THE CHALLENGES EXPERIENCED BY PEOPLE WITH DISABILITIES AS A RESULT OF CULTURAL BELIEFS: A SYSTEMATIC REVIEW

M. Sakala (MSc)

J. Frantz (PhD)

A. Rhoda (PhD)

Corresponding Address
Anthea Rhoda
Department of Physiotherapy
University of the Western Cape
Tel: 021 959 2542
Email:arhoda@uwc.ac.za

Abstract

Myths, legends, scriptures and folklore, are all part of the cultural belief system that shape our perception of disability which influence the challenges experienced by people with disabilities. This article reviewed literature on influence of cultural beliefs on the challenges experienced by people with disabilities.Twelve library data bases were searched forqualitative research articles and reviewed literatures. Articles wereexamined,analysed and tested for evidence and quality using the Critical Appraisal Skills ProgrammeTool. Of the nine studies included in the review the majority were conducted internationally and across different ethnic groups with diverse cultures.Cultural beliefs were found toinfluence the way thesociety perceives disability, and the accessibility and provision of health services (including rehabilitation). The perceptions of disability by both the disabled individual and their families were influenced by their religious and/or spiritual beliefs. It is important to consider the influences cultural beliefs when providing rehabilitation services to persons with disabilities.

Keywords: Physical disability, cultural beliefs, sexuality, accessibility

INTRODUCTION

Myths, legends, scriptures and folklore, are all part of the cultural belief system that shape the perception of disability(Ingstad and Whyte 1995). Some people living in Africabelieve that disability is closely linked to the concept of misfortune where it is consideredas one of the reasons for being struck by illness, or accident. It can thus be said that much of the discrimination experienced by people with disabilities in Africa is rooted in suspicion and fear of witchcraft (Schoepf, 1997). In any context, identification of the cause of an impaired state of well being will assist in determining the appropriate course of action. Thus peoples beliefs regarding the cause of disability influences the manner in which they seek for assistance (Ingstad and Whyte 1995).

All societies have explanations as to why some individuals and not others are disabled, the manner in which individuals with disabilities should be treated and what roles are appropriate and inappropriate for such individuals. This includes decisions about rights and responsibilities and individuals with disabilities are either entitled to or denied.Groceand Zola (1993), as well as Ingstad and Whyte (1995) suggested that in some cultures,thebeliefs about the origins of disability are particularly useful and necessary when searching for therapy. In other cultures however the mere presence of a disability determines whether one is going to be accepted by society or not. It follows that individuals with disabilities could be treated well or poorly, based on the cultural beliefs about how and why they became disabled (Groce 2004). Cultural beliefsthus contribute to the challenges people withdisabilities experience.

Groce and Zola (1993) revealed that the physically challenged frequently suffer more due to societal prejudices than due to their disabling physical conditions.Thus disability policies, programmes and practices of any country may be associated with theattitudes that people in different cultures share. The social and physical environment in which these

physically challenged live is often designed without much consideration of their special needs (Devlieger 1998; Kabzems and Chimedza 2002).

This review aimedto examine how cultural beliefs influencedthe challenges that people with physical disabilities experience.

METHODOLOGY
Search strategy

The selection process for inclusion into the review involved four steps. Firstly, the online data bases that were searched included MEDLINE and PsycINFO, Academic search premier, Africa-wide information, CINAHL, MasterFILE premier, MEDLINE, PsycArticles , Rehabilitation and sports medicine, SocINDEX , EBSCOhost,JSTOR and women's studies International. These are databases of literature emanating from a variety of disciplines including medicine, nursing, social care, psychology, sociology, and anthropology which were searched for potentially relevant articles.

Search terms/phrases used for the search included: "people with disability" or "people with physical disability" or "people with physical impairment" and "challenges/barriers experienced" or "lived experiences" or "barriers faced" and "cultural/traditional beliefs" or "impact of beliefs/myths" and "influence." Secondly, relevant articles (selected on the basis of the title and abstract) were retrieved for more detailed evaluation. The bibliographies of relevant articles were hand searched for additional references.

Inclusion criteria

Qualitative study designs were accepted, which required to report on physical disability, cultural beliefs or/and myths and influence of these beliefs/myths on the lives of persons with disabilities. These articles were required to have been peer reviewed, written in the English language and published between January 1990 and June 2010.

Search results

Articles that were appearing in two or more data bases were counted from the first data base where they were first retrieved.The abstracts were screened using the PICO that stands for population, intervention, comparison and outcome. A hundred and five (105) abstracts were found which were screened to ensure that they met the inclusion criteria using the PICO scoring tool. The PICO tool is meant to assist researchers to choose articles that according to Boudin et al (2010). The research problem or a population of interests which in this review the population of interest is the people with physical disabilities; the phenomenon that is being researched, which in this review is cultural beliefs or myths: other test/predictive or risk factor/intervention being compared with the first, which was not relevant for this review; and finally the outcome of interest which in this case of the current review is cultural beliefs and impact on lived experiences of people with physical disabilities. Of the 105 abstracts, twelve abstract met the PICO assessment criteria. Fourthly the articles that met the PICO criteria were further tested for quality and evidence.

Assessment for methodological quality

The twelve articles were further subjected to a methodological quality assessment using the tools developed by the Critical Appraisal Skills Programme(CASP). The aim of CASP is to enable individuals to develop the skill to find and make sense of research evidence, helping them to put knowledge into practice (CASP 2006).

The aims and objectives of the research are expected to be clearly defined, the sampling method should match the research design, and the sample should be appropriate to the design. The participants, the setting and the phenomena involved in the study should be well described. The data collection tools and procedure should be appropriate for the design. The data analysis and presentation of the results should be clear and appropriate to ensure trustworthiness.Ethic should have been observed by way of informed consent of participants and purpose of study explained to participants. The study must be relevant. The articles are scored according to the score out of 13 and those that scored less than 7/13 were not include yielding a total of 9 articles that met the CASP criteria. All the nine articles were independently reviewed by two reviewers.

Table 1. Articles and scores according to CASP

Title	Author(s)	Data base	Year of publication	Score	Accept
Disability Studies: The Old and the New	Titchkosk, T	JSTOR	2008	5	
Lived experience of middle-aged women living with a disability in Isaan, Thailand.	Rukwong, P.	CINAHL	2008	13	Yes
Social interventions of moderate discriminatory attitudes: the case of the physically challenged in India	Dalal, A. K.	MEDLINE	2006	12	Yes
Eco-cultural frameworks and childhood disability: A case study from Puerto Rico	Gannotti, M.	MEDLINE	2006	6	
The importance of cultural factors in the planning of rehabilitation services in a remote area of Papua, new Guinea	Byford and.Veensra	MEDLINE	2004	11	Yes
Barriers to accessing safe motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia	Smith, et al	CINAHL	2004	9	Yes
Stigma, Community, Ethnography: Joan Ablon's Contribution to the Anthropology of Impairment-Disability	Shuttleworth,	JSTOR	2004	7	
Disability, spiritual beliefs and the church: the experiences of adults with physical disabilities and family members	Treloar	Health Source: Nursing/Academic Edition	2002	12	Yes
Disability, space and sexuality: access to family planning services	Anderson and Kitchin	Women's studies international	2000	12	Yes
Cross cultural views of disability and sexuality: Experiences of Ethno-racial women with physical disabilities	Yoshida, Li, and Odette.		1997	13	Yes
Ethics, values, and world culture: the impact on rehabilitation	Banja, J.D.	MEDLINE	1996	13	Yes
Culture and rehabilitation	Hawker, A.	MEDLINE	1996	11	

Three articles were excluded on the basis of lack of ethical considerations, the participants not being well described and the source of data not provided.

RESULTS

A hundred and five (105) articles were found and were screened using the PICO scoring tool.Ninety three (93) articles whose abstracts did not meet the PICO inclusion criteria were excluded from the 105. Thetwelve (12) articles that met the PICO criteria were further subjected to the CASP tool for methodological quality. Seven (7) of the 12 studies qualified to be included in the review(Table 2).The majority of the 7 studies were conducted internationally and across different ethnic groups with diverse cultures.

In addition the most common method of obtaining information was in-depth interviews. Of the outcomes measured, cultural beliefs were linked to coping mechanisms, utilization of services, and the rehabilitation process and client sexuality.

Table 2: Description of articles included in the review

Reference	Design	Country	Subjects	Phenomena	Outcome
Treloar, L.(2002)	Qualitative interpretive study : indepth interviews	South West metropolitan of th e USA	Nine adults with physical disabilities	Disability, spiritual beliefs and the church:	The experiences of adults with physical disabilities and family members
Byford, J., andVeensr a, N. (2004)	Qualitative in depth interviews	New Guinea	Persons with disabilities number not specified	The importance of cultural factors in the planning,	The rehabilitation services in a remote area of Papua
Smith, E., Murray, S.F., Yousafzai , A.K., andKasonka, L.(2004)	QualitativeFocus group discussion and indepth interviews	In Lusaka, Zambia	Women with physical disabilities in reproductive age	Barriers to accessing safe motherhood and reproductive health services	The situation of women with disabilities
Anderson, P. andKitchin, R.(2000)	Review of Qualitative literature:	Northern Ireland	Disabled men and women of reproductive age	Disability, space and sexuality	Access to family planning services
Banja, J.D., (1996)	Qualitative: in depth interviewsand observation	Germany	Disabled persons, physiotherapists and nurses	Ethics, values, and world culture	The impact on rehabilitation
Yoshida, K.K., Li, A., and Odette, F., (1997)	Qualitative: Focus group discussions	Rural and urban Ontorio, canada	10 Disabled women aged 18 and above	Cross-cultural views of disability and sexuality:	Experiences of Ethno-racial women with physical disabilities
Rukwong, P., (2008)	Qualitative in depth interviews and observation	Isaan, Thailand	Sixteen disabled women 40-60years of age	Middle-aged women living with a disability.	Lived experience

28

DISCUSSION

The aim of the review was to establish the influence of cultural beliefs and myths on the challenges experienced by people with disabilities.After the review of the articles it is clear that people with disabilities struggle with accessibility of the health care services. This is so because the cultural beliefs of various ethnic groups affect the way health service providers relate with people with disabilities which in turn impact adversely on the services being rendered. There is also evidence showing that cultural beliefs have an impact on society's attitudes towards people with disabilities including their sexuality.

Accessibility of the health care services to people with disabilities

The Northern Ireland reviewed literature on culture and accessibility of reproductive health services, found that clinics are largely inaccessible in terms of physical access and informational and service provision. The authors further argued that such inaccessibility reproduces cultural representations and myths of disabled people as asexual beings and reinforces the idea that disabled people do not need availability of family planning services(Anderson and Kitchin 2000).

A study by Byford andVeensra, (2004) which employed in depth interviews, investigated how cultural beliefs affected the challenges that persons with physical disabilities experience in New Guinea, with regards accessibility and utilization of rehabilitation services. This in depth study reported that cultural beliefs impacted on both the rehabilitation process and on the lives of the participants. It was also reported that among the many challenges the key determinant was the cultural beliefs of people of New Guinea which played a major role.

A study carried out in Zambia employed both focus group and in depth interviews to explore the barriers to accessing family planning and reproductive health services among women of reproductive age. It was reported that cultural beliefs contributed to the difficulties and challenges that the participants faced to access the said services.In this study it was reported that 30% of persons with disability and their families attributed disability to sorcery and other supernatural causes. The authors also reported that

although there was widespread acceptance of western conventional medicine, help was more likely to be sought from the community for disabilities believed to have supernatural origin.

Effect of cultural beliefs on the provision ofhealth services

Given the importance of attitude within rehabilitation it was concluded that it is important that if rehabilitation is to be truly holistic, individualistic and needs based, then it must understand and reflect the person's cultural dimensions. Further this may mean that for many cultures the service delivery mechanisms may need to change to reflect a much more collective approach.Banja (1996) combined in-depth interviews with an observational approach to investigate the impact of ethics values and culture on the rehabilitation process of people with disabilities. In this study it was reported that cultural beliefs cause people to learn approved ways of being ill, influence their ascriptions of the cause and process of illness or disability. It is the cultural beliefs that determine what people expect from treatment and the one providing the treatment This study reviewed the medical professionals need to be aware of cultural differences that can affect the outcome of treatment. Banja (1996) concluded that rehabilitation can also be culturally diverse. The author further recommended that a universal, trans-cultural understanding of rehabilitation is possible. It can be so if it is understood that disabilities are concerned with integrated activities expected of the person as a whole. If culture distinguishes how we engage the world, rehabilitation universally addresses the form of that engagement in its physical behavioral and cognitive manifestations.

Rukwong (2008), who employed in depth interviews and observations to explore the experiences of middle-aged women living with a disability in Isaan, Thailand, reported that gender and cultural beliefs play major roles in the experiences of women with disabilities. The study further revealed the importance of health care providers' knowledge of clients' health history and application of gender and cultural sensitive health care. The study recommended that health care systems should incorporate formal and informal support (for example relationship, family, and community) that includes both health promotion and rehabilitation. The system should not only be concerned with women's health

and functional status but also help people with disabilities to maintain their gender role under the physical limitations that impact on all aspects of their life experience. This can only be achieved if the health care providers have the knowledge of the cultural beliefs of their clients.

Cultural beliefs have consistently been present in the health field, but not adequately examined. There is a need to examine the relationship with health services provision because communities are becoming more cultural diverse due to industrialization (Yoshida et al(1997).

Cultural beliefs and attitude towards people with disabilities

Treloar (2002) employed in depth interviews andsoughttoexplore the experiences of adults with physical disabilities that belonged to an evangelical church in relation to their beliefs and how it impacted on their lives. The article reported that spiritual beliefs had positive impact on how the disabled perceived disability. The belief that all human beings are equal before God their creator and each has a unique purpose in their lives were said to have positive impact and contributed to coping with everyday challenges of disability (Treloar 2008).

It has been observed that in modern western societies, people with disabilities are commonly viewed as abnormal, child-like, 'damaged goods', 'freak of nature', unattractive, dependent, in need of protection, a danger unto themselves, an object of pity, unproductive, anti-social, and tainted by disease and ill-health. These representations have been engraved into the core of society by ideas the difference from the normal and supposed inferiority and danger. Terms or labels such as 'invalid', 'cripple', 'handicapped' and 'retarded' all imply both a functional loss and a lack of worth. Such labels continue and justify offensive responses by non-disabled people including horror, fear, anxiety, hostility, distrust, pity, and overprotection and patronisingbehavior (Anderson and Kitchin 2000).

Cultural beliefs and sexuality

A study which employed focus group discussion was conducted in Canada by Yoshidaet al(1997) to investigate the cross cultural views and experience of disability and sexuality among ethno-racial women with physical disabilities. The results of the study found that culture of different ethnic groups influence the way societies perceive sexuality among people with disabilities.It was also reported that people with physical disabilities do not access health services that are related to sexuality and reproductive health because of their stereotype way of thinking that they are not expected to be sexually active or be involved in relationships and raise families. They also fear to seek information and help because of the negative attitudes of service providers. They end up not attempting to access the services(Yoshida, et al.1997).This study demonstrated that an understanding of cultural factors is fundamental to implementation of rehabilitation services that are culturally appropriate and address the social dimension of disability.

A study conducted in Zambia by Smith et al (2004) employing both a focus group discussion and in-depth interviews to explore the barriers to accessing family planning and reproductive health services among women of reproductive age. It was reported that generalized assumptions and beliefs among service providers that women with disabilities are not sexually active and not require reproductive health services, maylead to increased vulnerability to contracting infections that include HIV/STIs (Smith et al(2004). Once a woman with physical disability is pregnant, traditional beliefs about transmission of disability can create barriers to integration in antenatal clinics. Nurse/ Midwives fear of delivery complications in women with physical disabilities can also result in routine over-referral to tertiary maternity facility which is outside their locality and harder for women with mobility limitations to access (Smith et al., 2004).

CONCLUSION

It is clear that traditionalcultural beliefs result in challenges experienced by people with disabilities. These challenges relate to sexuality, negative attitudes by society and access to health care and rehabilitation services.Lack of full knowledge of such influences among the health service providers including physiotherapists, creates a barrier for physically challenged to access quality care.

RECOMMENDATIONS:

With the growing body of knowledge about human rights and disability, there is a need for more research on cultural beliefs and accessibility of

health services including rehabilitation to inform service providers on the sensitivity of cultural beliefs.

REFERENCES

Albrecht, G.L., and Davlieger, P.J. (1998). The disability paradox: high quality of life against all odds. Social Science & Medicine 48, 977-988.

Anderson, P., and Kitchin, R. (2000). Disability, space and sexuality: access to family planning services. Social Science and Medicine, 51(8).

Banja, J.D. (1996). Ethics, values and world culture: The impact on rehabilitation. Disability and Rehabilitation 18(6), 279-284.

Boudin, F., Nie, J., Bartlett, J. C., Grad, R., Pluye, P., and Dawes, M. (2010).Combining classifiers for robust PICO element detection.BMC Medical Informatics and Decision Making 10(29), 1186/1472-6947.

Retrieved from:http://www.biomedcentral.com/1472-6947/10/29 on 29/09/2010

Byford, J., and Veensra, N. (2004). The importance of cultural factors in the planning of rehabilitation services in a remote area of Papua, New Guinea. Disability and Rehabilitation, 26(3), 166-175.

Critical appraisal skills program (CASP) (2004). Public Health Resource Unit, England.Retrieved from: http://www.pru.nhs.uk.On 04/04/2010.

Davlieger, P.J. (1998). From handicap to disability; language use and meaning in the United States. Disability and Rehabilitation 22(11), 522-525.

Gannotti, M. (2006). Eco-cultural frameworks and childhood disability: A case study from Puerto Rico. Physiotherapy Theory Practice.22(3):137-51.

Groce, N.E. (2004a).Adolescents and youths with disability issues and challenges. Asian Pacific Disability Rehabilitation Journal2, 14-18.

Groce, N.E., and Zola, I.K. (1993).Multiculturalism chronic illness and disability.Pediatrics, 91, 1048-1055.

Ingstad, B., and Whyte, S.R. (1995).Disability and culture. Berkeley, University of California Press.

Kabzems, V., and Chimedza, R. (2002). Development assistance: Disability and Education in Southern Africa. Disability and Society 17, 147-157.

Nkabinde, Z. (1994). Special Education for Blacks in South Africa: A dream or reality. Paper presented at the Council for Exceptional Children, Denver.

Rukwong, P. (2008).Lived experiences of middle aged women living with disability in Isaan, Tailand.Nursing & Health Sciences 10(1), 59-64.

Schoepf, B. (1998). 'Inscribing the body politic: Aids in Africa.' In Lock, M. And Kaufert, P. (eds), Pragmatic Women and Body politics.Cambridge: CambridgeUniversity Press. pp 98-126.

Schoef, B. (1997).AIDS, gender and sexuality during Africa's economic crisis. In: Gwendolyn (ed) African Feminism: the Politics of survival in sub-SaharanAfrica. Philedelphia, Penn.

ShuttlewortH , R. (2004). Stigma, Community, Ethnography: Joan Ablon's Contribution to the Anthropology of Impairment-Disability. 18(2), 139-161

Smith, E.,Murry, S.F., Yousafzai, A.K., and Kasonka, L. (2004). Barriers to accessing safe motherhood and reproductive health services: the situation of women with disabilities in Lusaka, Zambia. Disability and Rehabilitation26(2), 121-127.

Titchkos, T. (2000). Disability Studies the Old and the New. Canadian Journal of Sociology.

25 (2):197-224.

Treloar, L. (2002). Disability, spiritual beliefs and the church: the experiences of adults with physical disabilities and family members. Journal of Advanced Nursing 40(5), 594-603.

Yoshida, K.K., Li, A., and Odette, F. (1997): Cross cultural views of disability and sexuality: Experiences of ethno-racial women with physical disabilities. Sexuality and Disability17(4), 321-337.

Zola, I.K. (1993): Self, identity and the naming questions: Reactions on the language of disability, in: Nagler, M. (Ed). Perspectives on disability, (2nded) (Palo Alto, Health Markets Research).