Photovoice Lessons from a Peruvian Program in Combatting Stigma for Caregivers of Children with Disabilities

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ABSTRACT

Background: Access to resources for children with disabilities and their caregivers are lacking worldwide, especially for low-middle income countries, especially those of Latin origin. Furthermore, decreased social visibility coupled with minimal support available for caregivers can negatively affect their overall mental wellbeing. Limited community-based participatory research (CBPR) has been done to understand the experiences of caregivers and identify effective measures of support.

Objectives: To explore the impact of childhood disabilities on caregiver wellbeing and to assess how interactions between caregivers and their community affect their mental wellbeing.

Methods: This study utilized photovoice and CBPR methodology. We recruited participants who had children enrolled in a rehabilitative program called Rehabilitation with Hope, located in Huancayo, Peru. Participants were given three photo assignments concerning their experiences as caregivers and they presented their photos at photo discussions after each assignment. We used thematic analysis to identify the main themes that arose from the discussions.

Results: Four main themes were identified: stigma, social support, self-esteem, and effects of photovoice. Caregivers often felt stigmatized by the community due to their child's disability. However, they found a stronger sense of social support and overall improved sense of self-esteem through the program and participation in photovoice.

Conclusions: Results of this study suggest the effects of stigma on caregivers may be mitigated through enhanced social support and self-esteem. Additionally, photovoice is an effective tool to combat community stigma by allowing caregivers to share their narratives.

KEYWORDS: photovoice, caregivers of children with disabilities, stigma, Peru, social support, self-esteem

Introduction

Approximately one in 20 children worldwide under the age of 14 have a disability classified as moderate or severe, with nearly 80% living in low- and middle-income countries where rehabilitation services are often scarce.[1,2] Disabilities affect the physical, social, and economic dimensions of a child's wellbeing and of their caregivers', most often the parents.[3-6] Continuous caregiving for individuals with disabilities can affect the physical health, psychological functioning, and relationships of caregivers,[7-9] which affects both the health of, and quality of care given, to the child.[7,8]

In Peru, a middle-income country, 5.2% of the population had at least one disability in 2012.[10] Only 10% of those individuals had access to rehabilitation services[11] and 25% reported lack of ramps, handrails, and adapted bathrooms in medical facilities, leading to underuse of the already restricted health services.[12] Access is even more limited for those from rural areas and low education or socioeconomic status.[11] The lack of social visibility in public arenas for these individuals may be associated with stigma and lack of social integration.[11,13-15] Such stigma is a sign of social shame in which an individual is devalued based on personal attributes including gender, ethnicity, or mental health issues.[16] Similar to other countries, caregivers of persons with disabilities in Peru report lack of emotional, informational, and tangible support.[11]

To increase access to care for individuals with disabilities in Peru, the Catholic Medical Mission Board (CMMB)— an international faith-based non-governmental organization— established Rehabilitation with Hope (RWH), which provides free physical, language, cognitive, and emotional therapy to children from low socioeconomic status. For caregivers, RWH offers psychotherapy, entrepreneurial workshops, and seminars on healthy living and nurturing.

While RWH was established in 2014, there are aspects of the client experience not explored that may add to the literature on caregivers for individuals with disabilities. Community-based participatory research (CBPR) can serve as a bridge for exploring the overall impact of such programs and in providing guidance for future programs. The 2011 World Report on Disability and United Nations Conventions on the Rights of People with Disabilities recommended integrating the consultation of individuals with disabilities into research and services.[1,17,18] This involvement allows community members to work alongside local decision makers while providing their experiential knowledge, contextual understanding, and shared responsibility.[19]

Photovoice is a CBPR methodology in which participants share their experiences through photography[19-22] to create awareness about community issues and catalyze social action.[23] Photovoice has been used with various vulnerable groups, including persons suffering from HIV/AIDS and tuberculosis, homeless individuals, senior citizens, and indigenous communities.[19,21,24] Previous studies employed photovoice with people with disabilities[25], however, there is limited research using photovoice with caregivers, especially in Latin America. Therefore, this study utilized photovoice to explore the impact of childhood disabilities on caregiver wellbeing.

Methods

This study took place between March and June 2017 in Huancayo, Peru, one of CMMB's two sites. We describe this study following the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.[26] This study was part of a partnership created between CMMB and the University of Notre Dame (UND) in 2015 as part of the UND's Master of Science in Global Health. Through the program, graduate students work alongside CMMB to conduct research projects to benefit CMMB's work. For this study, CMMB asked the UND to explore factors that impact the wellbeing of caregivers of children with disabilities to understand how RWH could better serve families enrolled in the program. The lead researcher was selected for this study by leaders from both institutions to ensure goals for the project aligned amongst all parties. As a CBPR study, the roles of CMMB participants, community, and staff are described throughout the paper.

The study was approved by the Institutional Review Board at the UND. Signed consent was obtained from all participants and oral consent was subsequently obtained for any use of photographs and de-identified direct quotes in this manuscript. Please note that the names [Jorge, Gabriela, Leticia, Mago, Mari] utilized in the results section are pseudonyms used to protect the identity of participants and are not their real names.

Several measures were taken to avoid power asymmetries between both institutions. To ensure the study was conducted in a culturally appropriate and respectful manner, the selected lead researcher was a native Spanish speaker from a Hispanic background and had extensive experience working with Latinx communities. Equal input from both institutions was utilized in every step of this study's development and CMMB contributions included integral authorship of this manuscript. CMMB staff members played an essential role in the field work by advising the lead researcher and facilitating relationships between the lead researcher and participants to create a collegial and collaborative environment. These included shared meals, immersion in CMMB activities, and home visits.

Recruitment and sampling

The study population consisted of primary caregivers of children with physical and/or mental disabilities enrolled in RWH. At the time of this study, there were 33 caregivers enrolled in the program. Participants were recruited in person through purposive sampling with the help of three CMMB staff members on the basis of four criteria: 1) long-term involvement in RWH (defined by CMMB enrollment, one year or longer); 2) participation in RWH activities (i.e., physical and language therapy for children and lifestyle or financial workshops for caregivers); 3) willingness to take photographs and share them during photo discussions; and 4) agreement to appropriately use cameras provided. All recruited participants agreed to participate in and completed the study. Participants did not know each other prior to the start of the study, although they had interacted with other caregivers involved with CMMB.

An orientation and training for participants was held to discuss the following aspects of the study: photovoice process, group goals, informed consent, technical and ethical aspects of photography, and ideas on what participants may want to highlight with their photographs.

Each participant received a digital camera to keep for the duration of the study. Before each photo discussion, participants selected 10 photos to share with the group. These photos were uploaded and saved onto the lead researcher’s laptop and displayed utilizing a projector. Each participant was identified by a number to preserve anonymity.

Data collection

In classic photovoice methodology, participants are asked to take photographs related to specific themes. To obtain a broader understanding of participants' perspectives, three photo assignments aimed at capturing their personal, interpersonal, and overall experiences working with CMMB were given. The first assignment asked participants to describe their typical day; the second assignment asked how they participate in society with and without their child; and the third assignment asked how their lives changed after enrolling in CMMB.

Participants were given three days to one week to complete each assignment. There was no limit on the number of photographs participants could take. However, due to time considerations, each participant was asked to select 10 photographs with an associated narrative to present during each photo discussion. Narratives addressed the significance of the photograph in relation to the photo assignment and participants' experiences as caregivers.

Each assignment was followed by a photo discussion in which participants' pictures and narratives were utilized to facilitate conversation.[20] Photo discussions focused on barriers and challenges faced while taking photographs and any positive or negative experience during the process. The photovoice technique known as SHOWeD was used to identify key aspects of participants' photographs.[27] *SHOWeD asks:*

> *What do you **S**ee here? What is really **H**appening here? How does this relate to **O**ur lives? **W**hy does this situation, concern, or strength **E**xist? What can we **D**o about it?*[27]

A a short semi-structured discussion guide was developed by the lead researcher and used for all photo assignments. This guide included the SHOWeD questions and requested participants to reflect if and how content of their photographs would differ if their child was not enrolled in RWH. During the last photo discussion, participants were asked their thoughts on the experience and what they learned. All three CMMB staff members and the lead researcher were present during the photo discussions while the lead researcher facilitated the sessions.

Analysis

Photovoice projects are analyzed in three stages: 1) participants select photographs they consider the most important in explaining their stories (selecting); 2) participants give narratives to provide meaning to the photographs (contextualizing); and 3) themes that emerge from the photographs and discussions are identified (codifying).[20] Participants in this study completed the first two stages of analysis as co-researchers.[28] The third stage of analysis was completed by the lead researcher. All photo discussions were recorded, transcribed verbatim in Spanish and analyzed using thematic analysis[29]. The lead researcher used field observations and notes to contextualize the transcripts, which led to development of a codebook using emergent codes drawn from the texts. The codebook was used to assign codes to the transcripts manually, which were later grouped into themes and subthemes. Key quotes from the transcripts were identified to serve as evidence for each theme and subtheme. All analysis was done in Spanish to maintain cultural meaning as significance can often be lost with translation. The three CMMB staff members performed the member check process as the lead researcher had returned to the U.S. at the end of her field work assignment. They shared write-ups of the results with each participant and requested comments on accuracy and fairness of the report. Participants were also asked if they would like to edit anything in the report and final reflections on their participation in the study. Key quotes were translated into English after analysis for the purposes of this manuscript. The original quotes in Spanish can be found on **Appendix A**.

Exhibit

To engage members of the greater Huancayo community in discussion, participants planned a two-day photo exhibit after completion of all photo discussions with the support of CMMB staff members and the lead researcher. Participants selected a theme for the exhibit that included a message they wanted to share with their community. In preparation for this, the lead researcher spent one to two hours with each participant to guide them on selecting 10 photographs and writing their captions to illustrate the exhibit's theme. These photographs were framed and displayed on easels in a plaza in the center of Huancayo.

The target audience included dignitaries and community leaders who could impact policy and action regarding children with disabilities and their caregivers. Attendees included the director of the Institute for the Youth and Culture, the director of Social Development of the Provincial Municipality of Huancayo, members of the Municipal Office of Attention to the Person with Disability (OMAPED), and the director of the Disability Department from the Regional Direction of Health in Junin (Diresa). The exhibit was also advertised to the general public on local newspapers and radio and through physical invitations distributed in high-density areas.

During the opening ceremony, a CMMB staff, the lead researcher, two participants, and two members of the target audience gave personal testimonies. The exhibit had three areas: narrative, social, and participatory. Details of this unique and interactive event are described in Table 1. During the exhibit's second day, each participant received a photo album containing all the photographs they took during the study.

Results

Eight caregivers, all parents of children with disabilities (seven mothers, one father), participated in this study. Participants took a total of 1,013 photographs during their assignments of which 240 were presented in the photo discussions. Overall, discussions from all photo discussions revealed four main themes: stigma, self-esteem, social support, and photovoice effects. Together, these themes revealed caregivers experience stigma throughout their communities which negatively affects their self-esteem and ability to receive social support. Through participation in CMMB, participants reported increased social support and self-esteem, allowing them to deal better with stigma. The photovoice methodology encouraged strengthening this social support and self-esteem. The quotes in this manuscript are representative of discussions with all eight participants and were selected for their strong exemplification of themes.

Stigma

All participants reported feeling social shame from their community for being parents of children with disabilities. They described witnessing feelings of disdain and fear towards their children and experiencing blame for their children's disabilities from family, strangers, teachers, and physicians.

> *"Seeing children like that [with disabilities], they say, 'Where did they come from?'…They're scared of them [the children]."* Jorge

Feeling judged by the community negatively affected participants for long periods of time and led them to feel excluded. One participant shared a story about taking his son, who is now 17 years old, to the hospital when he was an infant:

"When I went with my child, the doctors tossed me from the hospital. 'You will have him [your son] like that for life. Get used to it!' They closed their doors on me. That's why I'm afraid to go to the hospital." Jorge

Another participant shared feeling rejected by society.

"We are still rejected by society…but we have overcome many things…We no longer care that others point at us, tell us things, look us up and down." Gabriela

People constantly questioned participants about the cause of their children's disabilities, causing participants to feel guilty. Common accusations included age, drugs, and laughing at those with disabilities.

"Because I was young, they would tell me, 'Did you take a pill? What did you do?'" Leticia

"Even my own family would tell me, 'What have you done to have [a child with disability]? It's a punishment from God.'" Mago

Participants indicated constant questioning by others led them to distrust their community. To avoid feelings of disdain and blame, participants isolated themselves or hid their children when leaving their homes.

"I cried and preferred locking myself up at home so that no one could hurt me more than I already was." Leticia

"What I would do so [others] wouldn't see my son or so that no one would say something to me, so that no one would judge me… is wrap him [my son] really well… and I made sure he was asleep." Mago

Self-Esteem

Despite stigma, participants gained a sense of pride in themselves, their children, and improved self-esteem from their involvement with CMMB. This pride allowed them to overcome the fear of appearing in public. Participants shared photographs of their "CMMB families" marching in a parade in Huancayo to make their children's presence known in the community (**Figure 1**).

Figure 1 – Photo Exhibit Caption: Although stigma is prevalent, CMMB families are proud. Chilca's Parade exemplifies they will not be marginalized or discriminated against for having children with special abilities. Jorge

> *"We feel proud because it wasn't like that before [CMMB]. Before, we felt like we had done something, but really, we realized we hadn't done anything, no pills or anything. [People say] many hurtful things but [thanks to] CMMB we have learned to overcome that."* Gabriela

This self-perceived increase in self-esteem allowed participants to stop feeling guilty and accept their children's disabilities.

"Before CMMB, my life was simply depression, crying. I even refused to accept that my son had to sit in a wheelchair. I would say, 'My son will never sit there. Never.' I completely refused…CMMB's arrival into my life was a change in myself, to accept the things that happened to me, to accept all the good things I had to enjoy." Leticia

This new self-esteem allowed participants to be positive and have hope. One participant indicated while others may see having children with disabilities as impediments, in reality, nothing has stopped them from achieving their dreams.

"I have always said: 'One day, son, we will go on a plane. We'll travel.' I've always had the hope, and thanks to God, thanks to the [CMMB] program, we have travelled. I have fulfilled my dream." Jorge (**Figure 2**)

Figure 2 – Photo Exhibit Caption: Jorge's family achieved their dream of flying when they traveled to Lima for [their son]'s treatment as there are no specialists in Huancayo. Jorge

Social Support

Participants reported while they had felt excluded from and judged by their communities, they found a support system with other parents and therapists involved in CMMB.

Participants indicated that CMMB allowed parents of children with disabilities to join together in an environment of understanding, solidarity, and trust.

> *"I have become so familiar with CMMB, with all the mothers with the same issues. For me, it is a family. We haven't had an acceptance like we have now… We have found [a way] to understand each other, love each other, appreciate each other."* Gabriela

Participants found support in their CMMB family in times of celebration but also pain. For example, participants gathered in support of another parent whose child passed away (**Figure 3**).

Figure 3 – Photo Exhibit Caption: CMMB families unite in solidarity after the death of a child enrolled in RWH. Gabriela

Additional support from therapists in the forms of motivation allowed participants to be more resilient. The constant encouragement from therapists guided participants to improve the social aspects of their lives. For example, one participant indicated gaining more confidence with motivation from the therapists, allowing her to overcome many obstacles and construct her own home (**Figure 4**).

Figure 4 – Photo Exhibit Caption: With great effort, Leticia has succeeded in building her own home to provide a better life to her children. Leticia

> *"Sometimes we say, 'I can't anymore. I don't want to anymore.' But [the therapists are] there giving us strength… 'Keep going, keep going.' It's a motivation we have, they're always supporting us morally."* Gabriela

One participant shared having suicidal ideation before joining CMMB:

> *"Thanks to CMMB…I am still alive. My thinking was to kill myself so that tomorrow my son wouldn't suffer anymore. And I would say, 'I will make sure my son is dead and I'll kill myself with him. He will no longer suffer.'"* Leticia

This example illustrates the importance of a strong support system for caregivers, especially as it has the potential to save lives.

Photovoice Effects

The methodology of photovoice itself had a positive impact on the participants. All eight participants reported gaining communication and critical thinking skills.

> *"Thanks to this project, we are also able to see, communicate, and experience new relationships."* Mari

We noticed a change in the behavior of participants from the first photo discussion to the photo exhibit. While many appeared shy in the beginning, by the end of the study, they were more comfortable speaking in public and engaging with other members of the community. For example, in the three photo discussions, many participants went from presenting their photographs with surface level explanations to extracting the photographs' meanings, which was apparent in the ways participants shared their experiences with community members and journalists during the photo exhibit.

Participants also experienced increased solidarity during discussions with each other. Many indicated they felt others did not understand their circumstances and had not been able to share personal stories with anyone before the photo discussions. While the participants did not know each other prior to the start of this study, they formed new relationships by engaging with each other.

> *"Sometimes I think, 'Am I the only one who cries?' Or I think, 'I'm a cry baby', but I see that I am not the only one who suffers, that everyone has [their days]…[some of] our children can't walk, and seeing those photographs, those images, I take great comfort and say, 'Yes we can!'"* Leticia

Participants also enjoyed having a camera to capture important milestones in their children's lives. For example, one participant was able to capture her son's first steps after one year of physical therapy (**Figure 5**).

Figure 5 –Photo Exhibit Caption: Mago cheers on her son as he takes his first steps. Mago

> *"In the most special moments, when my child is doing something new, to capture it and keep it there in an image that does not disappear- that is a very beautiful experience."*
>
> Leticia

In addition, this study was the first time many participants used a camera. These participants indicated feeling happy and proud of themselves for learning a new skill.

> *"For me it has also been a beautiful experience because for the first time I have used a camera, and taking pictures scared me… I thought it [the photograph] wouldn't come out well… [I thought], 'However it [the photograph] comes out, but at least I have to*

try.' And I did it and I was happy… this time I had the opportunity to do something that I have always wanted." Gabriela

Furthermore, the photo exhibit exemplifies how photovoice can increase community awareness and affect public health. Participants chose to entitle their exhibit "CMMB's Special Families Fighting with Hope," showcasing the overarching theme from the discussions. The exhibit inspired community members— including art therapists, psychologists, business administrators, and entertainers— to become involved with CMMB by volunteering through workshops for parents and children. OMAPED wanted to create a partnership with CMMB by having CMMB therapists give talks to educate the community on disabilities. The exhibit also made several highlights in local newspapers, indicating that the exhibit could have had a much broader effect (**Figure 6**).

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ESPECIALISTAS LES ENSEÑAN A ESTIMULAR A 'NIÑOS ESPECIALES'

Mujeres aprenden a dar terapia por salvar a sus hijos

» Con apoyo de una misión médica en Chilca, unas 67 familias han vuelto a ver la esperanza con sus retoños con enfermedades neuronales

HERSON ALCÁNTARA

Ellas mismas son. Ayer, el brillo en los ojos de Mariluz Sánchez (31) era de emoción. Es que hace 5 años el pequeño Benjamin llegó a su vida pero a los 12 meses, un ataque convulsivo lo dejó en estado de coma. Ella cuenta que no perdia la esperanza y pese a que los médicos le pedían resignación, luchó. Un año después, el pequeño Benjamin, despertó. "Fue un milagro y cosas de Dios. Pero despertó con lesiones neuronales, no podia moverse", dice Mariluz casi llorando. Además refiere que cuando el pequeño se recuperaba, llegó a ella proyecto 'Rehabilitación con Esperanza' que ejecuta la CMMB desde hace cuatro años en Chilca y ayuda a familias con 'niños especiales', con síndrome de Down, parálisis cerebral, discapacidad intelectual y otros.

APRENDEN. Con el apoyo de los especialistas de dicha misión, ella aprendió a darle terapia física a su hijo que a la fecha ya da sus primeros pasos. Un caso similar vive Mery Pariona (24). Ella tiene a Keny (5) y él también sufrió convulsión y quedó con lesiones neuronales graves a los 8 meses. Ahora sufre de retardo, pero Mery también aprendió de terapias, las pone en práctica y Keny se recupera. Como estos casos hay otros 67 en el proyecto.

FELIZ Mariluz muestra los avances de su pequeño Benjamin./Herson Alcántara

Mari comenta que Keny esta mejorando./HA

48 casos de los 67 en total que atiende el proyecto, son mujeres solteras que a diario dan terapia.

» CMMB La Misión Médica Católica del Perú (CMMB), por sus siglas en inglés, es la ejecutora del proyecto Azapampa (Chilca).

Exposición fotográfica muestra día a día de niños especiales

Muestra fotográfica refleja vivencias y rehabilitación de personas con discapacidad

Exposición fotográfica muestra día a día de niños especiales

13 de Junio del 2017 - 18:05 » Textos: Correo » Fotos: Cortesía

A través de fotografías, la Gerencia de Desarrollo Social de la Municipalidad Provincial de Huancayo y la Misión Médica Cathólica del Perú (CMMB), mostraron la situación que viven y el proceso de rehabilitación de un grupo de personas con

EN MUESTRA FOTOGRÁFICA

Niños se lucen

Huancayo.- Con el objetivo de demostrar el desarrollo y progreso de los niños y niñas con habilidades especiales que se desenvuelven en un entorno saludable, la Misión Médica Católica del Perú realizó la exposición fotográfica denominada 'Familias especiales que luchan con esperanza'. Las fotografías fueron tomadas por los mismos integrantes de las familias en un entorno de cotidianidad, las cuales fueron mostradas al público en la explanada del Instituto de la Juventud y la Cultura de la municipalidad provincial de Huancayo.

Figure 6 – Media Presence at the Photo Exhibit.

In addition, participants stated being able to present their work in public at the photo exhibit gave them confidence to keep advocating for their children and each other in the greater community. One participant shared after the exhibit how she almost did not attend due to nervousness. However, she stayed the full time both days and even helped explain her colleagues' photographs when they could not be present.

Discussion

We found participants felt stigma and social shame through their experience as caregivers to individuals with disabilities. The negative effect on mental wellbeing led participants to isolate and hide themselves and their children, furthering the cycle of stigma.[16,30] However, through CMMB's RWH, participants felt the effects of stigma were mitigated with enhanced self-esteem and increased social support. The methodology of photovoice itself worked to decrease stigma by increasing exposure of participants' narratives to the community (**Figure 7**).

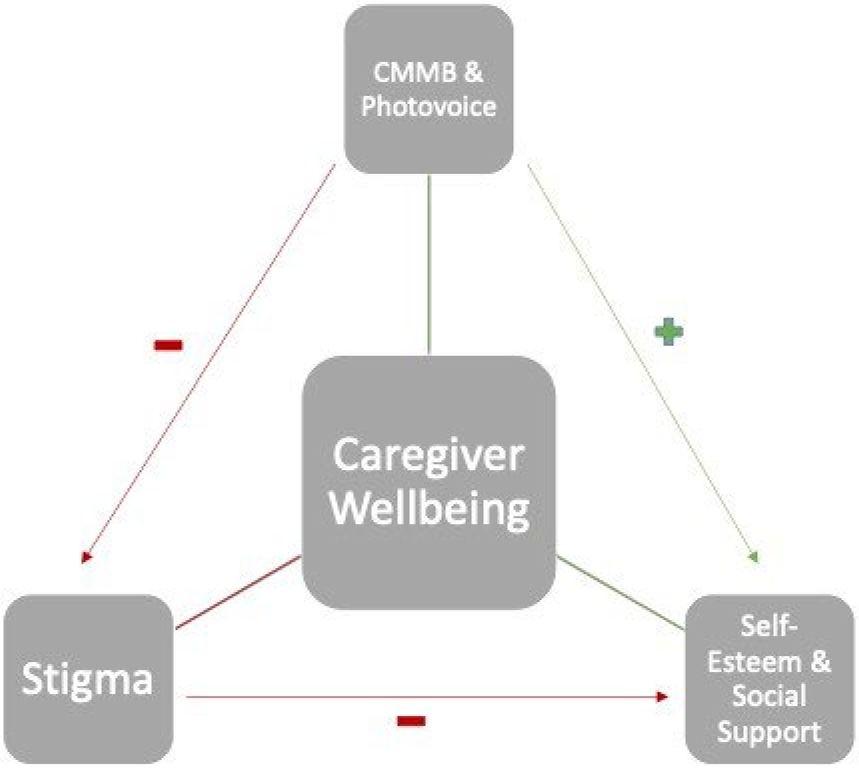

Figure 7 – Combatting Stigma for Caregivers Model.

This study demonstrated how stigma affects families of children with disabilities from low-resource settings in various aspects of their everyday lives. The stigma participants experienced seemed to stem from a lack of education and awareness regarding disability in the community, as previously found in Peru.[11] In another Peruvian study, people reported their belief that intellectual disabilities could be due to domestic violence, economic insecurity, and substance use disorders.[13] Such beliefs in familial causation were also seen in this study, as the majority of participants indicated being accused of taking pills or committing something to deserve a "punishment from God." These experiences caused negative impacts on participants' self-esteem and perceived social support, consistent with other studies.[16,31,32] Prior studies have suggested higher levels of self-esteem and social support are effective tools in combatting stigma and have called upon family-centered approaches to treating disabilities.[31-34] One study suggests that self-esteem can be protected from stigma when stigmatized individuals identify with each other instead of the majority of society.[35] One way to increase this self-esteem is with disability pride, or viewing disability as an empowering and valuable experience. In our study, this was apparent in the strong relationships formed in CMMB, participation in the community's parade, and participants no longer hiding their children.

Our study further highlights how the negative effects of stigma surrounding disabilities can be combatted through an integrative approach to rehabilitation such as CMMB's RWH. CMMB fostered social capital that allowed participants to create a support system and form their own community to uplift each other. The motivation from CMMB's staff members also helped participants accept their children's disabilities and feel empowered by not letting the disabilities limit either their children or own potential. This not only improved caregivers' wellbeing, but also their children's health outcomes by empowering caregivers to consistently take them to physical therapy and community events, increasing socialization for improved development. At therapy sessions for children, caregivers also received information about their rights, resources, and social services to improve their own physical and mental wellbeing.

The study's methodology itself provided an avenue to increase participants' self-esteem, social support and overall decrease experienced stigma. Photovoice provided context for participants' narratives, which has been considered essential to overcome societal stigma and loss of identity and increase coping mechanisms.[36,37] Through the photo exhibit, we showed how photovoice can be used to educate the greater community, helping mitigate the misinformation and fear propagated against children with disabilities and their families. Our unique approach to the photo exhibit showcasing three focus areas may be beneficial to future photovoice studies that aim to increase awareness and education surrounding their specific aims. Our study also highlights the value of CBPR when working with vulnerable and marginalized populations as to empower participants to use their voice and be heard.

The outpouring of support at the photo exhibit suggested people were willing to listen to, learn from, and empathize with those living with disabilities, opening further opportunities to increase education and awareness. Participants also indicated feeling happy and proud at the exhibit for being an example of overcoming barriers for other caregivers. Furthermore, collaboration between CMMB and community organizations in planning the exhibit illustrates the power photovoice has in fostering relationships between groups that otherwise may not have a chance to work together, thus increasing support for participating organizations.[20]

The results of this study have implications for similar programs, which should aim to create strong support units and consider incorporating photovoice into their own program evaluations. It is also important to consider the caregivers who may not belong to such programs and how they can be engaged. It may be beneficial for participants in programs like RWH to reach out to other caregivers in their communities to share their journeys of awareness and resilience to help them regain their self-esteem and serve as social support.

The following limitations are important to consider. The external validity of our findings should be interpreted with caution as our findings are based on a small sample of caregivers who were already involved in a rehabilitation program. While the small sample size allowed for in-depth discussions, our findings may not be representative of the overall caregiver community in Huancayo. Particularly, only one participant was male, limiting the paternal perspective. The training on photography and photovoice may also have influenced the types of photos participants took.

Conclusion

Our study provides unique insights into the lives of caregivers of children with disabilities in rural communities in Peru. Caregivers experience stigma in all sectors of their community, negatively affecting their wellbeing. However, through support groups and self-perception of increased self-esteem, caregivers can gain the tools to overcome the effects of stigma. The photovoice methodology itself seemed to improve participants' self-esteem and social support from solidarity and the opportunity to learn new skills, highlighting the importance of CBPR when working with vulnerable and marginalized populations.

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Table 1 – Descriptions of the Three Areas in the Photo Exhibit.

Exhibit Area	Description	
Narrative	Participants displayed their photographs with captions to convey the importance of their image	
	Participants explained their narratives to attendees	
Social	This area fostered awareness about disabilities and solidarity among the community despite community-level stigma	

	Three large canvases: attendees wrote messages of support for CMMB families	
	Peruvian Law of Disability: attendees learned about the various rights for people with disabilities	
Participatory	Attendees learned about disabilities through interactive activities.	
	Jigsaw puzzles displaying CMMB's work: those who built the puzzles were asked to reflect on the meaning of the photograph taken by participants.	
	Photoshoot: participants took photos and shared on social media to increase awareness about disabilities.