CBR students' understanding of the oppression of people with disabilities

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According to the social model of disability, there are clear links between the barriers that people with disabilities experience and their oppression by able-bodied people. Community based rehabilitation students have been taught to work from a social model perspective of disability. Through action research, this study investigated how community based rehabilitation students understand the oppression of people with disabilities. Following an initial phase of interviews with past students, changes were implemented in the CBR course. Subsequent interviews with students demonstrated that they have a greater understanding of the complexities of the oppression of people with disabilities than past students. Recommendations are made to link training on the oppression of people with disabilities to a human rights approach to disability.

Key words: community based rehabilitation, oppression, social model of disability, action research, community rehabilitation facilitators

Introduction

In the most recent Joint Position Paper on Community Based Rehabilitation[1] the World Health Organisation (WHO), International Labour Organisation (ILO) and United Nations Educational, Scientific and Cultural Organisation (UNESCO) embrace the social model of disability and its understanding that environmental barriers are the cause of disability[1]. In the same Joint Position Paper, Community Based Rehabilitation (CBR) is described as promoting the rights of people with disabilities and as working towards inclusive communities. In the past, a number of CBR programmes internationally have focused on medical intervention and rehabilitation aimed at the impairments of individuals[2,3,4,5]. However, more recently some CBR literature has been concerned with inclusion, empowerment and the rights of people with disabilities[6,7]. The Joint Position Paper[1] also tacitly acknowledges that disability can result in oppression and that CBR should attempt to overcome this through equalisation of opportunities and social integration.

In order for CBR programmes to move beyond a medical and individual deficit approach to disability, it is necessary that the personnel working in the CBR programme have an understanding of the social model of disability, the human rights approach to disability and related issues. This article reports a part of an action research study, which focused on the training of CBR students and their understanding of the oppression and empowerment of people with disabilities.

The aim of the study was to contribute to the field of CBR through its investigation of how a CBR training curriculum could assist CBR personnel to understand the oppression of people with disabilities and work with some of the factors that sustain that oppression.

Disability and oppression

In the social model, disability is understood as a form of oppression in which the social environment excludes and oppresses people with disabilities through failing to adapt to their needs and aspirations[8,9,10]. Proponents of the social model of disability have argued that the restrictions people with disabilities experience in their daily life are not intrinsic to their impairments but are rather a result of the social environment not taking into consideration their differences.

The social model of disability can be linked to a human rights discourse of disability, which emphasises the rights of people with disabilities to independence, equality and self-reliance. In order to respect the rights of people with disabilities, various societal barriers must be overcome. In this approach to disability, it is then the responsibility of the State in particular, and civil society, to address socially created barriers so that the dignity and human rights of all people are respected. Although the rights approach to disability provides a framework for the empowerment of people with disabilities, people with disabilities at a grassroots level may find it difficult to access these rights. Thus community rehabilitation facilitators (CRFs) can play an important role in empowering people with disabilities and helping them to access their rights. The rights discourse of disability is also important because it situates disability in the context of all forms of oppression, including racism and sexism.

To those who follow the social model of disability, the links between disability and oppression are clear. The attitudinal and physical barriers that people with disabilities experience are manifestations of their oppression by able-bodied people. As Barnes and Mercer[11] put it, "Common experiences of exclusion led to disabled people's growing sense of themselves as an oppressed minority." Watson[12] goes so far as to claim that the social model of disability defines the term 'disability' as social oppression, rather than as the form of impairment that a person has.

In order to understand disability as a form of oppression, it is helpful to examine different definitions and models of oppression. Hardiman and Jackson[13] describe oppression as a *system* of domination rather than random acts of discrimination or simply an ideology of superiority. One model of oppression that has been used in this study describes discrimination and the resultant oppression as occurring at the personal, cultural and structural levels[14]. At the personal level, the thoughts, feelings and actions of an individual eg, a person in a position of power, can cause inequality and oppression. However individual behaviour needs to be considered in the broader context of cultural patterns of beliefs and behaviours. Cultural actions occur within the social, economic and political aspects of the social order, which is seen as the structural level.

A different conceptualisation of oppression which has also been used in this study is that of Young[15]. Young writes about five "faces" of or forms that oppression takes, which are exploitation, marginalisation, powerlessness, cultural imperialism and violence. A group of people can be considered to be oppressed if they are subject to one or more of these conditions or faces of oppression. Young's explanation of oppression deals with the manner in which people are oppressed, rather than the levels at which this happens or the processes that maintain oppression. Some authors[11,16] use Young's 'five faces of oppression' to describe the situation of people with disabilities.

This paper presents Young's 'five faces of oppression' and the description of oppression at the personal, cultural and structural levels, as theoretical constructs to analyse the CBR students' understanding of the oppression of people with disabilities.

Background to the action research study
The study was conducted as one cycle of action research between October 2003 and March 2006 in Pietermaritzburg and surrounding areas in KwaZulu Natal. The study was based at CREATE, a non-government organisation that trains mid-level CBR personnel – community rehabilitation facilitators or CRFs. The following groups participated in the study:

1. Six qualified CRFs who had completed the CBR course between 1998 and 2002 at either CREATE or the Institute of Urban Primary Health Care (IUPHC). The initial reflections on the CBR course were based on the interviews with this group, ie phase 1.
2. One class of six CBR students participated in the study throughout their two-year CBR course ie, phase 3. Four of the students were from rural areas, while two were from urban townships. There were four male students in the class and two females and the students ranged in age from 21 to 39 years.
3. Fourteen people with disabilities and parents of disabled children

The researcher was a staff member who was one of the trainers for the CBR course.

Action research has been described by various authors in terms such as critically reflexive practice and self-reflexive enquiry[17]. The distinguishing characteristic of action research is that it systematically integrates research with practice. Unlike other methods of research, in action research the practitioner can study his or her own actions and the impact of them within the context in which the action occurs.

The action research cycle in this study consisted of the following phases, as recommended by various authors[17,18,19]: initial reflections, planning action, taking action and observing the action and then a final reflection before the cycle begins again. A variety of research methods were used in the different phases of the action research, including semi-structured interviews, focus groups and document analysis. The data were collected through interviews with six qualified CRFs who completed their training between 1998 and 2002; interviews with six CBR students and two focus groups with people with disabilities and parents of disabled children in 2006. The interviews and focus groups were tape recorded and transcribed. The interviews were conducted in English and the focus group discussions were conducted in Zulu with the help of an interpreter. Informed consent was obtained from all participants in the study and participants were given the assurance of confidentiality and anonymity in the reporting of the data. Ethical clearance for the study was obtained from the University of KwaZulu Natal.

The data from the interviews with the qualified CRFs were analysed qualitatively, through a process of coding the data, searching for patterns and identifying themes. The data from the interviews with the CBR students and from the focus groups relating to the oppression of people with disabilities were categorised using Young's 'five faces of oppression' and Thompson's three levels of oppression. In order to enhance the credibility of the research, the data from the interviews was triangulated with the data from the focus groups.

The following sections of the article report on the activities and findings of the different phases of the action research cycle.

Findings

Phase 1: Initial reflection on the CBR curriculum from the first qualified group of CRFs
The purpose of the initial phase of action research was to clarify the situation and identify the problem which was to be acted upon.

In order to understand the situation of CREATE's CBR training and the skills, knowledge and attitudes of the community rehabilitation facilitators (CRFs), six in-depth interviews were conducted with the qualified CRFs.

The stated purpose of the CBR course, "to empower people with disabilities and communities through providing well-trained CBR personnel", indicates the values of empowerment and social justice underlying the course. However in spite of these values and orientation, prior to the action research study, CBR students had been taught about the social model of disability but not specifically about the oppression of people with disabilities.

During the interviews a number of the CRFs were not able to explain the theoretical construct of the social model of disability at first. However, it was clear from their practice that some of them have been able to begin implementing the social model principle of removing barriers in a way that leads to the social integration of people with disabilities. One CRF described how she was attempting to remove attitudinal barriers in her community:

We used to call workshops and do the disability awareness in churches, communities and even in schools. So that is where we are trying to fight that negative attitude about people with disabilities. We want people of the community to recognise them as human beings. CRF C

Other CRFs gave examples of working to remove physical barriers such as lack of space for wheelchair users at till points in shops and inaccessible municipal toilets. One CRF specifically related an account of how the removal of barriers can lead to the social integration of people with disabilities, which is a key element of the definition of CBR.

Now in the community you find out that maybe the house is not accessible. So he's always in the house. So I'll make sure I do home visit and do follow ups that 'Please, the ramp must be there. And then I'll come next week to see.' When I went there I don't find the client. He's visiting the friend because of the ramp. Because most of the time you go there in the house, he can't get himself out. But now because they've got a ramp even in the gate, you know, he can push himself now to the community. So that's social integration, not to isolate himself. CRF B

During the interviews most of the CRFs did not have a clear understanding of disability as a form of oppression. Some CRFs were able to identify oppression on an individual or personal level, but they were unable to talk about oppression at a cultural and structural level. Because the concept of oppression had not been taught in the CBR course up to 2003, it is not surprising that the CRFs did not have the tools to analyse what is happening to people with disabilities in terms of oppression. Some of the CRFs have been able to speak out about discriminatory conditions, which could be an opening for further training on oppression and empowerment. It was of concern that the CRFs often seemed to act on behalf of, rather than with, people with disabilities. Part of the disability struggle is the struggle against asymmetrical power relations[8]. At the time of the interviews most, if not all, of the CRFs interviewed took on a position of dominance rather than giving equal power to the people with disabilities with whom they were working.

Phase 2: Taking action to improve the CBR course
In order to address the shortcomings in the knowledge and understanding of CRFs as identified in the initial reflection of the action research, a number of changes to the two-year CBR course were planned and implemented. The initial teaching about the social model of disability was changed during this action research from being largely theoretical to include experiential learning. In addition, to assist the students to relate the social model to their practice of CBR, the staff of CREATE introduced the social model of disability as a framework for the students to use to help review their practical work throughout the course.

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It was also decided to add a number of lessons on oppression and liberation to the CBR course. The lessons on oppression started with the students' own identities as oppressor and oppressed, and their experiences of oppression such as sexism, racism and disablism. The students then worked through the cycle of socialisation[20] looking at specific examples of the experiences of people with disabilities and also how these people experienced oppression at individual, cultural and structural levels.

Another addition to the CBR course to assist the students in developing skills to undertake action to overcome the oppression of people with disabilities was the development of a week of teaching on advocacy and lobbying. The week included practical sessions such as how to make a banner and write a letter to the press, learning from people with disabilities about mobilising disabled people and confrontational, peaceful action and more theoretical sessions on the advocacy cycle and dealing with people in positions of power. Part of the purpose of the sessions on advocacy and lobbying was to give the CBR students skills in using the human rights approach to disability.

Phase 3: Observing the effects of the changes in the CBR curriculum

In this phase of the action research the effects of the changes to the CBR course mentioned above were observed through interviews with staff and students, participatory rural appraisal exercises with students and focus groups with parents of disabled children and people with disabilities. The data on CBR students' understanding of the oppression of people with disabilities was gathered through interviews with six students towards the end of the CBR course. This data was triangulated with data gathered from two focus group discussions that were held with people with disabilities and parents who live in areas where two of the CBR students have been working. Thompson's[14] description of oppression occurring at personal, cultural and social levels and Young's[15] 'five faces of oppression' were used to analyse the data.

In their explanations of oppression, the students identified all five faces of oppression through practical examples from experiences in their own lives and in the lives of people with disabilities with whom they have worked in their communities. The most commonly mentioned faces of oppression in relation to people with disabilities were exploitation and marginalisation. In the focus group discussions, the parents and people with disabilities most frequently mentioned marginalisation as the way in which they experience oppression.

Exploitation

Three students related situations in which people with disabilities were exploited for their disability grants. As Student C explained:

But what really hurts me is that when the families of people with disabilities, they use these people as a source of income, because they bring the grant in the family. So for them, that's like a blessing in disguise for them because they've got this person to bring in the money…..Because these people, the families, only take care of these people on the pension day. From then they forget about them until another pension day. And they don't like use this money to help these people [with disabilities]. It's just their money.

Student E spoke of an equally serious situation in which family members of a woman with a disability worked together to steal her first grant payment of about R9 000. These examples of exploitation illustrate the complex nature of the oppression of people with disabilities and thus the difficulties that the CBR students face in trying to address the oppression of the people with disabilities with whom they work.

Marginalisation

Marginalisation can be seen as the situation wherein oppressed people may be excluded from decision-making processes and the

workings of power[14]. Young[15] extends this definition to a situation where, "A whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation and even extermination." (pg 53) Findings from both the CBR students and the parents of disabled children and people with disabilities bear witness to the fact that people with disabilities often experience marginalisation as a form of oppression. One of the students, Student A, reported an extreme version of marginalisation that, unfortunately, is not uncommon in the areas where CRFs work.

If we are talking about oppression it is something that is when like normal people, like the families of those disabled people used to lock them in the houses.

Student B, who is disabled, found that the source of her marginalisation was not her family, but other able-bodied people in her environment — a nurse at the hospital and visitors to her home. As Student B recounted:

Sometimes my mother asked me to make tea for the visitors. The visitor, she said 'No, why are you asking this child because she is not able to do all things?' and she said it's not right.

The stereotype this visitor had of people with disabilities as not able to do anything useful, contributed to her attempting to marginalise Student B.

A number of the participants in the focus group discussions, both people with disabilities and parents of disabled children, spoke of similar damaging stereotypes that community members have in relation to people with disabilities in their areas. One mother lamented the views of people from her area concerning people with disabilities, including her child:

Our community is not educated. People with disabilities are not accepted at all, and that hurts us as parents because we love our children. But the way they are being treated, it is like they don't belong in this society, they belong to the zoo or a cage.

One person with a disability has had painful reminders of her own oppression resulting from negative attitudes that have marginalised her.

Like myself when I visit other people in their houses, I could see that I am not accepted. They even ask you "Can we help you?" as if you are lost or you are not the kind of person to visit them. And I realise I made a mistake by coming there, then I leave immediately. (S4, Focus group 2)

In the experience of the CBR students, marginalisation of disability did not only happen through community members who may have been relatively uninformed about the rights and potential of people with disabilities. Student D reported that in a forum where participants should have known better – a meeting on inclusive education with the Department of Education – disability issues were still marginalised.

Thompson[14] makes special mention of speakers of minority languages experiencing marginalisation. A number of the CBR students gave examples of people with communication disabilities being marginalised because of their difficulty in using the standard forms of language used in those communities. One of the participants in the focus group discussions who is deaf, recounted her own marginalisation.

Before I know [the CBR student] it was quiet. People did not know me. Others did not want to communicate with me. They were not prepared to learn how to communicate with me. I was isolated, let alone getting a job.

The marginalisation of people who do not use the majority language happens not only at an individual or personal level but also at a structural level as Student F illustrated when talking about the participation of sign language users in community meetings.

If you take a loudspeaker and shout, they [deaf people] cannot

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hear that you have a meeting, you see. Which means they do not have rights to attend those meetings. Even in a meeting, they can go to a meeting but no interpreter there to accommodate them

According to Student B, marginalisation of people with disabilities happens not only because of the negative attitudes and behaviour of able-bodied people and the stereotypes they hold, but also because of their sometimes well-meaning over-protection.

But the families of those [disabled] people, they overprotect. The people with disabilities don't need to do anything. They stay at home only and obtain the disability grant.

Powerlessness

Powerlessness has been described as a situation in which the oppressed person has little control over his or her life and he or she also has minimal choice concerning what to do with his or her life[11]. In this study, the most strident voice on the powerlessness of people with disabilities was the disabled student, Student B, who reported a number of her own experiences at the hands of able-bodied people. When Student B had applied to study nursing, she was interviewed along with other applicants. On seeing that Student B was disabled, the head of the nursing school summarily dismissed Student B without completing the interview. Student B was powerless to change the situation.

Similarly, one of the participants in the focus group discussions described his powerlessness to contribute to decision-making within a close personal relationship.

And the other thing, my girlfriend is not treating me like a normal person. She is taking decisions for me as if she is the only person with rights. We cannot share ideas. She is Miss Know-all. (S4, Focus group 1)

Powerlessness is not only created by the intentional and negative use of power over someone or some group. As student B discovered, in one of her earliest recollections of being oppressed, powerlessness can also be the result of a person's well meant actions which are nevertheless very hurtful and disempowering.

I was in the hospital, sitting there on the bench and the nurse asked me to go to other ward to ask other nurse. She was giving me the paper and when I stand up and take this paper, the nurse was told me, 'Sorry, I didn't see you [as a person with a disability]. You are not [able to] walk.' And I told her, 'No, no problem, I can go.' And she refuse. She told me, 'No. Thanks. Sit down. I ask someone [else].' And I know the place. It's not good because when the patient doing like that, she not feeling good.

The CBR students seem to be largely unaware of the effect of their power relative to the people with disabilities with whom they work. Clearly this is a crucial issue which needs to be addressed with the CBR students if the service they provide is supposed to empower people with disabilities.

Cultural imperialism and violence

Cultural imperialism refers to the form of oppression in which the experiences and understandings of the dominant group become the norm against which members of subordinate groups are judged. A number of the CBR students referred to experiences that people with disabilities have of oppression which may be classified as cultural imperialism. Student D related the experiences of a deaf woman who received the wrong medication at the hospital because the doctor was not able to use sign language nor did he find and use a sign language interpreter.

Violence is the last of the five faces of oppression mentioned by Young. None of the students mentioned violence with regard to the oppression of people with disabilities although one student had had personal experience of the violence of oppression while working on a farm. According to Barnes and Mercer[11] violence against people with disabilities is, in fact, widespread and may take the form of physical or sexual attacks, verbal abuse or eugenic policies (abortion of disabled foetuses).

Personal, cultural and structural levels of oppression

When analysing the students' understanding of oppression according to the personal, cultural and structural levels of oppression, the group of students involved in this study were able to identify oppression operating at all three levels. Student B experienced oppression at a personal level when, as a child in Std 1, she was told to leave the local mainstream school by her teacher because she was disabled. Student C's account of the exploitation of a disabled woman for her grant could also be considered as oppression at the personal level.

Student E is clear that there is oppression of people with disabilities at a cultural level in his community:

People they believe that people become disabled because of certain things, like they are being witched and they are maybe, it's a gift from God. I think those are two that people believe. So like to oppress people with disabilities, they just think they are useless. I've seen that the parents are become shy to take them out and seen by other people, like people will laugh at us if we have got such children.

This quotation shows clearly that Student E sees the oppressive actions of family members as occurring within the broader context of cultural beliefs and practices. These cultural manifestations of discrimination and oppression operate within the societal or structural level in which there are systemic inequalities. Both Student F and Student D mentioned systematic and structural level oppression as occurring within the education system.

I can say the thing that worries me a bit is the school and disabled people. I do not know why these schools do not want to take disabled people. (Student F)

One of the participants in a focus group also identified with being oppressed at a structural level because of the lack of access to schooling for people with disabilities.

Conclusion

The findings of this study suggest that the CBR students have a greater understanding of the complexities of oppression than did their predecessors. The students demonstrated an awareness of the exploitation, marginalisation and powerlessness that people with disabilities face in their communities. The students' reports mirrored reports by people with disabilities themselves and their family members. However, none of the participants in the research specifically mentioned violence as a face of oppression that they had experienced or were aware of, with regard to disability. Future research could investigate the experiences that South Africans with disabilities have of violence.

CBR students and people with disabilities in this study were also able to identify oppression as occurring at personal, cultural and structural levels. In order to undertake action to overcome the oppression of people with disabilities at a systemic level, the CBR students need an understanding of the relationship of the social model of disability and the oppression of people with disabilities. The students in the current study were better able to make the connection between these two concepts than previous students. Although there was not an explicit focus on a human rights approach to disability in the CBR course, in future training it would be possible to link the concept of the oppression of people with disabilities to an understanding of the violation of their rights. This will be important as South Africa has now ratified the UN Convention on the Rights of Persons with Disabilities and CRFs can play a role in helping people with disabilities to monitor its implementation.

Although this study has specifically examined the training of CBR students and their understanding of the oppression of people with disabilities, it also has applicability to the training of other

health professionals working with people with disabilities. The current dispensation in South Africa, with its emphasis on human rights, encourages service providers to understand disability as socially created through barriers such as negative attitudes and lack of accessibility. If service providers have an orientation towards overcoming the oppression of people with disabilities, this can contribute to the positive development of people with disabilities within the framework of the South African Constitution and the UN Convention on the Rights of Persons with Disabilities

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