Research Articles and Essays

Videovoice Study Finds Transactional Benefits and Personal Impact of DPO Membership

Nicole Butcher[1], Prerana Singh[2], Fairlene Soji[3], Nathan Grills[1,4]

[1]Nossal Institute for Global Health, University of Melbourne, Australia

[2]Emmanuel Hospital Association, India

[3]CBM India, Karnataka, India

[4]Australia India Institute, Melbourne, Australia

Abstract

This study investigates the experiences of Disabled Persons' Organization (DPO) members in rural North India. We utilize 'videovoice' methodology wherein participants create videos to explain the impact of their DPO membership, then expand further in interviews and group discussions. Thematic data analysis identified two meta-themes: transaction-type, immediategains and personal or environmental impact.

Keywords: disabled people's organization, disability, videovoice

Background

Disabled persons' organizations (DPOs) and disabled persons' groups (DPGs) are representative organizations or groups of persons with disabilities or lived experience of disability, which aim to promote the rights of their members, improve their lives and create social support mechanisms (CBM, 2012; Enns, 2008; World Health Organization, 2011). The activities undertaken by DPOs and DPGs are not standardized but vary by context and constituency. Since 2007, the Nossal Institute for Global Health, working with the CHGN Uttarakhand Cluster, has supported disability-inclusive development in the state of Uttarakhand in North India. The main mechanism of the Uttarakhand Cluster has been supporting the formation of DPOs and DPGs. To date, eight DPOs have been established through this collaboration.

Despite DPOs being accepted as an important element in any approach to disability and development, there is little evidence of their effectiveness or impact on the lives of their members (Young, Reeve, & Grills, 2016). The process of DPO formation has been found to decrease barriers and increase access and well-being (N. J. Grills et al., 2020). Yet whether they in fact create new social or civil opportunities, influence individual or societal perceptions of people with disabilities and how any such impacts arise, remains poorly documented. Understanding how and when DPOs impact their members is therefore an important area that requires further research.

Addressing this gap using the novel participatory action research approach of videovoice, we aim to generate data regarding DPO impact on members. Meanwhile, our methodology seeks to benefit participants, implementers and community members in

Uttarakhand by creating platforms for self-expression and self-realization. Participatory action research in the form of digital storytelling can tap into the voices of DPO members in novel ways and further "advance an agenda for service provision and recovery that is built upon community, solidarity and social justice" (De Vecchi, Kenny, Dickson-Swift, & Kidd, 2016). While exploring the nature and extent of impact of DPO membership on their members and, by extension, their communities, we also aim to understand the value of this novel research methodology in disability studies.

Methods

This study was undertaken by Nossal Institute for Global Health (University of Melbourne) in partnership with three organizations for people with disabilities in North India, with approval by the Human Research Ethics Sub-Committee of the University of Melbourne and the Ethics Committee of the Community Health Global Network – Uttarakhand Cluster. The study was conducted in locations where the partner organizations currently implement community-based inclusive development activities.

Additionally, this research uses the novel approach of videovoice, which is a health advocacy and promotion methodology wherein participants use participatory videography and interviewing techniques to identify issues of concern, communicate knowledge, and advocate for community health (Catalani et al., 2012). This methodology allows participants to intentionally construct the video and introduce a reflexive element in the capture of video (Holliday, 2000; Rich, Woods, Goodman, J Emans, & H DuRant, 1998). Videovoice reportedly aims to promote deeper understanding of lived experience, which can, in turn, serve to shape policy development (Gubrium, Hill, & Flicker, 2014), foster learning processes for participants (De Vecchi et al., 2016) and promote community awareness (Matthews & Sunderland, 2013).

To do so, videovoice builds on the photovoice methodology, which has been shown to be a robust method to explore factors that contribute to inclusion and well-being (Fernandes et al., 2018; N. Grills, Porter, Kumar, & Varghese, 2017; Reid & Alonso, 2018). Photovoice has also been used to investigate the experience of using mental health services (Tang, Tse, & Davidson, 2016) and to identify mental health concerns post-disaster (Ingram et al., 2018). It can create advocacy opportunities for people with disabilities and inform local programming for them (Han & Oliffe, 2016). Videovoice has not been implemented effectively in the field of disability, but its use in other fields has shown it to be an effective tool for gathering evidence and bringing about change.

In this case, the study was conducted in three locations across Uttarakhand state, following a modified version of the ten-point framework for photovoice (Hergenrather, Rhodes, A Cowan, Bardhoshi, & Pula, 2009). Purposive and convenience sampling was used to recruit 23 participants at the three sites: 15 people with disabilities (direct members of a DPO) and eight carers of DPO members. To be included in the study, participants with

disabilities were to be: (1) aged over eighteen years, (2) able to follow instructions and communicate verbally and, (3) members of a DPO for six months or more. Additionally, carers were to have been in their care-giving role for at least six months and unrelated by vocation to any participant with disability.

Additionally, male and female field staff were selected in each location by locally operating disability organizations and trained for research facilitation, including principles and objectives of research, ethics, video recording and storyboarding, interviewing and facilitation skills. A videovoice training manual was designed for the staff to ensure consistency across the sites.

With this structure in place, all participants gave written informed consent to participate in the study. Participants were instructed to take up to two minutes' worth of footage within a week depicting the impact on their lives of DPO membership. Field staff then followed an approved interview guide to investigate the motivations, ideas and sentiments behind participants' video clips. Participants explained what was in the clips, and generally what it meant or tried to convey. The interviews (conducted in Hindi) were audio-recorded, transcribed and translated into English.

Subsequently, transcripts from narrated videos, semi-structured interviews (SSI) and focus group discussions (FGD) formed the data for the analysis. Data were sorted under à priori-designated categories. The categories were determined according to the goals of DPOs and prior experience in disability research in the region. The list of *à priori* categories included skills, social, personal, information/awareness and material. Once data had been assigned to the categories, the data within each category was coded and thematically analyzed by the principal investigator. The themes were validated through discussion between investigators and with field staff.

Results

Table 1
Study Participants Disaggregated by Type, Sex, Age

Description	Persons with disability		Carers	
Consent	Female	Male	Female	Male
- Recruited	6	9	4	4
- Lost to follow-up / excluded	1	1	2	0
- Remaining	5	8	2	4
Of remaining, Age 18-30	3	2	2	1
Of remaining, Age 31-50	2	5	0	2
Of remaining, Age 51+	0	1	0	1

There were 19 eligible submissions (table 1). Four submissions were excluded by loss to follow-up (e.g., no answer in timeframe, out of age range). The data set was cleaned by

way of assessing correlation between the content in participants' videos and their responses to interview questions. Videos and SSI responses that did not address the research question (e.g., a video showed one participant's daily routine, and interview responses did not explain change in relation to DPO membership) were excluded from analysis. One was excluded from site C and D respectively, but these two participants still contributed to the FGD (Table 2). All videos and transcripts from site E were analyzed. Validity of response was not associated with sex or disability. The findings from the analyzed data are presented firstly as themes and secondly in a hierarchy of categorical significance by demographic.

Table 2
Numbers of Study Participants Disaggregated by Site (of Data Analyzed)

Descriptor	Site C	Site D	Site E	Mean / Total
Geography	Plains	Hills (not remote)	Plains	n/a
No. pax	7	6	6	Total: 19
Male:Female	5:2	3:3	4:2	M=12; F=7
Disability:Carer	6:1	3:3	4:2	D=13; C=6
Focus Group Disc.	8	7	5	20
Age range	20-60	19-60	24-35	Mean: 37

Thematically, the impact of participation in a DPO/DPG was typically represented in two ways. The members and their families/carers spoke of rather immediate transaction-type gains (i.e., I join and I get…), and/or of the spins-offs that affected the person and/or their environment.

Transactional gains

Transactional gains are classified by the kind of rewards that a member and/or their family will 'get' from joining a DPO. They are expressed in many of the responses, some as the main benefit of joining the DPO, some as secondary spin-off-type gains. Some participants noted that these benefits made them happy or had a positive impact on their personal state.

Information / awareness

Joining a DPO/DPG afforded most participants with information and knowledge gains that made them happy, grateful or relieved. Increases in knowledge and/or access to information related to government disability pensions/schemes, rights of persons with disabilities and/or options for care of persons with disability (e.g., therapy services or techniques).

While some participants spoke of simple knowledge gains, such as becoming aware of the local area and services, others like participants C03 and D01 expressed how these gains had affected them personally:

"… earlier we didn't know anyone and also [didn't know] about anything. But now we know and have information about the government departments and all." – FGD-E

"We have understood our rights. We are very happy. We feel very good by joining in the group." – C03

"Through the DPG I gained knowledge of where the police station, block office, bank, and [other services] were, and I gained knowledge about these places ... My participation through the DPG helped me to go out of my home." – D01

The information/awareness was transmitted through participation at DPO/DPG meetings and/or workshops, receiving information in a formal sense or through fellow members, as explained above and by the following individuals:

"When we go to meetings, we learn so many good suggestions." – C09

"After becoming a member of the DPO what I have liked most is we have got an opportunity to come forward and we can share our personal experience with DPO [members] and the benefit we have found is, when we share our experience with others we get various information to grow." – C06

This type of benefit of participation was described with gratitude and a sense of relief: material relief through access to government services (as per D06, cited below); personal relief through access to support services (therapy or otherwise) (D07); and, personal relief afforded to members and their carers/family (C09):

"Since we joined the DPO we got to know a lot of things and the DPO also helped us a lot." – D06

"I didn't have knowledge but after joining the group I gained knowledge and I have got lots of benefits." – D07

"We get good quality and lessons. So, I like this group." – C09

Additionally, a small proportion of participants expressed their interest in others with disability becoming part of a DPG in order for them too to benefit in similar ways. Two young participants, C06 and C01, exemplify this in their comments:

"I want everyone to know their rights. And after becoming the member of DPO group, I have got this information." – C06

"I want that the kind of change that has happened in my life to happen in the lives of my other disabled brothers and sisters." – C01

Material benefits

Another very tangible 'benefit' frequently referred to was material gain. Participants reported what they had acquired from joining the DPO/DPG: goods such as chickens (to undertake livelihood activities), toilets, assistive devices and access to government pensions. With respect to the latter, participants noted that they had gained access to a pension – some calling it 'financial help' – thanks to the information or facilitation the DPO had given them:

> *"After joining the DPO group, we have got this profit, that ... my pension is being made. We have been able to see many good things. Free of cost, we travel to different meetings. In a great way, the government is supporting us."* – C09

> *"We benefited after being together as a group; we were able to make our pensions/ certificates whereas when we were alone if we went we would not be able to get the work done but now it has changed."* – E02

The latter quote shows the sense of collective action that facilitated access to the pension, which in turn allowed persons with disabilities to begin working according to their rights.

Skills

The acquisition of skills was both direct and indirect – direct, where participants had had the opportunity to participate in livelihood skills training facilitated by the DPO (as per C03, below), and indirect, through access to education opportunities and through increased confidence to learn new skills (as per C01):

> *"After joining the group, we have gone through various trainings like candle making, mushroom composting and many more."* – C03

> *"Whatever change that has happened in my life is through the DPG. I have now completed my studies and am preparing for a job."* – C01

Acquiring these skills helped members achieve what they would otherwise not have been able to, e.g., expand their livelihood activities, further their education, or gain independence.

Personal and social impact

A strong focus of respondents' explanations of the impact of DPO/DPG participation related to the changes in their personal and social situation – in their social relations, their self-esteem and attitude towards disability, and/or in their outlook on life.

Personal

Three kinds of personal change were evident in the participants' responses: awareness, confidence and motivation. Through exposure to information about the rights of people with disabilities, and from interacting with other people with disabilities, DPO members gained a reference point for their own experience of disability:

"We came to know each other. Even this is what we came to know: that there are many who are like us." – E04

"I used to think that I was the only person with disability alive… [At the DPO], I saw there were many people who were more disabled than me who have difficulty in walking. When I saw them, my spirit was uplifted." – E02

This awareness altered the participants' mindset towards disability, and reduced their fear of disability, their fear of being counted or of interacting with others outside the home. The following citations demonstrate how members of Uttarakhand DPOs experienced a paradigm shift in regard to their social relations and civil participation:

"People with disabilities are still in darkness. They think so much but are unable to do anything. They feel scared to do anything and keep thinking about what society will say about them. … We have to go from darkness towards the light. We need to keep our voice and opinion in front of society so that they also know that we are capable of doing something. We accept that we are disabled, but we are disabled only physically, but not disabled in our minds." – E06

"I started meeting people. I was not able to talk with people the way I am doing right now. If a guest came to our house, I was always inside my room. All these people here are from my village, but I never knew them. They also didn't know me." – FGD-E

DPO members had come to recognize the 'darkness' and ignorance about disability that had clouded their minds and had limited their imagined possibilities. Involvement in a DPO gave them an awareness of their value and rights, which provided a platform for new life experiences.

By extension, participants also improved their self-image and confidence, in some cases finding an added motivation to 'do something':

"I have been busy after joining the group and taking care of my livelihood/earnings." – E02

"I stay happy now, and the desire to live has grown in me. Now I do tailoring, I study and also help in the chores of the house." – E01

"I thought I should start a livelihood, and for that I took a loan from the DPG, and in time returned it faithfully to them, and I did my own livelihood. Now I purchase things on my own, and by selling the things I am able to make my own earnings." – E02

By now operating with greater confidence, skill levels and self-respect, DPO members could also feel more independent and exert that independence confidently, as C03 captures in her statement:

"... we always want to remain in the group and enlarge our work and make ourselves independent so that we don't depend on anyone. [We want] to make our own identity. We want to live with self-respect. We want to have our specific identity. We should be able to do our own work. We should work with our own hands. We don't want to give our work to anyone else. Through the group only, we can do all these things. Alone we can do anything." – C03

Social

In addition to the impact of membership on a person's well-being and self-perception, it also led to growth in social interaction, through the enlarging of their social networks. The following quotes demonstrate the new openings in members' social lives:

"[The title for my video is] 'Knowing and being familiar'." – E04

"The biggest change [since joining the DPO] is that we started knowing each other." – FGD-E

"Since joining the DPG I have benefitted in many ways. Earlier, we were not in this position, because we had never come out of the family and stayed in our family, and we never used to talk with people around us. We used to feel shy in front of people. But when we joined the DPG we gained confidence and we felt so good by meeting different people. And there have been other changes as well." – C03

Thus, the benefits of membership had been getting to know others, 'getting out of the family', beginning to 'talk to people around us'. One carer (A04) reflected that some members had 'merged into society well'.

Furthermore, among some (like C01, C04 and C06) was a sense of collective identity and potential, the creation of support networks and the DPO becoming like family to them:

"We want our DPG to develop further together, and through unity we can grow together and we can do anything. Having unity within us is very necessary for us." – C06

"We all disabled brothers and sisters come together, and we try to understand each other's feelings. We try to understand what their needs are and what their problems are. We try to solve their problems." – C04

"I thank the DPG, which is my family… Earlier I used to stay alone, as I used to feel that people would make fun of me if I went out of the house." – C01

One participant (E02) believed that their collective action had shifted societal perception, explaining they had held a rally to showcase "[people with disabilities] can do something good" and change attitudes towards them. Another (C05) reported that his community had stopped discriminating against him:

"Earlier people use to look down on me. They used to tell others not to come close to me. Now the people do not do that or say such things. Now I am able to stand on my feet and work. If I can stand up and work, so can you." – C05

Hierarchy of categorical significance

The data were assessed in terms of the frequency a certain response type was given, and by demographic. The quantitative analysis highlighted the importance to respondents of personal and social impact – 50 percent of dialogue focused on these topics. Information/awareness and material benefits comprised 40 percent of dialogue, while skills and other accounted for only 10 percent of dialogue. In terms of demographic distinctions, participants at sites C and E showed gratitude for personal benefits, while those at site D noted the helpfulness of information/awareness opportunities. Participants with disability cited the personal gains ahead of carers who noted the information/awareness-related benefits. Between participants with disability versus carers were moderately different orders of response, although carers and persons with disability both recognized the social, material and 'other' benefits to similar extents. Males tended to focus more on material gains while females were primarily concerned about the personal benefits. This was consistent in responses across age ranges.

Discussion

Through engaging DPO members in participatory action research using videovoice via smartphone technology, this study generated interview-based data that demonstrated positive benefits of DPO/DPG membership. Participants articulated that the impact had been both personal and social, often by virtue of the information/awareness, material and skills-based gains. No inherently negative effect or impact was reported.

First, if the goal of DPOs is to promote the participation, well-being and rights of persons with disabilities (World Health Organization, 2010), then this study confirmed increases in participation in domestic and social activity, some degree of improved well-being in terms of physical functioning and livelihood capacity, and notable improvements in member knowledge of rights. Participant expectations and motivations for joining the DPO were not assessed so we were unable to determine the degree of congruence between expectations and experience. There was some indication from the data, however, that members joined 'to get something' (material, informational, opportunity-related), which the data also indicated was attained from participation.

Meanwhile, this study yielded numerous accounts of participants finding courage to participate more actively in domestic life, livelihood activities and the community, having become more aware of their own personal value and 'validity' in the world or having gained new skills. As in the cases of E01 and D01, "This inferiority complex I had is finished," and, "Wherever I have to go, I go freely. Before, I was very scared to go to the market but now with the help of the DPG group I am more confident." These findings concur with those of

Young et al. (2016), who noted increases in confidence, and of Leung et al. (2019), to whom DPO members reported "increased social connectedness, personal development, livelihood, improved sense of community, and participation within the family." Many members in this study spoke of the DPO as being a place they belonged, felt comfortable and were accepted, a place where they could bring questions and find answers.

Furthermore, the socialization that Montgomery et al. (in press) and Young et al. (2016) describe as being a key outcome of DPO participation has also been confirmed by these data. The DPO has enhanced "the breadth and diversity of social networks" by expanding members' social circles, increasing their desire to socialize, and creating the impression that others in the DPO/DPG are "like family." Concurring with findings of Montgomery et al. (in press), our study found that increased social connections are associated with greater confidence/self-esteem, greater access to services, and increased opportunities for friendship/advocacy.

Whereas Young et al. (2016) noted the role of local village leadership in establishing and sustaining DPOs, this data did not reveal that the presence or influence of village leaders was important for the DPO outcomes. As the research question focused the attention of benefit on the member and not on wider societal shifts related to the organization/group's establishment/existence, participants' responses focused on changes at the individual or family nucleus more than at the societal level. However, some participants indicated that opportunities for collective action, lobbying and awareness raising had been created and utilized. The findings are thus consistent with the few prior studies into this question (N. J. Grills et al., 2020; M. Leung, A. Devine, L. Singh, T.-W. Yip, & N. Grills, 2019; Montgomery et al., (in press); Young et al., 2016), but further exploration of the impact of the DPO on collective action and/or the social environment would help define the broader-reaching impacts of these structures.

Evidently, some variation in the participant experience of the DPOs was anticipated. As compared to those with disability, carers ordered the importance of outcomes differently, reflecting their different experience of disability. However, both carers and persons with disability recognized the social, material and 'other' benefits to similar extents. Comparing responses between the sexes, women seemingly valued personal and social benefits more highly while men placed more emphasis on material and information/awareness-related gains. This reflects the gender-specific roles in rural India whereby the male is typically the breadwinner, and the female is more involved in family duties and individual caregiving. Differences in age, however, did not tend to influence respondents' values remarkably.

Finally, the study unveiled pathways from immediate transactional-type gains (information, awareness, skills, material goods) to personal and social impact, without explicitly exploring the mechanisms or conditions for the impacts to have taken place. Further to the pathways or explanations noted, the data suggests that supportive family, social and physical conditions/environments must be established in order to realize the benefits of

membership. For example, family support was raised as important in facilitating achievements and changes for participant E01. For DPOs to respond to evidence and ensure that conditions are optimal for impact, there may be some benefit in exploring theory-of-change models in subsequent studies.

As concerns the methodology, the participatory action research approach to data collection successfully engaged persons with disabilities in generating findings on DPO impact through their own voice rather than that of spokespersons or representatives. This allows DPOs to enhance their activities, promote the importance of DPOs, raise awareness about disability and advocate about the roles and rights of people with disabilities – a stated aim of this approach. However effective this method was in achieving the aims of the project, it was not clear that videovoice was significantly superior to the photovoice approach (antecedent to videovoice) used by the authors in the same geographical area (N. Grills et al., 2017). As literature suggests, both approaches generate rich data, contribute to advocacy opportunities and informed local programming for people with disabilities (Han & Oliffe, 2016). In practice, however, videovoice was considerably more difficult than photovoice, given the participants' unfamiliarity with story building or film generation and their camera shyness. Videovoice also required a higher level of competence in effective use of smart phones, and specifically the confident use of the video application.

Furthermore, a lack of confidence among participants to complete the task required field staff to spend longer than expected explaining and supporting participants to capture a story of personal relevance and impact. This created a risk of bias whereby fieldworkers may have suggested ideas in explaining the process. However, the field staff did not accompany the participants whilst filming, and the semi-structured interviews allowed participants to voice relevant responses without field worker involvement.

In essence, photovoice could have been simpler and may have produced similar findings, however feedback from the field staff concerning the methodology alluded to the positive nature of the exercise insofar as it created learning opportunities for participants around technology that may offer a new mode of self-expression and communication for them (e.g., potentially leading to use of social media platforms where available). Thus, in deciding to use videovoice over photovoice or other qualitative methods, one must consider the research question being asked, the familiarity of participants with adopting technology, ethical considerations, and the importance of empowerment of the research participants. As a research methodology, videovoice would be useful for capturing stories that have more content than a before-and-after story line, and for exploring topics that require a particularly visual response.

Conclusion

This study aimed to provide DPO members of rural North India with a novel, participatory means of assessing the DPO's impact on their lives. It vividly captured the

experience of participating in a DPO, and revealed the transformative impact of DPO membership on personal and social circumstances as a result of transactional-type gains. In particular, increased understanding and awareness of disability and disability rights, together with greater socialization, had given members confidence and motivation for greater social and civil participation. Additionally, the participatory action research methodology helped empower participants to generate community recognition of their situation, advocate for their rights and promote societal change. Videovoice, despite the technical challenges, proved an effective methodology in the field of disability for describing impact and advocating for change.

Acknowledgments

Conflicts of Interest

None declared.

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