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Using SMS as a tool to reduce exclusions experienced by caregivers of people with disabilities in a resource-limited Colombian community

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Abstract

Purpose: The community of El Codito, located in the mountainside on the perimeter of Bogota, Colombia, is considered one of the most vulnerable and resource-limited communities in the region. This community-based research (CBR) project used SMS messaging as a tool for information access and social interaction with caregivers of PWD.

Method: Using a focused ethnographic method, this research evaluated the experience of caregivers participating in the project. In addition to primarily qualitative methods, supplementary quantitative message data was also collected. This project utilized free and open source software for SMS message distribution.

Results: Caregivers experienced the project as a window to possibility; the possibility of a social support network, the possibility of community participation and the possibility of change. During the three-month implementation, a total of 56 information messages were sent to caregivers, 20 question messages were received from caregivers and 30 social interaction messages were sent by caregivers to the group.

Conclusions: The proliferation of mobile phones in this resource-limited setting provided a feasible method for reducing the exclusion of PWD and caregivers. SMS was a useful tool for sharing information and reducing the isolation experienced by this socially excluded population.

Introduction

Chronic violence and unrest plagued Colombia throughout the latter half of the 20th century, particularly in the rural areas. Many Colombians who were displaced from their homes by violence or socio-economic factors settled in the mountainside on the perimeter of the capital city, Bogota [1]. Characteristics of these communities include low socio-economic status, limited access to municipal services such as electricity and sewage, and high crime rates. Community members, including a high proportion of people with disabilities (PWD), also experience a lack of access to fundamental health services, health education and health promotion strategies. One of these mountainside communities is named El Codito, located in the northernmost region of Bogota.

El Codito has a high population density and is considered one of the most vulnerable communities in the city, classified under the lowest strata in the Colombian socioeconomic stratification system [2]. El Codito has a mountainous environment that makes it very difficult for PWD and their families to leave their homes or access their community, leaving them both physically and socially isolated. While no official numbers are available, the community of El Codito is believed to have a high population of PWD. The World Health Organization (WHO) has indicated that approximately 15% of the world population experiences personal disability [3] and 80% of those individuals live in low and middle-income countries [4]. With a population of over 32,000 [2], El Codito could have over 4000 people with some form of disability if using the WHO global proportion of disability (15%).

This paper will use the term resourced-limited setting to refer to a community or country that experiences some form of resource limitation or inequity. Resource-limited settings include, but are not limited to, low and middle-income countries. Although Colombia is classified as an upper-middle income country, significant inequities exist with over 16% of the population unable to meet basic nutritional requirements (World Bank, 2013).

This project was a collaboration between Canadian and Colombian researchers and the community of El Codito. The Colombian researchers have been actively involved in the community of El Codito since 2007. They are experienced with research, community development and social action work with vulnerable populations in Bogota. Canadian researchers brought experience in health and rehabilitation research and assistive technology (AT).

We used a community-based research (CBR) approach, which is often used in community development projects and is characterized by 'research that is conducted by, with, or for communities' [5]. This collaborative method acknowledges the expertise that community members and organizations can contribute to the project and involves them in the research process from the beginning [6]. The goal of CBR is to address a community issue or create a positive change in the community [6]. CBR has also been effective at improving health outcomes and has become a preferred method for working with marginalized and socially excluded populations [7,8].

In August 2011, Canadian researchers visited Bogota, Colombia, and the community of El Codito to begin preliminary discussions about health and rehabilitation issues experienced by PWD, including access to AT, and how to address them. Discussions were held with key stakeholders, including the Colombian researchers, community leaders, clinicians, PWD and their families. In these discussions, two key issues arose: PWD and their caregivers had limited access to health information and limited opportunities for social interaction.

This community development project used social exclusion as a theoretical view to frame the challenges experienced by the community. While no universally accepted view of development exists, development generally refers to the act of progress and growth in a resource-limited setting [9]. Sen emphasizes a multi-dimensional approach to development, which acknowledges that poverty is perpetuated by social exclusion [10,11]. Social exclusion is a process where individuals, households, groups, or communities are prevented from participating in their community or society [12]. The United Nations (UN) Development Programme [13] outlined a theoretical framework for social exclusion, acknowledging the multi-dimensional process that leads to exclusion. The three main dimensions of social exclusion include: exclusion from economic life, exclusion from public services and exclusion from civic and social life [13].

PWD are believed to be one of the most (if not the most) vulnerable and excluded members of society, particularly in resource-limited settings [14,15]. This project addressed two exclusions experienced by PWD and their caregivers in El Codito: exclusion from information and social interaction, which fit within exclusion from public services and social life. Exclusion from information and social interaction has been associated with poor health outcomes and is an area of concern in resource-limited settings [16,17]. These exclusions not only impact PWD, but their family members have also become isolated as they must remain in the home to act as a caregivers.

Background

Information and Communication Technologies (ICTs) such as computers, the Internet and mobile phones are the primary mode of information sharing and knowledge transfer in high-income countries [18]. Rates of computer and Internet use differ drastically between low/middle-income and high-income countries. In high-income countries, 74% of households have a personal computer compared to 25% in low and middle-income countries [19]; and 78% of households have broadband internet compared to 28% in low and middle-income countries [20]. In contrast, global statistics indicate that 89% of people in low and middle-income countries have a mobile phone subscription [19]. Global ICT statistics for low and middle-income countries are consistent with ICT use in Colombia. According to the International Telecommunications Union [21] 29.9% of Colombian households have a computer, and 23.4% of households have Internet access; however, there are 103.19 mobile phone subscriptions for every 100 people in Colombia [21].

During preliminary discussions, community members indicated that most households in El Codito had a basic mobile phone that was capable of voice calls and SMS (commonly referred to as text messaging) and that mobile phones could be a feasible method to improve information access and social interaction in the community. Colombian researchers also felt that using SMS on mobile phones would be feasible and affordable.

Information and Communication Technology for Development (ICT4D) is an expanding field, which uses ICTs as tools to address community development goals [9]. Mobile phones have become the preferred technology for ICT4D projects because of their widespread adoption in resource-limited settings [22]. The use of mobile phones in ICT4D typically utilizes the basic connectivity of mobile phones, i.e. voice and Short Message Service (SMS) [23]. ICT4D projects using mobile phones have ranged in focus from social action, commerce & marketplace communication, agriculture, emergency response systems, and health service delivery [24].

Research has found that the use of SMS messages in ICT4D projects has created a distinct new form of communication in resource-limited settings [25]. This new form of communication has resulted in new networks of social support [26]. The SHM Foundation [27], a charitable foundation that conducts social action and health projects using mobile phones, has completed numerous projects focused on social interaction for marginalized and isolated populations. Project participants reported feeling less isolated, having greater support networks and improved relationships [26]. Other research has found that mobile phones and SMS are a potential tool for reducing the social exclusion of marginalized populations [28].

No ICT4D research was found that specifically used mobile phones to target the needs of PWD within resource-limited settings. The literature suggests that mobile phones pose a potential method for reducing physical and social barriers experienced by PWD in resource-limited settings [28]. Rather than focusing on disability, the majority of health-related ICT4D projects in resource-limited settings have focused primarily on infectious diseases [29]. There is a gap in the literature regarding projects and research that address the needs of PWD, particularly in the field of ICT4D.

There are several guiding principles in the ICT4D literature. First, rather than having a top down solution, active community involvement improves participation in ICT4D projects [30] and results in greater sustainability [31]. Second, rather than using a universal approach and applying global solutions to multiple contexts, local solutions have a much smaller scale, have had greater success and are more likely to result in valuable knowledge sharing [31]. Finally, ICT4D projects should first identify the contextual needs of the community, and then select an appropriate technology [9]. If possible, projects should utilize an ICT that already exists in the community that requires basic skills rather than additional technical knowledge [24].

In this project we applied ICT4D principles by using a CBR approach, starting with a small manageable project providing locally relevant health information and a method for social interaction, and only requiring technology and skills that the community members already had, SMS on mobile phones. The following research question was addressed: What is the experience of caregivers participating in the project for accessing health information and social interaction?

Methods

This CBR project used a focused ethnographic method, targeting the culture of the participants in the El Enlace project, a specific segment of the culture in El Codito. While ethnography is the exploration and description of a community or culture [32], focused ethnography targets a specific part of a culture [33,34].

Partnership development: Partnership development for this project began in August 2011 and continued through 2013. The following partners were involved in all phases of this research and served as the coordination team for the implementation of the project: a Canadian researcher (occupational therapist), a Colombian researcher (sociologist), an El Codito community clinician (occupational therapist) and an El Codito community leader. The community clinician and the community leader consulted with and represented PWD and their caregivers in the project development and implementation.

Participants: A purposeful sample of eight caregivers (seven mothers, one father) were recruited by the community leader. The community leader, who is also a caregiver of a PWD, has developed a trusting relationship with PWD and caregivers in El Codito. All participants met the following inclusion criteria: each participant was a caregiver of a PWD, had a mobile phone subscription and was able to successfully demonstrate sending an SMS message (in some cases with minimal assistance from a family member). Caregivers ranged in age from 27-54 years old and their children ranged from 7-32 years old. One PWD, a 32-year-old woman with cerebral palsy, also participated in the project with her mother; she was able to access her mother's phone without any need for adaptation. See table 1 for details on participants.

Table 1 – General participant information

Caregiver	Caregiver Role	Age	PWD: Disability	PWD: Age	MDSEI Score	MDSEI Classification
C1	Mother	38	Developmental disability, blind, hyperactivity	9	14/24	Socially Excluded
C2	Mother	54	Developmental disability, cognitive impairment	25	12/24	Socially Excluded
C3	Mother	41	Developmental disability, blind, hydrocephalus	19	12/24	Socially Excluded
C4	Mother	27	Cerebral palsy, cognitive impairment, visual impairment (myopia)	8	15/24	Socially Excluded
C5	Mother	35	Encephalitis, brain damage, upper extremity paralysis	7	11/24	Socially Excluded
C6	Mother	44	Hearing impairment	20	10/24	Socially Excluded
C7	Father	37	Down Syndrome	16	3/12	NOT Socially Excluded
C8	Mother	54	* Cerebral palsy, spastic-quad	32	12/24	Socially Excluded

* This PWD participated along with her mother in the project.

Social exclusion, also shown in table 1, was measured and classified using the Multidimensional Social Exclusion Index (MDSEI). This index was developed by the United Nations Development Programme [13] and assesses the degree that households are excluded from the three dimensions of social exclusion. This index, administered prior to the intervention, was useful in describing the exclusion of the population of participants, but is not sensitive enough to identify small changes in social exclusion [13] and therefore was not used as an outcome measure.

Materials: The software used for this project was FrontlineSMS, an open-source SMS messaging program used in international development [35]. The system requires one computer running FrontlineSMS connected to one mobile phone, no Internet connection is required. This computer, with a connected mobile phone, acts as a two-way SMS-messaging hub for sharing information and interactive communication. The coordination team believed it was necessary for the project to cover all participants' costs associated with sending messages during the project.

In FrontlineSMS, keywords that correspond with various actions in the software can be used to facilitate two-way messaging. For this project, two keywords were used: CUIDADORES and PREGUNTA. The keyword CUIDADORES (Spanish for CAREGIVERS) was used by participants to send a social interaction message to other participants in the project. Messages sent to the SMS-messaging hub with the keyword CUIDADORES were automatically forwarded to the caregivers participating in the project (figure 1). The keyword PREGUNTA (Spanish for QUESTION) was used by caregivers in order to ask health-related questions. Messages sent to the SMS-messaging hub with the keyword PREGUNTA were automatically forwarded to the community clinician (figure 2).

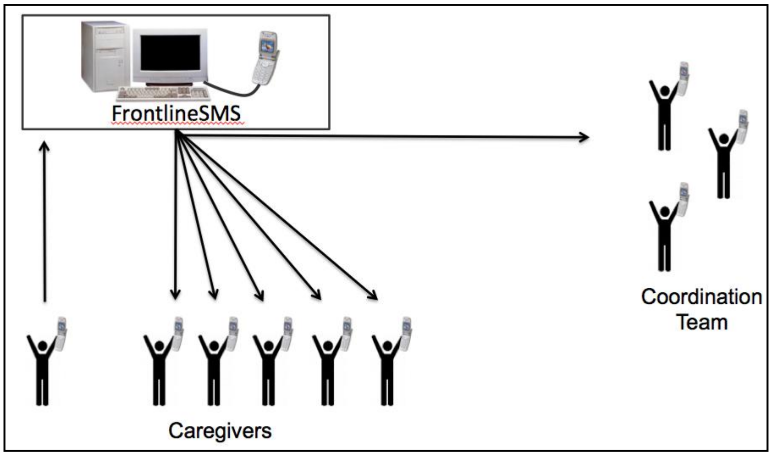

Figure 1 – The use of the keyword 'CUIDADORES'

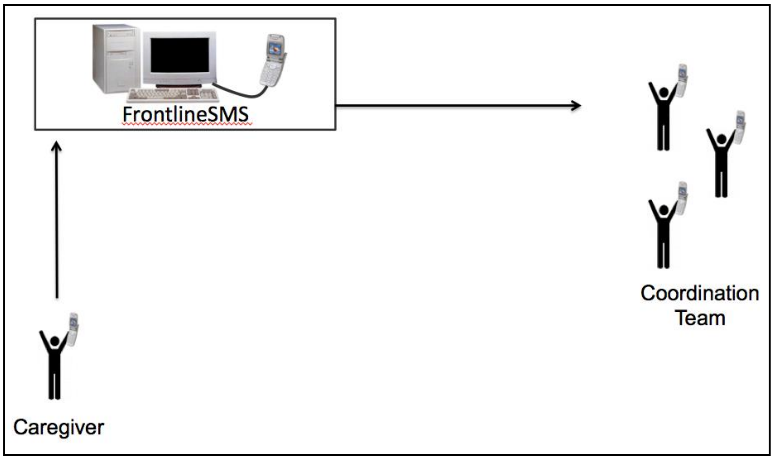

Figure 2 – The use of the keyword 'PREGUNTA'

Intervention: For three months (September-November 2012), caregivers were sent information messages, had the opportunity to send social interaction messages to the other caregivers, and had the opportunity ask health questions using SMS. Monthly SMS messages were sent to participants reminding them how to use keywords and to encourage participation.

Data collection and analysis

Quantitative data: An emphasis was placed on qualitative methods, however quantitative data, such as message data, was gathered to compliment the qualitative data. Message data included the number of information messages sent to participants, number of social interaction messages from participants and number of health questions from participants to administrators.

Qualitative data: The primary data collection method was a focus group. A focus group supports the co-creation of knowledge that is critical in CBR [36], but most importantly, this type of data collection has been used successfully in El Codito for other research activities completed by the Colombian researchers. They have found that focus groups and group interviews are an effective method to gather information and get a detailed understanding of the experience of this community.

The coordination team intended to conduct the focus group in El Codito, but due to recent insecurity and violence in the community, it was conducted at the Colombian university. The Colombian researcher, community clinician and community leader co-facilitated the focus group. Focus group questions were aligned with the primary research question and explored the experience of caregivers participating in the project. The focus group was completed entirely in Spanish. A recording of the focus group was transcribed in Spanish and then translated to English prior to analysis.

Three methods were used to ensure a rigorous translation of the focus group transcript from Spanish to English: content equivalence, comparative equivalence and backwards translation. Cross-cultural research has found these three methods to be the most appropriate translation methods, ensuring that the meaning of the text does not get lost in translation [37,38].

Co-analysis: A co-analysis occurred in English and in Spanish. The Canadian researcher conducted a content analysis with the English translation while the community clinician (in Bogota) conducted a content analysis with the Spanish transcript. The content analysis was completed according the thematic analysis proposed by Braun & Clarke [39] in conjunction with the content analysis outlined by Mayan [34].

Member checking: Upon completion of the co-analysis and reaching a consensus on the overarching themes and sub-themes, the results were then reviewed with project participants for final validation. For this step the coordination team met with participants in order to discuss the results of the analysis and confirm our findings.

Results

Quantitative results

The message data from the project was broken down into three categories:

1. Information messages sent to all participants: During the intervention, a total of 56 information messages were sent to participants by the coordination team. An example of an information message was:

> 'Info: Vaccinations for children under 10 will be available tomorrow from 8-12 in the Codito sector'

2. Questions from participants: Participants used the PREGUNTA keyword 20 times. Of these 20 occasions, 7 were health-related questions (e.g. one of the participants asked a question about a specific bacterial infection), 6 were expressions of gratitude (e.g. 'Thank you very much for the useful information'), 4 were general clarification questions (e.g. 'what is the address for the event mentioned in the last message') and 3 messages had no meaningful content (e.g. a blank message). The community clinician responded individually to each caregiver question.

3. Social interaction messages from participants: Participants used the CUIDADORES keyword 30 times. There was a combination of greetings, prayers and encouragements shared between participants. The following is an example message from a participant:

> 'From Astrid: good day, our special people always carry an angel inside and are an example of quality of life and peace as they please our heavenly father'

Total messages

Table 2 shows the total number of messages sent by each participant during the project.

Table 2 – Distribution of messages sent by participants

Caregiver	Question Messages Sent	Social Interaction Messages Sent	Total Sent Messages
C1	3	1	4
C2	12	8	20
C3	2	5	7
C4	2	2	4
C5	0	1	1
C6	0	8	8
C7	0	0	0
C8	1	5	6
TOTAL	***20***	***30***	***50***

Each information and social interaction message was forwarded to 8 participants and 3 coordinators, resulting in 11 additional SMS messages per initial message. Every question message was forwarded to 2 coordinators and 1 automatic reply was sent to the participant confirming the question was received, resulting in 3 additional SMS messages. Thus, there was a total of 1112 SMS messages sent during the three-month project, including the forwarded messages to participants and researchers.

Qualitative results

The following overarching theme and categories emerged from a content analysis of the focus group transcript. The categories and theme are not necessarily the views of any one participant; rather they are general findings that emerged from the participants as a collective.

Project experience - Project as a window to possibility

The primary overarching theme was that the project was a window to possibility. The project was a window that opens away from loneliness, isolation and limited participation. The categories that emerged from the content analysis indicated that the caregivers experienced a window to three possibilities:

1) Possibility of a social support network
2) Possibility of community participation
3) Possibility that things could change

Possibility of a Social Support Network

The project was a window to the possibility of a social support network. Participants experienced a life that was lonely and isolating, but with the project they were no longer alone in their disability experience.

> ‘We have more trust in each other. We know we are sharing the same gift and a common experiences.’
>
> ‘It is like we share a particular experience of our lives with others in the project’
>
> ‘one no longer feels loneliness’

Participants were presented with an opportunity to be a support to one another and find strength in their shared experience. Participants in this project experience numerous challenges and stresses, but the project gave them strength.

> ‘It was nice to receive messages from other caregivers. When one is stressed, one receives the messages’
>
> ‘I liked (her) messages, because those messages gave me strength’
>
> ‘The messages arrived when one is depressed or worried, but also when one is happy. That’s why for me the project was a way of accompaniment that was very important’

The project was a window to the possibility of becoming a collective rather than isolated individuals. The next statement exemplifies how a participant transformed from saying ‘I’ to ‘WE’.

> ‘in the neighborhood I feel like I am alone with my son because I do not know if there are more children with disabilities. We, the parents, should join together and make a committee, a meeting or something like that. We should take advantage of the spaces we know with our children. In the community hall we can make an event, a meeting and then we can accomplish the integration with other neighbors, because perhaps they can come… and get information about us.’

Possibility of Community Participation

This project was a window to the possibility of community participation. Many of the messages sent to participants included information about community events, which had an impact on their social isolation. Five participants mentioned during the focus group that they attended a community event after receiving one of the project text messages. One participant stated that these events were the only events that they attended in the community for the past year. Coordinators did not necessarily believe that occasional attendance of community events suggested community participation, but they did think that the project was a window towards the possibility of community participation.

> 'No word of a lie, this year I have only been at this (focus group) and one community activity…and I found out about that through the text messages.'

Attendance at community events also occurred due to receiving messages from other participants. One of the participants, while at a community event, sent out a message to other participants to invite them to come to the event.

> 'When I was in the event, I sent a text message: come, this is very good…come you still have time.'

Another participant described one of the community events that she attended with her daughter as a result of the project.

> 'My daughter and I were there, listening to the orchestra. We were listening to orchestra made up of children with disabilities playing the saxophone, the drums, everything was really exciting, the crowd was cheering loudly!'

Participants acknowledged that they were not always aware of things that are happening in their community or what they are excluded from. The project increased their awareness of the possibilities for participation that exists in the community.

> '…sometimes one is blind to the projects that are being made for people with disabilities'
>
> 'Probably there are some unknown spaces or places for participation.'

Possibility of Change

Participants described their lives as 'truncated' and with limited possibilities, but the project was a window to the possibility that this could change. The analysis highlighted the possibility that there could be new meaning in participants' daily activities.

> '…you help us to have dreams.'

Participants, while hopeful for the possibility of new opportunities, expressed sadness for their child's lack of opportunities in the past.

> 'I cried very hard; I felt sad for my daughter, for all the time wasted…I did not know of these things'

The project also changed the adult PWD's perspective on disability. Previously, she believed that disability must be isolating, that there are no other options for someone with a disability. But a change occurred; she now believes that disability does not automatically isolate you. The project helped her see that PWD have the right to participate in the community.

> 'With you, I was able to learn that disability is not a disease that isolates you. I learned that a person with disability has the same rights as a person who does not have a

disability.’

Discussion

Using the MDSEI, it was identified that 7 of the 8 participant households scored as socially excluded. The one caregiver whose household did not score as socially excluded did not send any messages during the project. He also reported that the project was not useful to him because his family is not excluded from information and he did not feel socially isolated. He is employed (runs his own business), reports having numerous familial and community supports and his daughter (a 16 year old PWD) attends an educational institution five days per week. Orr [40] suggests a cautious approach when generalizing social exclusion across a community. Thus, it should not be generalized that all caregivers of PWD in El Codito are socially excluded, as was the case with this caregiver. In contrast to this one participant, all other participant households did score as socially excluded. These caregivers had limited financial resources, lack reliable employment and had less familial and community supports. Although social exclusion exists on a continuum and is not a binary value of ‘excluded’ or ‘not excluded’, this project was most beneficial for participants who scored as socially excluded on the MDSEI. The MDSEI could be used as a screening tool for future projects.

Information access and social interaction

Initially the coordination team thought that information shared during the project would focus on health information and service delivery. However, iterative changes in the project extended the type of information shared to include information pertaining to community events or activities. The community clinician and community leader, having an understanding of the context, sought to share information that brought participants out of their homes.

While it was initially thought that participants would have interactive conversations over SMS, this did not occur. The use of the keyword CUIDADORES was used primarily to broadcast one-way messages (e.g. greetings) rather than two-way interactions. Possible reasons include: participants’ limited experience using keywords or that participants in this context do not view SMS as a conversational tool. This was not further explored in this research.

Experience of caregivers

Caregivers experienced the possibility of a social support network. The term social support network is a combination of two concepts in the literature: social support and social network. Social support is an important function of social relationships that can be broken down into four aspects of supportive behaviors: emotional support (empathy, trust and caring), instrumental support (practical aid, service and assistance), informational support (advice, suggestion and information) and appraisal support (constructive feedback, encouragement and affirmation) [41]. In this project, there was basic evidence of all four aspects of social support.

Social networks are connections between people that may or may not involve social support [41]. One of the functions of social networks is to encourage the acquisition of social capital [41,42]. Social capital is the view that family, friends and other associates make up an important asset, an asset that can be used by individuals when desired or when necessary [42]. Social networks, in combination with social support, are likely to result in social cohesion, which is the social solidarity that results from development of shared values, common bonds and sense of community [43]. With social cohesion comes a sense of belonging [44]. In this project, there was some initial evidence of social cohesion in the group, for example, in the transformation from 'I' to 'WE' statements. Participants had a shared experience with people in similar situations, developing a sense of belonging.

Social capital along with social cohesion is believed to contribute to collective action, reduced marginalization and ultimately reduce social exclusion experienced by a population [43]. Through this project participants developed an interconnected social network, although it is not clear to what extent social capital was acquired or social cohesion occurred.

Given the above discussion, a <u>social support network</u>, the term proposed in this paper, is a group of interconnected individuals that acquires social capital, demonstrates social cohesion and in turn demonstrates supportive behaviors. A social support network has the potential to decrease social exclusion. A longer-term implementation of this project, having the potential to develop into a social support network, also has the potential to reduce social exclusion.

Caregivers experienced the possibility of community participation. Community participation is the involvement of people in activities that serve the needs of the community [45] or contributes to change in the community [46]. Furthermore, community participation requires citizens' active involvement in seeking solutions [47]. Community participation is not simply the attendance of events in the community. Thus, it cannot be said that community participation occurred in this research project. However, there were two existing factors that contribute to the <u>possibility</u> of community participation of these participants in the future: 1) participants' increased community involvement and 2) development of social cohesion among participants. Participants became more involved in the community during the project, both through attending events in the community and through their involvement in the project itself. Through this involvement, participants became aware of possibilities they never knew existed. According to Zakus and Lysack [47], involvement in community can be an initial step that leads toward community participation.

It is also through this involvement in the project and in community events that participants began to develop social cohesion. Participants built relationships with people who have a similar experience, beginning to form a common bond. Rolfe [48] stated that social cohesion contributes to a group's sense of community and ultimately to community participation. Social cohesion can also help marginalized populations overcome hesitancy and resistance to participation [49]. This project created an environment that sparked the possibility of future community participation.

The possibility that things can change is an optimistic possibility that is interconnected with the previous two possibilities. It reflects a potential transformation from the participants' previous disability experience towards something new. Stillman et al. [44] identifies that social exclusion often results in hopelessness. Yet with optimism there is a potential for a renewed sense of purpose, motivation and reduced feelings of exclusion [44]. This optimism was most clearly represented by the focus group quote: 'you help us to have dreams'. Participating in the project helped participants to see beyond their exclusion. The possibility of change brings a new optimism that can help motivate participants towards having a participatory role in the improvement of their situation.

The context of El Codito

Contextual factors in the community of El Codito, are a primary constraint to the overall sustainability of the project. Two contextual factors were at the forefront throughout the project and its analysis: insecurity and inaccessibility. Insecurity in the community placed the project in jeopardy during the early stages of the intervention, even placing one of the coordinators in danger. Inaccessibility of the physical terrain prevented at least one caregiver from attending community events during the project. Insecurity and inaccessibility are contextual realities in the community of El Codito, and likely a reality in other resource-limited settings in Colombia and internationally. However, in spite of these contextual factors, the use of SMS in this project made it possible to reach participants who were isolated by insecurity and inaccessibility.

Practice implications and future research

The project was not simply a window to possibility for participants; it opened a window to possibility for researchers and practitioners. This research has implications across a broad range of practice areas: ICT4D, community-based research, rehabilitation and occupational therapy. This type of project would be useful for practitioners and organizations that are interested in laying a foundation for a social support network and development of community participation with socially excluded populations.

Future research could include projects that use SMS or other low cost technology or social media to reduce social exclusion of PWD in high-income countries. This could potentially be beneficial in rural, isolated communities in high-income countries. Future comparative research could also be completed in other resource-limited settings, comparing the findings and further explore the development of social support, social cohesion and social capital. It is also recommended that future research have PWD as participants and consider assistive technology to access the mobile device as part of the research methodology.

Conclusion

This is the first known ICT4D and CBR project using mobile phones to address the needs of PWD and their families. Based on a partnership between the Canadian researchers, Colombian researchers and the community of El Codito, this project used SMS as a tool for information access and social interaction with eight caregivers of PWD and one adult PWD in the community of El Codito. These caregivers, where seven out of eight were considered socially excluded, participated in a 3-month project using technology they already owned, mobile phones. The project was evaluated using primarily qualitative, but also quantitative methods. The evaluation identified in this paper explored the shared experience of caregivers in the project. Caregivers experienced the project as a window to possibility; the possibility of a social support network, the possibility of community participation and the possibility of change for this socially excluded population. Contextual factors of community insecurity and inaccessibility presented challenges for this project. However, the proliferation of mobile phones in Colombia, and other resource-limited settings, provided a feasible method for reducing the exclusion of PWD and caregivers, even in insecure and inaccessible locations.

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Declaration of interest

The authors report no declarations of interest.

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