Promoting human rights:
understanding the barriers to self-help groups for women who are carers of children with disabilities

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ABSTRACT

Mothers and other caregivers of children with disabilities are usually the main advocates for the rights of their children. For them to effectively advocate for the inclusion of their children with disabilities (CWD) into their communities, they need to be empowered to ensure that their rights are respected. Support or self-help groups are modalities which may facilitate processes promoting their empowerment. This article describes the factors which influence the functioning of a parent support and self-help group in an impoverished community in Cape Town. An action research study was conducted to explore the barriers influencing the achievement of desired advocacy and support goals of this parent support and self help group. Data were gathered through a series of focus groups.

The study yielded three themes, namely: "Tensions with becoming a self-help group", "I versus We" and "The process". The themes highlighted that women experienced missed opportunities, multiple roles, negative habitual behaviour and time poverty as consequences of their socio-political and socio-cultural environment. These impacted on the efficiency with which they could address their self-help goals, more particularly they compromised their contribution to community development. The implications of this for occupational therapy practice are identified.

Key words: Support groups, self-help groups

Introduction

Being a carer of a child with a disability (CWD) can be a difficult task and carers often neglect their own needs in order to focus on the needs of their children[1]. Added to this, the needs of carers of a CWD are often ignored by societies and communities as they are isolated by negative attitudes towards disability[2,3]. Societal, cultural and religious expectations largely impose caring duties upon women, implying that mothers in particular are left to carry the burdens associated with caring for a CWD[4,5]. Within the South African society women are known to be allocated this caring role more so than their male counterparts. Barret[6] argues that this burdens women in sub–Saharan Africa with triple roles, that is, the roles of mother, social producer and economic producer. It is suggested that if women spend the bulk of their time caring for their disabled children, they could neglect their other roles, especially that of economic producer. This could lead to perpetuating poverty and a consequent loss of control over their circumstances[2].

Not having a sense of control over ones' circumstances may lead to difficulty in directing actions, resulting in possible feelings of powerlessness. Freire[7] argues that powerlessness causes people to lose their ability to make decisions, leaving them at the mercy of others. Individuals who experience powerlessness may feel inferior, dependent and lack faith in their abilities to change their circumstances. This may result in alienation and social marginalisation which potentially compromises the experience of citizenship[8]. Citizens who are marginalised or alienated and experience a sense of powerlessness over their lives are vulnerable to exploitation and human rights violations. Such citizens may not be in positions to assert their human rights and access opportunities which they should be afforded as equal members of society. This may lead to situations of occupational injustice[9]. Occupational injustice occurs when socially structured and socially formed conditions lead to stressful occupational experiences[9]. It recognises that people need different access to resources and opportunities to promote equity.

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In South Africa a sense of powerlessness and the associated vulnerability is often experienced by women living in poverty and of particular significance here, to those who are carers of a CWD. The amount of time and energy they spend on the care of their CWD may limit their opportunities to direct and have control over their personal lives[4,10]. The consequence is that they may disregard their physical, emotional and social well being. This disregard adds to their vulnerability and may further disempower them[7]. Further to this, women caring for a CWD may feel obligated to take less or no notice of their own needs in an attempt to ensure that the needs of their children are taken care of. The women's sacrifice draws attention to the complex interface between asserting the rights of children with disabilities while also respecting the rights of those who care for them. The Disabled Children's Action Group South Africa (DICAG) is an example of an organisation initiated by parents of children with disabilities that recognises the need to respect and promote the rights of both parents and children with disabilities. This organisation addresses the isolation and negative attitudinal barriers experienced by parents by promoting the empowerment of parents of children with disabilities[10]. One way for women, such as mothers with CWD to empower themselves is to join a support or self-help group such as those offered by DICAG. Within these groups they might find the help and support to develop their capacities and empower themselves.

The purpose of a support group is to offer knowledge, physical support, as well as to serve as an "outlet for women to be acknowledged, heard and emotionally supported as a parent of a disabled child"[4:103]. Similarly, self-help groups consist of individuals who share similar problems, concerns or circumstances[11], they provide emotional and physical support to members, as well as act as vehicles for members to learn from and share with each other. However, self-help groups prioritise community development and aim to facilitate change by changing both the group members' and their childrens' environments[10]. Through taking responsibility for advocating for environmental change, self-help group members may be able to begin to assert their human rights. Self help groups are thus forms of social structures that promote citizenship. Although some aspects of parent support groups overlap with self-help groups, the fundamental difference between these groups lies in the outcome of the group. Self-help groups not only focus on the individual, personal change, but also have societal empowerment as an outcome[4]. Individual problems are turned into common ground, which can lead to members of the group experiencing feelings of acceptance and affirmation[12] through being supported and listened to. These experiences together with the opportunity to network, improve their knowledge and coping skills can all lead to an increase in self-esteem for carers[12]. Consequently it can shift members of groups from being victims to being agents of change in both their own lives and that of those around them. The ability to perceive oneself as an agent of social change is essential to the promotion of human rights.

Although there are many benefits to attending groups, they are often poorly attended or are only in existence for a limited time[13]. Various reasons for this are cited. Smith[12] conducted a survey in which 45 families were asked whether they attend parent support groups, why they attended and which factors encouraged their attendance. They reported that the main reason for not attending meetings was that members felt that they no longer needed it[12]. Lagerdien[4] explored the meaning and experiences of women with CWDs in parent support groups in two communities in Cape Town. She found that there was a discrepancy between meeting personal goals versus collective group goals within these groups. This discrepancy proved to be detrimental to the groups' success. Most of the women came into the group wanting individual benefits and this impacted on their ability to work and think as a collective thus, impacting on the perceived success of the group and on being successful as a group. It was also highlighted that organisational dynamics related to power struggles, poor communication, limited skills to manage tasks as well as the fact that the group was struggling to maintain and increase membership[4] impacted on the

effectiveness of the group. Although these studies offer different reasons for self-help or support groups not always being successful, they urged researchers to explore and understand self-help groups further and to investigate why some groups are able to function as a group for longer periods[9]. It was suggested that understanding the factors that impact on the groups' functioning could inform future interventions with groups.

Context of the study

The Outlook Parents Support Group (OPSG) in Ocean View, Cape Town is an example of a self-help group. Ocean View is a peri-urban suburb about 64 kilometres south of Cape Town. The profile of the community is it consists predominantly of coloured people and in 2000 it had a population of 34 000 and an unemployment rate of 70%, (Valley Development Project, Annual Report, 2000). The OPSG's goals and activities included: empowering themselves to establish a support group, advocating for the rights of their children, raising awareness about disability issues within the community and personal development according to individual interests and ability. They intended to work cohesively, continue with their personal/home activities in order to sustain and improve their own lives and those of their children, as well as being agents of change in the community.

Upon reflecting on their goals and activities, it was apparent that they had included both support and self-help group goals. However, despite their self evaluated progress achieved through training, they expressed experiencing difficulties with attaining their group goals. Their difficulties were said to inhibit their effectiveness as a support and self-help group. The nature of their difficulties was not clearly articulated by the group members. It was assumed that identifying the causes and consequences of the inhibiting factors would enable the group to address the barriers in order to overcome these and reach their potential. The OPSG as a collective expressed their interest in gaining insight into the factors inhibiting their group.

Methodology

This study explored the barriers inhibiting the Outlook Parent Support Group (OPSG) from reaching their stated goals. The objectives of the study were to:

❖ identify factors that inhibit the group's functioning.
❖ describe how these factors inhibit the group's functioning.
❖ understand the consequences of these inhibiting factors for the group's functioning.

The study design was that of Action Research (AR). This design allowed participants to be involved in identifying the need for research and setting the research agenda themselves[14]. The participatory nature of the design matched the sentiments of the self-help group.

Demographic profile of the sample

Since the OPSG was an existing parent support group, all the members were selected to participate in this study and thus convenience sampling was applied[15]. The group consisted of seven women, between the ages of 20 and 50 years. Only one member had completed her senior secondary certificate, while another was in the process of completion. None of the group members held any tertiary qualifications. Three of the members were married, whilst one lived with a long-term partner. All the members had either full or part time work. Their children's disabilities included diagnoses such as intellectual impairment, cerebral palsy, visual and hearing impairment, or a learning disorder.

All the members grew up in, and were still living in Ocean View. They had all lived through the oppression of the previous apartheid regime. This had impacted on opportunities available to them as women and limited their ability to have control over their own lives and development[4]. The group met every Thursday evening, in a garage at one of the member's homes. One of the problems that they experienced was irregular meeting attendance.

Data gathering

Data were gathered through eight focus group sessions held over a period of seven months. Focus groups[16] allowed for the exploration of participants' attitudes, opinions and perceptions related to the factors that inhibited their group's functioning. The consecutive focus groups allowed for extensive data collection and gave participants an opportunity to build on each other's responses. This ensured that discussion and meaning could be taken to a deeper level[10]. Each group meeting was audio taped and transcribed verbatim.

Data analysis

Data analysis occurred in two stages:

Stage one involved the first author listening to the audiotapes at least twice after each focus group meeting, making notes of the emerging factors as she listened. Thereafter, a content analysis of the transcribed data was completed. Attention was focused on explicating the factors related to the group process and outcomes for the session. This information was reported back to the group during the next session for members to check and to use the information as the point of departure for discussions in the next session.

Stage 2: During stage two, the data were further analysed and interpreted through open-coding. The identified codes were grouped into sub-categories, which in turn were linked to categories[16]. From these categories, themes were identified. Data were analysed with the aid of the Nudist Vivo (NVIVO)® Software Package.

Trustworthiness was ensured through member-checking, peer-debriefing, theoretical triangulation, prolonged involvement, reflexivity by the researcher, provision of a time-line and a detailed audit-trail, ensuring adequate saturation of data as well as documentation of a dense description of the context, methods and outlines[15]. The member-checking was completed with three members of the OPSG. They confirmed that the categories and themes were a true reflection of how the participants perceived the problems.

Ethical considerations and Trustworthiness

The first author obtained written informed consent from group members of the OPSG once the research study and process had been explained to them during the first meeting. The information sheet and consent form were available in both English and Afrikaans. Subsequent consent was obtained verbally every time the group met. The boundaries for confidentiality were negotiated and set by the participants during the first group meeting and included in the group contract, which was strictly adhered to.

Findings

The study yielded three themes, as presented below.

Theme 1: *'Tensions with becoming a self-help group'*

This theme described the difficulties that the participants experienced during the process of transition from a support group to a self-help group. A significant finding was that the group struggled to achieve goals inherent to a self-help group. This contrasted with the support group tasks.

The outcomes of support groups focus solely on support and on the building of knowledge to benefit the individual within the group. Support groups centre on support functions that are performed at regular meeting or between group members as necessary. This made 'support tasks' and 'support goals' easier for this group to perform. This was expressed by one of the participants as:

"Nee, dit is goed as `n mens soe praat oor jou problems. Daai is hoekom ons hier is. Om te leiste. Die anne goed kan wag." Joan

["No, it is good if a person talks about their problems. That is why we are here. To listen. The other things can wait."]

This quote emphasised the priority assigned to support each other rather than engage in other activities, such as advocacy which would be associated with a self-help group task.

Self-help groups not only focus on individual empowerment, but also on societal empowerment[4]. The OPSG felt they were not equipped to facilitate a self-help group since:

"Ons moet `n chairperson en `n secretary het om meetings te run en om te help om die group te run."

["We must have a chairperson and a secretary to run the meetings and to help run the group"].

Their assumptions about being a self-help group were that it was more formal in contrast to a support group. The group also identified that they thought that they would have to be skilled in organising events, liaising and networking with other organisations and addressing groups of people. This was accurate since self-help tasks require members to liaise with other community organisations plan and execute public events and transfer knowledge and skills to the community. However the members of the OPSG carried the burdens of work, study and caring for their CWDs and were left with limited time to do these tasks.

Although they thought that they were learning about and were becoming more skilled in tasks associated with self-help groups, problems usually arose when they had to work together as a group. They found that although they planned and organised their personal daily lives, it differed from planning and organising for communities or other people. This skill and roles, therefore, did not come naturally to them.

"Diane* (previous researcher) het ons gehelp om te wiet wat aangaan, met wie om te praat.." …"Sy het gehelp…ons hettie altyd gewiet hoe en waar nie. Ons lee mos nog".

["Diane* (previous researcher) helped us to know what is happening and who to talked to."…"She helped …we did not always know what or where. We are still learning."]

The participants recognised that they relied on assistance with the self-help functions. The participants acknowledged the need for both support and self-help groups for themselves and other parents with disabled children in Ocean View. However, they expressed that they were more comfortable and confident with performing the functions of a support group since their identities, skills and occupational profiles made it easier for them to be fulfil the tasks associated with support groups. This created tensions with their desire and need to become a self-help group.

Theme 2: *'I versus We'*

This theme described the tensions between the participants' personal responsibilities, habits and goals and their ability to fulfil the functions of a self-help group. It highlighted the struggle the members had with their commitments as part of the group. The first barrier that the group identified was that they felt that they had too many priorities and too little time. This was emphasised by one of the participants when she said:

"Die kinnes en die studies hou my soe biesag, I hardly have time for anything else. Maa Mrs. Minton* wiet mos dat ek studies het, daarom is ek nie by die meetings nie."

["The children and the studies keep me busy; I hardly have time for anything else. But Mrs. Minton* knows that I have studies (and) that is why I cannot attend meetings."]

The consequence of absence from meetings for this participant, was that she was not fully informed about current events in the OPSG. It also meant that the group did not receive regular feedback on the tasks which were assigned to her. This included meetings that she was supposed to attend on behalf of the group. Her family and studies were her priority, making it difficult for her to be a fully active, contributing member of the group. Another participant said:

"Fazlin wiet dat ons is maa almal maas. Ons moet alles doen….want

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* Names were change to ensure confidentiality.

14

alles is mos osse responsibility. Fazlin wiet mos in ons communities issit soe." Shahieda

["Fazlin (researcher) knows that we are all mothers. We have to do everything…because everything is our responsibility. Fazlin knows it is so in our community."]

Their poor economic living conditions, forced the participants to find employment to supplement the family income. Although the women from the OPSG shared the responsibility of being an economic provider, they did not share their caring responsibilities with their male counterparts. This meant that while the women adopted traditionally male responsibilities, this was not reciprocated by the men. Partaking in the three roles of being a woman, carer and worker left the participants with little time or energy for anything else. Caring for their disabled children also took up a significant portion of their time.

Another issue identified by the group within this theme was that there was a disjuncture between individual needs and group goals:

"Ek moet eers die skool kla maak, dan het ek mee tyd vir goet. Om te werk innie group. En ek sal dan bieter kan werk innie group."

["I first have to finish school then I will have more time for things, to work in the group. And I will be able to work better in the group."]

All the participants acknowledged that it is essential that they be at least partially empowered at an individual level, before creating opportunities for others to empower themselves. They saw all the courses that they have attend as a means to develop themselves and thereby empowering themselves. Although as a group they had self-help goals, this was not reflected in their individual actions.

Theme 3: *'The process'*

This theme described the participants' experiences of the research process and their feelings of control over their group processes. The women felt that the research process gave them opportunity for dialogue so they could identify their own problems. As the group became familiar with the format of the focus group meetings, they became more confident within the group. This impacted positively on their participation in the group sessions. Their interaction within the group increased and they started to initiate discussions themselves. The researcher had to pose less questions to facilitate equal participation during discussions. One of the turning points in the group was when one of the members said:

"Let's be honest with each other. Ons was slap.:"

[We were slack.] "That is why things was not happening."

This statement caused members to be less sensitive about what they said. Through identifying the barriers to the group's functioning as a self-help group, the action research process facilitated the group's agency. This created the further opportunity for them to access resources and acknowledges their limitations.

Discussion

This study explored the barriers experienced by the OPSG during their attempts to make their community more inclusive for children with disabilities. The themes identified various factors that impacted on the abilities of the members of the group to empower themselves as a self-help group. The findings of this study suggested that the women from the OPSG were and still are being deprived and disadvantaged by poverty, gender discrimination and their role of caring for a disabled child. It was found that the women were disadvantaged by socio-cultural (engendered roles as women), political (apartheid) and economical (poverty) influences, thus leaving them caught in the deprivation cycle. These influences created feelings of powerlessness. According to the women, it isolated them and made them vulnerable. The legacy of these influences compounded by caring for a disabled child continued to affect the women's abilities and behaviour. It caused them to miss opportunities to develop themselves. For example, due to circumstances many of them did not have the opportunity to matriculate and gain a secondary

education. Now, due to time consuming role of being a carer, they still could not achieve this. This was so, despite their personal goals to improve their employability by accessing the available evening adult education classes. The multiple influences left them to independently bear the burden of the numerous roles allocated to them as women and mothers in the community. *Figure 1* provides a diagrammatic representation of the way that these influences sustains the deprivation that perpetuates the marginalisation of women caring for a CWD.
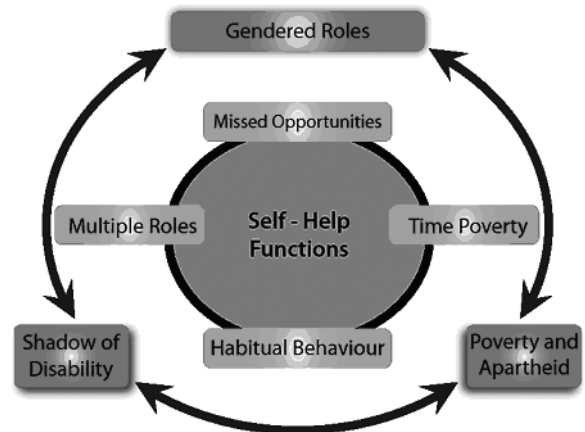

Figure 1: Sustaining the deprivation trap[18]

The outer circle represents the root problems and the inner circle represents the consequences of these. The root causes that influence each other cause the consequences and impact on the women's ability to perform self-help functions

The women were left with too many responsibilities (at home and at work) and very little time and resources to deal with these responsibilities. All these factors forced the women to form personal habits which allowed them to cope with, rather than, challenge their situations. Growing up in an impoverished environment during the apartheid era, having to make sacrifices for the well-being of their families and the socialisation of their role as women and mothers shaped their emerging habits.

It was also found that they had the knowledge to perform the self-help group functions, but due to who they were, did not always have the skills, confidence or the time to perform them. Barberton also found that "…poor people often do not have the kinds of resources, particularly skills and information, that are needed to address many of the problems they face"[19:253]. This powerlessness experienced inhibits their ability to 'do' which makes it difficult for them to bring about social change. Within an organisational context like a self-help group, this lack of appropriate skills diminishes the efficiency and effectiveness of organisational initiatives and often jeopardises the sustainability of this initiative[19]. The lack of skills can also cause dependence by the organisations on outside 'help'. This can lead to the collapse of the organisation on withdrawal of the assistance[19].

The members of the OPSG identified the need for a self-help group within their community, but were not fully familiar and confident with the tasks and responsibilities of a self-help group. This made it difficult for them to perform these tasks independently. They often looked to the previous group facilitator as 'the expert' to help and assist them with networking, planning and decision-making around awareness-raising and advocacy tasks. Upon her withdrawal, it was more difficult for them to perform these functions effectively. Therefore, they struggled to achieve their goal. This raises the question: Was the group adequately prepared and ready for her withdrawal? According to the previous facilitator of the OPSG[20] she followed a situational leadership approach which involves shaping expert opinions as experiences as opposed to a directive leadership approach (giving orders). Despite this approach, the OPSG members still leaned heavily on her, thus impacting negatively on their ability to fully develop themselves. This raises

15

additional questions such as: At what point is a group of marginalised women, who established a group with the help of an outside facilitator, adequately prepared to facilitate the group by themselves? Would an 'expert facilitator' be more equipped and thus essential to facilitate the process of achievement of goals within a self-help group? Seeking to engage with these questions is fundamental to developing the occupational therapists' contribution to self-help groups. It requires that therapists realistically consider what they can contribute to enable groups to take control. In particular, it draws attention to the need to explore the complex individual and societal factors which impact on a self-help groups' functioning.

In a country, such as South Africa where self-help is promoted and professional assistance is scarce, this research emphasises the need for occupational therapists to re-orientate their practice to addressing underlying barriers to self-help groups' functioning. It supports the view that the occupational institutions may violate human rights by restricting participation in occupations and thus lead to occupational injustice[21]. This study emphasised the significant contribution that professionals, such as occupational therapists can make to enhance the function of self-help groups. Through applying expertise on the community development processes and group facilitation, the process can be guided so that groups such as the OPSG can identify and implement strategies to overcome hindrances that affect the groups' achievement of goals. For the group to function effectively as a self-help group, this would have to be negotiated so that the facilitator assists with initiating the process, but that the ultimate goal is for the group to be able to sustain the processes necessary for advocating for social change.

Conclusions

When addressing the barriers to self-help, the members of the OPSG attempted to challenge the factors related to their missed opportunities, time poverty, negative habitual behaviour and multiple roles in order to alter their situations. They educated themselves and voluntarily participated in this research in the hope of improving the effectiveness of the group. However, by addressing the above factors, they only addressed the consequences of the problem and not its root causes.

Given the benefits that were derived from this study process, it is suggested that future research could involve exploring the consequences of the socio-political and socio-cultural environment on members' abilities to fulfil the self-help group functions. The associated reflection would allow them to analyse the root causes of the hindrances to the achievement of their self-help goals. It would also create the opportunity to explore possible solutions to the hindrances.

It is also recommended that organisations such as DICAG, promoting the empowerment of carers and parents of disabled children, should consider the barriers identified in this study when planning programmes. It is concluded that addressing the social marginalisation of women as carers of CWD's involves advocating for their human rights by addressing the factors that perpetuate their occupational marginalisation.

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