitative research (44, 52). The use of thematic analysis can also be seen as appropriate considering that it is a

method suitable for inexperienced qualitative researchers such as me, because it is easy to learn and the process of analysis is clearly described in the article by Braun and Clarke (44) in 2006.

How well the themes and subthemes derived from the thematic analysis by me covered the original data was controlled by the contact person, who had a good insight into the original data after having been a part of the data collection and checking the transcripts.

Confirmability

The concept of confirmability in qualitative research relates to how objective the findings of the research are, meaning that the findings are the result of the experiences and ideas of the informants, rather than the predisposition of the researcher (52).

My previous experience as physiotherapist could influence the interpretation of the findings in a way that makes them fit my pre-understanding of what are the benefits or motivations for participating in rehabilitation. My knowledge about CBR from a previous literature review and experiences from volunteering at the Piña Palmera centre might also affect the interpretation of the findings in a way that make them fit what I believe the benefits, motivations and future hopes of the participants are. To ensure that the results of the thematic analysis were representative of the original data, and not affected by my pre-understanding, they were checked by the contact person.

Dependability

The issue of dependability in qualitative research relates to whether a future researcher would be able to repeat the work; however due to the nature of qualitative research not necessarily to gain the same results (52).

The data collection was done by using semi-structured interviews following an interview guide, which makes the interviews follow a similar line of questioning, thereby enhancing dependability. The same interview guide was used for all the interviews, however small adaptations in how the questions were asked were made as a result of insights from the first interviews in order to improve the understanding among the participants. The changes made might affect the dependability in the

study; however the changes made did not change the meaning of the questions. All the interviews were conducted by me and the same interpreter, which might also increase the dependability. Variations in the location where the interviews were held might affect the data collected since it was sometimes hard to find a completely private location; however the participants were all consulted about the location chosen to ensure that the interviews were conducted in a location where they felt comfortable.

The use of thematic analysis as defined by Braun and Clarke (44) in 2006 may also be seen as something that increases the dependability of the study. In their article Braun and Clarke (44) give a detailed and easy to follow description of the process involved in thematic analysis, making it easier for other researchers to repeat the same process. However, one needs to recognise that the nature of qualitative research makes it unlikely that the results will be exactly the same, due to the influence of the researcher's pre-understanding and experiences (52).

Transferability

The transferability of the findings in qualitative research depends on the similarity of the participants and the local context (52).

The findings in this study might be transferable to other CBR programs working in a similar context and with similar kinds of disabilities. The findings can give guidance for what to focus on in order to motivate participation. However, since the nature of any CBR program is that it should be adapted to the local context this should not be seen as a blueprint for what will be perceived as benefits of other CBR programs, since this will depend on the local context.

Conclusion

It was found that what motivates program participants and their family members to participate in the Piña Palmera CBR program often coincide with the benefits of being a participant. The motivational and beneficial factors indicated in this study are that Piña Palmera is a place where you get the opportunity to learn, that you have a feeling of being part of a group, and that the program is different from other options in the state in the way they work, treating everyone as equals and seeing abilities, not disabilities. It seems that the Piña Palmera CBR program can be an important resource for persons with disabilities in Oaxaca, decreasing problems with unemployment, discrimination, and lacking governmental support for persons with disabilities. The findings coincide with the results of previous studies of CBR programs and it can also be seen that the Piña Palmera CBR program is working according to the CBR guidelines, supporting persons with disabilities on different levels.

Recommendations

A recommendation would be for the Piña Palmera organisation to create constant places out in the different communities where persons with disabilities can come on a daily basis. This might not be easy to do, but it could possibly improve the feeling of being in a group, help raise awareness in the community and give the participants a further opportunity to learn, all important beneficial and motivational factors.

I recommend the Piña Palmera CBR program to continue supporting and promoting access to inclusive education and giving the participants opportunities to learn.

Piña Palmera should try to decrease the amount of people not attending the meetings with Piña Palmera and thereby decreasing the negative effect this might have on the motivation of participants. This might be done by making sure that the meetings happens on set dates, that information about the meetings is distributed to the participants, and that information on what one might expect when participating in a CBR program is given.

In light of the lacking support from the government it is important that Piña Palmera continues their work providing a much appreciated and needed support to persons with disabilities in southern Oaxaca.

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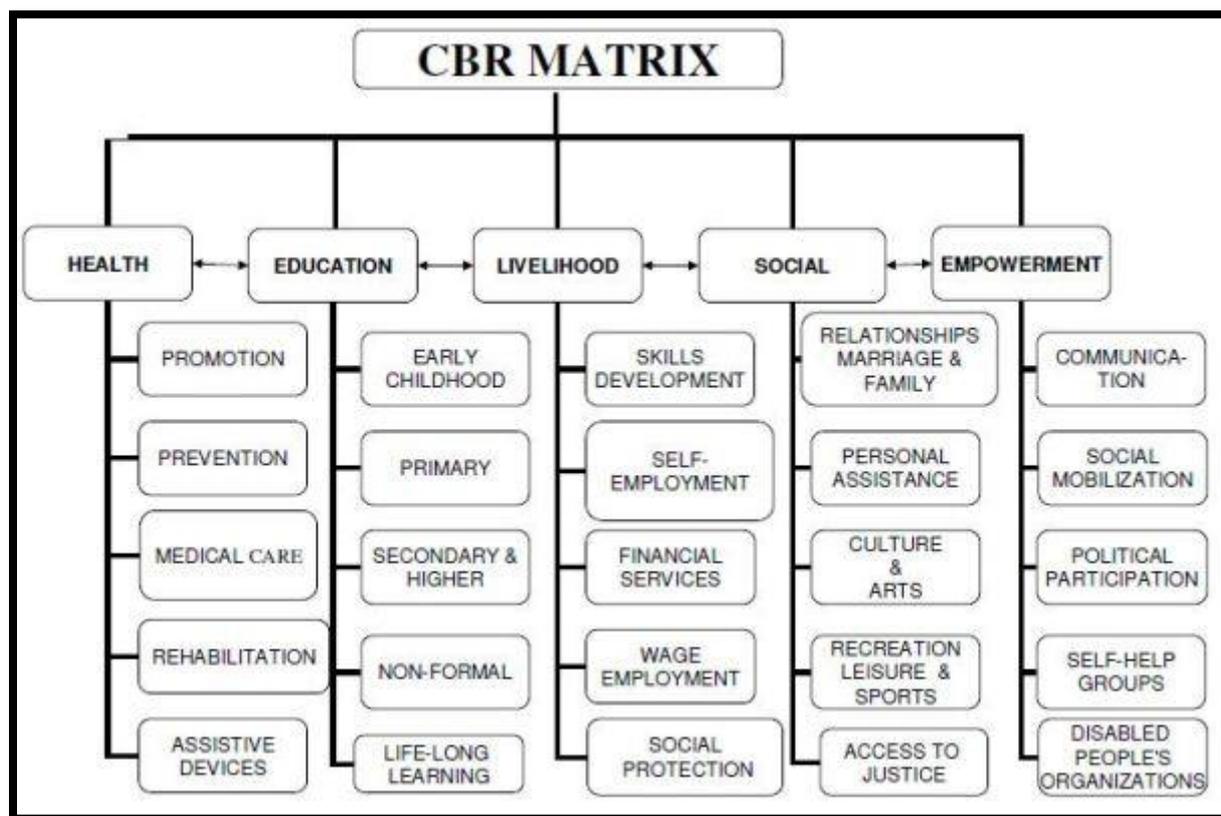
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Annex 1

CBR Matrix (WHO 2010)



Annex 2

Interview guide

Location: Private and convenient place where the interviewee feels comfortable.

Equipment: Tape recorder, batteries, water, pen, paper, information sheets and consent forms.

Before the interview:

- Participants are informed about the study and topic of the interviews.
- Information that the interviews are tape recorded.
- Information about confidentiality, anonymity, privacy and that participation is completely voluntary and will have no effect on future care.
- Written informed consent is obtained.

The interview:

- Social opening with introductions of interviewer, translator and interviewee.
- Introduction of the interview topic and opening question.

Questions:

- **Could you please, in your own words, tell me about your role, tasks and responsibilities in Piña Palmera?**
- How did you find out about Piña Palmera?
- What made you decide to contact Piña Palmera?
- What were your expectations when you contacted Piña Palmera?
- **Could you tell me about how you have developed during the years that you have been involved in Piña Palmera?**
- **What made you engage in the CBR/Piña Palmera program? What keeps you motivated to continue participating?**
- **Have you seen any results, changes or achievements from your engagement, for you, your family and/or the community?**
- What do you hope will be a result of your engagement, for you, your family and/or the community?
- What are the biggest challenges?
- Is there anything that decreases your motivation of being engaged?
- Do you have any ideas or hopes, which you would be willing to share with us, for how the program could develop in the future?
- **Do you have anything you would like to add regarding what we have talked about today?**

Possible probing/follow up questions:

- Can you tell me more about that experience?
- Can you give me an example of that kind of experience?
- How did that make you feel?
- Any specific moments you can describe?
- Is there any special activities or persons that help keep you motivated and engaged in the program?

Annex 3

Research Participants Information sheet

Date:

Title: A qualitative study exploring what makes people engage in a CBR program and the benefits of long-term participation in the Piña Palmera-program in Oaxaca, Mexico

Invitation: I am doing a study using interviews with Piña Palmera participants. We would like you to take a few minutes to read this information sheet before making up your mind about whether or not you would like to help us with our research.

Purpose: The purpose of the study is to explore what makes people engage in the Piña Palmera program.

Participation: Your participation is completely voluntary. You have been invited due to the fact that you are currently a participant and we believe you can provide important information to us that may be relevant to the study.

What will I do if I take part: If you agree to participate in the research we will ask you to read this information sheet, sign the consent form and return it to us. The research consists of an interview in Spanish lasting 1-1 ½ hours held in a location that guarantees privacy.

Disadvantages: The interview will take 1-1 ½ hours and no economical compensation will be provided.

Benefits: We cannot promise the research will help you but the information we get from the interview will help to understand what makes people engage in the program which can help in the development of the program.

Confidentiality: To protect individual confidentiality and anonymity during and after the research, no participants' names will be used and each transcript collected will be coded. All data collected will only be available to members of the research team.

What will happen to the results: Results from the study will be processed and presented in a written report in the form of a Master's thesis by Jonas Hamrén and this will be made available to both Uppsala University and the Piña Palmera organization.

We will be glad to answer your questions about this study at any time.

Main researcher: Jonas Hamrén

Supervisor: Sofia Wolfbrandt

E-mail: Jonas.Hamren.9159@student.uu.se or caipinapalmera@gmail.com

Annex 4

Consent form

Participant consent form

Project title: A qualitative study exploring the perceived benefits of participating in the Piña Palmera-program in Oaxaca, Mexico.

By signing below, you are agreeing that:

- You have read and understood the Participant Information Sheet.
- Any questions about your participation in this study have been answered satisfactorily.
- You are aware of the potential disadvantages.
- You are taking part in this research study voluntarily (without coercion) and that you are free to withdraw at any time, without giving any reason and without your rights being affected.

This study has been cleared to proceed by the Program Director at Piña Palmera Centro de Atención infantil, A.C.

| | |
|---|-------------------------|
| _____ | _____ |
| Participant's name address and relationship (Printed) | Participant's signature |
| Date _____ | |
| _____ | _____ |

Name of person obtaining consent (Printed) Signature of person obtaining consent

Date _____