

Knowledge of, beliefs about and attitudes to disability: implications for health professionals

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Abstract

Background: South Africa is a multicultural, multiracial and multilingual nation with many different values, traditions and cultural practices. Different belief systems may give rise to different attitudes and practices relating to disability, which may impact on rehabilitation. The purpose of this study was to investigate the knowledge, attitudes and beliefs relating to disability in three broad cultural groups in the Western Cape.

Method: Sixty primary caregivers were interviewed by using a knowledge, attitude and belief (KAB) survey in a structured interview format. Probability and non-probability (systematic and purposive) sampling were used. The study used both quantitative and qualitative methods.

Results: While caregivers from coloured and white communities generally had become acquainted with disability from an early age, caregivers in black communities often only learnt about disability following the birth of a disabled child. All caregivers had only a rather rudimentary knowledge of the causes of disability, but held positive attitudes towards people with disabilities and their integration into society. The qualitative data showed some differences in beliefs between the three groups in relation to the causes of disability and the need for rehabilitation. The data also revealed negative experiences across the groups in relation to education and the availability of transport, particularly amongst caregivers from black and coloured communities.

Conclusions: Health professionals need to understand the culture, values, beliefs and expectations of their clients when providing rehabilitation services within a community-based model. There appears to be a need for improved disability awareness in schools and amongst transport service providers.

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Introduction

In a multicultural, multiracial and multilingual society, a lack of awareness of the diverse cultural beliefs and attitudes may hinder the outcome of rehabilitation, leading to misunderstandings between professionals and clients due to differing points of view.¹ An understanding of different cultures can help health care professionals to understand how and why families make decisions concerning healthcare and rehabilitation.²

The International Classification of Functioning, Disability and Health (ICF) stresses that 'participation' is the essential component of functioning in

the home, school, workplace or community.³ Thus, participation in all aspects of life is influenced by functional activities and contextual factors, both personal and environmental. Whilst some factors are physical, others reflect the knowledge, attitudes and beliefs of communities. Therefore cultural practices are determinants of contextual factors.⁴

The following questions therefore arise:

1. What knowledge, attitudes and beliefs (KAB) relating to disability are held by caregivers of physically disabled children in different cultural groups in the Western Cape?

2. How might these influence the rehabilitation of disabled children?

Method

A cross-sectional study design was used.

Study population

The children and their caregivers attending the physiotherapy departments at the Tygerberg and Red Cross Children's Hospitals are representative of the three main cultural groups in the Western Cape. The Population Registration Repeal Act, No 114 of 1991 forbids the use of racial classification. However, the nature of the research question and

the implications for rehabilitation require the authors to refer to the classification of the SA Population Registration Act, No 30 of 1950.. Purposive as well as random sampling was used to identify 20 caregivers from each of these groups (n=60). Every third caregiver accompanying a disabled child for treatment to the physiotherapy department was invited to take part, provided that they met the inclusion criteria.

Inclusion criteria

The inclusion criteria for this study were that the child was prevented from performing at least one activity of daily life by the disability, was between two and 13 years old and that the caregiver was biologically related to the child, living with the child and sufficiently proficient in English to participate in the study. All the caregivers gave informed consent.

Instrumentation

A KAB questionnaire was adapted from the World Health Organisation's (WHO) Global Programme on Acquired Immuno-Deficiency Syndrome (AIDS) Research Package,⁵ and included:

1. Demographic data
2. Closed-ended questions and

statements on KAB

3. Open-ended questions to expand on the responses in part 2.

After piloting, the questionnaire was administered in the form of a structured interview. Data were analysed descriptively and qualitative data were analysed into themes and sub-themes.

Results

Profile of the sample

Fifty-five percent (n=22) of the black and coloured caregivers were 21-30 years old, whereas 45% (n=9) of the white caregivers were older, namely 31-40 years old. In total, 73% of the caregivers were the mother (n=33) or grandmother (n=11), while 16% were male (n=11). All of the children were two to five years old and 83% (n=50) were diagnosed with cerebral palsy.

Thirty-five percent (n=7) of coloured caregivers were Moslem, whereas 95% (n=19) of each of the other two cultural groups stated their religious beliefs as Christian (p< 0.01). Three percent (n=2) of caregivers had received schooling up to primary level, and 18% (n=11) up to tertiary level.

Knowledge

Knowledge of disability had been

acquired when young by 27% (n=16) of the white and coloured caregivers, but only after the birth of the child by 15% (n=9) of the black caregivers. Although views on the causes of disability were varied, there were no statistical differences between the groups. Table I provides an indication of the responses by the participants on the causes of disability.

Some of the comments made by the participants in relation to the causes of disability are:

- "... if you drink and smoke when you are pregnant. That is very dangerous, man, because the child can be born with any type of disability."
- "... if the child is premature the brain can get affected like Michael, and he can have cerebral palsy."
- "If the child gets infected when she is in you by meningitis, the doctor says it is very dangerous and causes damage to the brain. The child will never be normal again."

Attitudes towards children with disabilities

At least 75% (n=15) of respondents in each group felt sorry for disabled people because they "struggle", "always need help" and "cannot live a normal life". However, 92% (n=55)

Table I: Responses on the causes of disability

Responses	Black group	Coloured group	White group	Totals
Do not know the cause	8	4	4	16
Accidents	1	3	6	10
Illness	4	3	4	11
Problems with pregnancy	4	3	0	7
Difficult labour	3	1	1	5
Premature labour	0	1	1	2
Wrong medication in labour	0	1	0	1
Drugs and alcohol	0	2	2	4
No immunisation	0	1	1	2
Inheritance	0	1	1	2
Totals	20	20	20	60

Table II: Attitudes about the integration of disabled people

Responses	Black	Coloured	White	Totals
They should be accepted	4	9	4	17
They need to be treated like other people	5	2	7	14
They are human beings like us	4	3	5	12
They need to know what is happening around them	4	2	3	9
They should socialise	1	4	1	6
You will not get help from other people if you hide them	2	0	0	2
Totals	20	20	20	60

indicated that disabled children were not inferior, with only 3% (n=2) expressing a fear of disabled people.

All the respondents strongly disagreed with the statement that “Families having disabled people should completely hide them”, while 97% (n=58) agreed that “Disabled persons should associate with the other members of the community.” (See Table II.)

Sub-themes relating to the attitudes of the children’s relatives were:

- They treat the child like other children
- They help the child to do things
- They give the child special attention
- They take care of the child

Opinions on the attitudes of society towards people with disabilities were varied – 50% (n=30) felt that society “did not care”. In this regard, ‘Transport’ formed the main sub-theme. Sixty percent (n=12) of each cultural group indicated that persons with a disability should be allowed to use public transport, with the proviso ‘if they are capable’ commonly added. The only sub-theme for a negative response was ‘safety issues’, illustrated by ‘Public transport does not respect them’ and ‘they can get injured’.

Further comments revealed the many problems that were experienced:

- “Taxi drivers don’t want wheelchairs in their taxis. They charge you for the wheelchair, the child and yourself because you occupy three spaces. Sometimes they drop you

far from the hospital when it is raining.”

- “My baby gets sick because I walked a long distance to the taxi rank...waited a long time in the rain for the taxi.

Actions that respondents might take if they were President of the country confirmed these problems:

- “I can buy beautiful buses for disabled children to take them to the doctor. I can also give them money for petrol.”
- “I can punish all the taxi drivers and bus drivers for refusing to take disabled people.”

All of the respondents (n=60) disagreed that ‘disabled children should not attend school’. However, 72% (n=43) agreed that ‘disabled children should have their own schools’. The reasons for these views are summarised in Table III.

Some of the comments indicating negative perceptions of the treatment of the disabled child in a ‘normal’ school were:

- “They are better off in their own schools where they are accepted and respected ...In the normal schools the other children and teachers mock them and ill treat them badly.”
- “They call them names and refuse to help when they need help. They say they are stupid.”
- “When your child comes he is crying and tells you they called

him this and that. Those teachers don’t care, man; enough is enough.”

Beliefs

There was a cultural difference in the main sub-themes of whether disability is ‘man-made’. The main sub-theme of the white and coloured groups was ‘human errors’, e.g.

- “It is our fault...if you don’t take the child to the clinic for injections she can get sicknesses like polio or these funny measles.”

However, a second main sub-theme of black caregivers was ‘witchcraft’ –

- “Because my husband chose to marry me instead of their daughter, they decided to make me barren. I have only this one child who they also bewitched. He cannot talk or walk.”
- “They put the medicine for me when I was pregnant. My body was full of that medicine and it passed to my child.”

Statements from all three groups on whether disability was ‘sent’ by God were either ‘neutral’ or ‘positive’:

- “Everything is from God” and “God plans everything.”
- “God gives you this type of the child because He loves you and trusts you.” “He presented us with this precious angel to show His love to us.”
- “[She] is a blessing to our family...without her we feel empty.”

Table III: Attitudes about school attendance by disabled children

Responses	Black	Coloured	White	Totals
If severely disabled they need special teachers	4	4	6	14
In regular schools other children and teachers will make fun of them	6	5	2	13
Regular schools don’t take care of them	6	4	0	10
In their own schools they will be accepted the way they are	1	2	2	5
Children in regular schools will hit them	1	0	0	1
Totals	18	15	10	43

Table IV: Responses concerning the need for further treatment following diagnosis

Responses	Black	Coloured	White	Totals
Very necessary	2	4	2	8
Necessary	10	6	13	29
Unnecessary	4	7	4	15
Absolutely unnecessary	4	2	1	7
Not sure	0	1	0	1
Totals	20	20	20	60

Table V: Attitudes towards religious and traditional leaders

Responses	Black	Coloured	White	Totals
Worst idea	1	0	4	5
Bad idea	10	11	8	29
Good idea	7	6	4	17
Best idea	2	0	1	3
Don't know/not sure	0	3	3	6
Totals	20	20	20	60

Ninety-five percent (n=57) of the respondents needed to believe that the disabled child would be cured. This is illustrated by comments such as:

- *“Hope gives strength”* and *“God helps”*.

Beliefs and attitudes concerning the management of children with disabilities

Eighty-five percent (n=51) agreed strongly that the parents of children with a disability should participate in the treatment of their child and that the child should be taken for treatment once they had been informed that the child was disabled (see Table IV). The most common sub-theme was to seek a ‘second opinion’.

Responses to the statement: “It is a good idea to take the disabled child to other healers besides the western (hospital) healers (e.g. religious or traditional healers)” are presented in Table V.

Comments from across the cultural groups expressed the need to *“pray to God”* and/or *“to rely on the doctors”*. However, 35% (n=7) of black respondents expressed an additional sub-theme of *“traditional healers as well as doctors”*. Comments included:

- *“It is good to take him to the ugqirha (traditional healer) too, because he tells you who has done this to your child.”*
- *“At hospital they are good because they exercise the child, but you never know who has made your child like this. So your child is still in danger if you don't know the person.”*
- *“They say, I sucked it from my mother and Sisiphiwe got it from me.... We will go to Transkei when my mother has money to slaughter the cow. I don't like to have another one like her.”*

DISCUSSION

In this sample of caregivers, the majority of children in their care were two to five years of age. One reason for the absence of older children attending for physiotherapy might be that the health system provides free treatment to children under the age of six years. Another reason may be the transport problems referred to by many of the caregivers, with the further difficulty that transport to hospital by bus or taxi becomes more difficult once the child is too heavy to carry. This situation is likely to result in poor long-term rehabilitation and medical follow-up.

Knowledge

Although few caregivers were fully informed on the causes of disability, coloured and white caregivers were able to give a wider variety of causes. Many mothers living in sub-economic areas, including informal settlements, do not attend antenatal check-ups, with home delivery of infants being common.⁶ Peri-natal and postnatal factors are still frequent causes of neurological disability in the black population.⁷ The lack of antenatal care and counselling may not only have resulted in limited knowledge of the causes of disability, but might also delay the identification of disabilities and the subsequent early rehabilitation of infants – especially those with potentially minor deficits. A resultant lack of appropriate stimulation and management of the child could lead to the development of secondary complications. Problems with transport are also likely to adversely affect the ability and motivation of the parent to seek rehabilitation services.

It is important, therefore, that health professionals advocate increased community education on the causes

and prevention of disability, especially during the peri-natal period. In addition, in recognising the huge difficulties experienced by carers in attending health care services, the health care team should strive to utilise more effective home-based screening tools so that carers can identify the signs and symptoms of potential disability. Similarly, appropriate home-based rehabilitation programmes for implementation by carers are necessary, especially as 85% of this sample agreed strongly that the parents of children with a disability should participate in their treatment.

Attitudes

Most caregivers across all three groups were positive about bringing their child for regular therapy and participating in treatment. However, major obstacles in the black and coloured groups were transport difficulties and the attitudes of taxi drivers. This is one of the main reasons for parents not attending rehabilitation programmes. It also suggests a need to identify effective strategies to deliver rehabilitation services that require less frequent contact sessions. This need is highlighted by the following statement, which demonstrates a preference for community-based rehabilitation (CBR) services:

- *“I would give the nurses and doctors cars to go and check all the disabled people in their homes.”*

Wade emphasised that the aim of rehabilitation is to reduce handicap, not disability.⁸ In the terminology of the ICF, this is expressed as improving participation in all aspects of life and empowerment to optimise a behavioural repertoire, not only through therapy, but also by utilising positive

personal and environmental contextual factors.³ The concept of participation focuses on family and community integration, achieved by community-based rehabilitation programmes.

The respondents in all the groups supported family involvement in planning their child's education and medical management. However, attitudes towards the participation of the disabled child in a mainstream school were more ambivalent. The problems centred on the perceived negative attitudes of teachers and learners towards disabled children.

Beliefs

The belief that God or Allah is influential in determining disability and that a disabled child is a gift or a blessing is also common amongst Mexican American and African American families.⁹ Medieval Christians also believed that the disabled possessed special gifts bestowed by the grace of God.¹⁰ This positive belief may help the caregiver to cope better with the problems posed by these children. However, the belief that the child was ordained to be disabled might result in parents being less enthusiastic about seeking rehabilitation services to minimise the effects of the disability.

The belief in the role played by witchcraft and spirits was confined to black caregivers. This finding is similar to those of studies done in Zimbabwe, where the causes of disability were ascribed to both witchcraft and ancestral spirits, as well as to God and natural causes.^{11,12} Both the current study and that of Jackson¹² reveal that a belief in witchcraft is also present in those who profess Christianity. Caregivers with mixed beliefs resort to praying to God as well as consulting traditional healers and health professionals. This suggests their need for a meaningful explanation for the illness, and being attuned to their cultural beliefs as supported by traditional healers, who are perceived to identify the source of the problem and give the solution, usually focused on overcoming the causative spiritual power.^{11,13} Loveday found that Xhosa

mothers in Khayelitsha seek folk healing before seeking medical advice.¹⁴ This practice may also delay early diagnosis and intervention.

Conclusions

The conclusions to be drawn from this study are threefold. Firstly, health professionals need to be trained to be culture-sensitive and to respect the value systems and beliefs of their clients. Some beliefs may delay the early identification and rehabilitation of children with disabilities. Professionals therefore need to advocate and implement disability awareness programmes that will accommodate the viewpoints and expectation of caregivers. Closer co-operation and interaction between health professionals and traditional healers needs to be fostered, as it would open avenues for communication, discussion and the dissemination of information. It is important that an understanding of and respect for the roles of both health professionals and traditional healers in relation to disability is incorporated in the training of health care professionals.

Secondly, it is essential that health care workers be aware of the impediments to rehabilitation and participation, and that they advocate programmes to assist teachers, children, the general public and civic authorities to better understand disability and for the right of a child with a disability to participate in all aspects of life. Therefore, more projects within the health care sector should focus on addressing the perceived negative attitudes towards children with disabilities and on raising disability awareness.

Thirdly, community-based rehabilitation (CBR), which is supported by the WHO, is an integral part of the primary health care structure and service delivery being developed in SA. It is imperative that tertiary institutions should not be solely responsible for providing therapeutic services for children with disabilities, not only for reasons of cost-

effectiveness, but also because of the physical and financial problems of transport experienced by the caregivers of these children. The newly instituted system of community service for the health professions may help to alleviate this, especially if the undergraduate curriculum for health professionals addresses issues related to cultural sensitivity and rehabilitation in health care. 🙏

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