

Traditional beliefs and care system towards persons with disabilities in Papua New Guinea

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Abstract

According to World Health Organization, in developing countries one out of ten is a disabled person. People with disabilities face considerable barriers in their lives in terms of access to services, education and participation in social life. The aim of this study was to find out how people with disabilities and their families, living in a remote area, perceive and interpret causes of disabilities as well as to describe medical practices related to disability. This mixed methods explanatory study was conducted between August and September 2011. Data were collected from 127 disabled persons and their families by semi-structured interview in a few locations of rural Madang and Easter Highlands province. Three quarters of participants (76%) attributed disability to supernatural causes such as punishment from the spirits for breaching taboos or sorcery. These beliefs were stronger in the highlands than in the coastal locations. The qualitative part of the study provided explanations and deeper understanding of Melanesian concepts of disease and disability causality. Interestingly, the most common help seeking pattern for a person with disability was to seek first help from the traditional medicine. This study contributes to deeper comprehension of the common belief model in Melanesian society connected with disability which is essential in planning and implementing rehabilitation services for people with disability.

Key words: disabilities, traditional beliefs, care systems, medical practices related to disabilities, Melanesian, rehabilitation, people with disability

Introduction

The Global Burden of Disease report in 2004 estimated that over 100 million children under the age of 15 years, the majority of whom live in low and middle income countries, had a moderate or severe disability (World Health Organisation, 2011). According to World Health Organization (WHO) and United Nations (UN), the prevalence of disability in developing countries is at least 10% (Department of International Development, 2000). Furthermore 80% of the world's disabled people live in remote rural areas of developing countries (United Nations, 2006). Almost 87.5% of the PNG population live in rural and remote areas (World Health Organisation, 2012). A recent study in the Middle Ramu area of the Madang Province, PNG, reported the overall

prevalence of disability at 3.2% (Byford, Veenstra, & Gi, 2003). The world report on disability confirms that more than 1 billion people with disabilities face substantial barriers in their lives (World Health Organisation, 2011). Disabled women showed a lower literacy rate and were more likely to be victims of physical and sexual abuse than women without disabilities (Department of International Development, 2000). In many children, the presence of disability leads to rejection and isolation (United Nations, 2006).

There is an increasing awareness of the importance of understanding traditional beliefs and attitudes towards disability (Mallory, Charlton, Nicholls, & Marfo, 1993). Anthropologists studying the socio-cultural aspects argue that the culture constitutes a central element for the understanding of societies' beliefs and practices related to illness and disability. One cannot really comprehend how people react to illness, disability or other misfortune without understanding cultural lenses through which they perceive and interpret their world (Helman, 2008). A common feature for Melanesian culture is a holistic view of the reality. In relations to illness and disability, this holistic view is expressed in acceptance both of natural and underlying supernatural causes of illness or disability. Melanesian societies perceive illness and disability as the result of some kind of evil power in the persons (sorcery) or in the guardian spirits of objects in their environment. They worry about broken taboos or tribal laws, about failure to placate spirit beings, about being punished by the guardian spirits or gods (Pulsford & Cawte, 1972). For many people in PNG health and illness have their origin in the invisible realm of spirits, ghosts and sorcerers. Even though a high proportion of disabilities were associated with natural causes, such as trauma, accidents, and illness, the underlying cause of disability was mostly attributed to social or supernatural factors, such as spirits, sorcery or breaking cultural taboos (Byford et al., 2003; Gibbs, 2003; Lewis, 1975).

Another aspect of the Melanesian concept is the crucial role of the community implying that care for the ill and disabled always takes place within a social context (Lewis, 1975). In any study of the social organization of a health care system, it is essential to include the ways the people become recognized as ill or disabled, the attributes of those affected, and the ways the illness or disability is dealt with (Helman, 2008). The knowledge of traditional beliefs and practices towards disability is of vital importance to provide culturally relevant services to plan and implement programs for people with disability that will make a real difference in the lives at individual and community levels (Capstick, Norris, Sopoaga, & Tobata, 2009; Mallory et al., 1993; Samu & Suaalii-Sauni, 2009). Wade and Halligan (2004) suggested that the recognition and adoption of a common belief model might improve the health care delivery more than any other change in health care system. Furthermore community based rehabilitation (CBR) programs emphasized the importance of cultural factors and community attitudes towards the disabled for the successful implementation and sustainability of the program (Byford & Veenstra, 2004; Monk & Wee, 2008). Other authors implied that some aspects of cultural beliefs were a hindrance to the development of better care for persons with disabilities (Van Amstel, Dyke, & Crocker, 1993). In addition, it was pointed

out that identifying current attitudes is a first step towards the establishment and promotion of the rights of people with disabilities through supportive environments (Monk & Wee, 2008). On the contrary, marginalization of people with disability often extends to their exclusion from meaningful participation in transforming policy which impacts on their lives (Kleintjes, Lund, & Swartz, 2013).

Recently the issues of disability are gaining place in the political agenda. At the second Pacific Disability Ministers Meeting held in Papua New Guinea in 2012, all unanimously agreed that it is necessary to include disability issues in Post-2015 Development Agenda, which is essential if the global goal of poverty eradication is to be realized (Tavola, 2012). Also PNG National Health Plan 2011-2050 includes the objective to improve CBR programs that enable people with disabilities to be less dependent and more able to participate in community life (Papua New Guinea Department of Health, 2000).

Thus the aim of this study was to find out how people with disabilities and their families, living in a remote area, perceive and interpret causes of disabilities as well as to describe medical practices related to disability.

Methodology

This mixed methods explanatory study was conducted between August and September 2011. Interviews were conducted in the local language (Tok Pisin) based on a semi-structured questionnaire which incorporated both open-ended and closed questions for data collection. Information documented included the demographic characteristics and nature of the disability, biomedical cause, the perceived cause of disability, as well as the kind of medical help sought for the disability. Participants of the study were persons with disability (PWD) and/or their close relatives. The participants (n = 127) were recruited from rural locations of the Eastern Highlands Province (Okapa Health Center catchment area [n=40]; Kassam (EBC sub- Health Centre catchment area, which is in Arona Valley in Kassam Pass [n=20]) and Madang Province (Saidor, Health Center catchment area [n=40]; Sumkar (Bunabun Health Center catchment area [n=27])). Convenience sampling was used to select participants visiting health centers as well as during health patrols in villages. Answers to the questions were manually recorded in the questionnaire. Field workers (university students) were trained by the authors to conduct the interviews.

The qualitative and quantitative strands of data were analyzed separately and triangulation was performed at the level of inferences. Content analysis was performed for the qualitative data, and main themes were identified according to common threads in the data. The quantitative data were summarized by descriptive statistics. Voluntary informed consent was obtained from all participants. The study received ethical clearance from the Divine Word University Research Ethics Committee.

Results

Demographic characteristics

Of the 127 participants, there were 70 males and 57 females. Their average age was 32 years (range 16-55). Almost all participants had no formal job (97%, n=123). They were subsistence farmers or unemployed and more than one third were illiterate without any formal education (37%, n=47).

Causes of disability

Table 1. Causes of disability as expressed by the participants in different sites of Papua New Guinea, 2012*

		Causes of Disability					
Site	No	Spirit	Sorcery	Broken taboos	Accident	Disease	Unknown
Saidor Madang	40	2	12	11	6	5	4
Sumkar Madang	27	5	13	3	8	8	0
Okapa EHP	40	25	5	5	2	3	0
Kassam Pass EHP	20	8	7	1	2	2	0

*Some participants gave more than one cause

Looking at differences between the coastal (Madang) and highlands (EHP) regions, in the highlands spirits were more likely to be seen as the causes of disability (55% versus 10% respectively, table 1). On the contrary, in Madang broken taboos were viewed as a cause of disability six times more often than in EHP (61% versus 10%). Furthermore, in Madang, biomedical causes of disability such as accidents and diseases were recognized in 43% of the cases (29 out of 67), whereas in the EHP only in 15% (9 out of 60) of cases.

While quantitative data created a basic profile of people's beliefs towards causes of disability, the qualitative strand provided explanations and deeper understanding of Melanesian concepts of disease and disability causality. By way of example, in Okapa, it is a common belief that a child born with disability is "a result of spirits' punishment upon the parents who made a mistake by having sexual intercourse in the forbidden area" (disabled women from Okapa area). When such a disabled baby is born, the parents are obliged to compensate for their mistake to mother's and father's relatives by offering them some pigs, kina shells, money or garden food.

A woman from Bunabun Health Center reported that pregnant women are forbidden to eat certain meat, such as parrot fish, shark, wallaby, turtle and tree kangaroo. Transgression of these taboos can cause congenital abnormalities to

the baby. Apart from food taboos, there are certain customs which the pregnant women have to follow. For instance, when somebody dies, the families of the deceased normally prepare a meal for those gathered for that occasion. However, a pregnant woman is forbidden to take food during this gathering in the belief that the food is unclean and can result in a child with disability (Bunabun H/C).

Help seeking and expectations

The majority of participants (73%; n=93) admitted that a person with disability would first seek help from traditional medicine, and only if that has not helped them to recover then they would try Western medicine. Basically three approaches to traditional medicine were noted including traditional herbs and other medicine, help from traditional healers (glassman) and compensation to relatives. Within traditional approach, approximately half of them (53%; n=67) would try traditional herbs or medicine; 26% (n=33) would take “a wait and see” approach hoping that the condition would improve in time, 15% (n=19) would attend to traditional healers, and 6% (n=8) were not sure what to answer and only 2(1%) participants mentioned compensating to relatives (table 2).

Table 2. Sources of help seeking for persons with disability expressed by the participants in different sites of Papua New Guinea, 2012*

Site	Saidor H/C (Madang) (40)	Bunabun H/C (Sumkar, Madang) (27)	Okapa H/C (EHP) (40)	Kassam Pass H/C (EHP) (20)	(127)
1 st traditional approach	26(65%)	18(66%)	33(82%)	16(80%)	93(73%)
Herbal medicine	12(30%)	8(30%)	21(52%)	12(60%)	67 (53%)
Traditional healer	5 (12%)	2(7%)	8(20%)	4(20%)	19(15%)
Compensation to relatives			2(5%)		
“Wait and see” approach	11(27%)	6(22%)	9(22%)	7(35%)	33(26%)
Western medicine	13(33%)	10(37%)	8(20%)	3(15%)	34(27%)

*Most of the participants sought help from more than one source, H/C – Health Center

The large discrepancy between total number of those resorting first to traditional medicine (65% in Sidor, 66% in Bunabun) and the sum or two approaches recorded including herbal or other traditional medicine and traditional healers (42% in Saidor and 37% in Bunabun) may require further study (see table 2). This discrepancy might suggest that some approaches or sources of traditional help were not disclosed to the investigators. Generally, in both highlands locations the participants sought more often traditional help than in the coastal area while in the participants from the coastal locations more often that those from the highlands tried Western medicine.

When asked what help for the disabled they expect from the government, more than half (53%, n=67) wished the government would build facilities to care for the disabled while 16.5% (n=21) of respondents wanted specialist doctors to visit rural health centers. In Sumkar district the majority (77.7%, n=21) wanted a community rehabilitation center. Few of the participants noted the lack of any equipment in local health centers for the disabled. Sixty percent (n=76) of the participants expressed they felt stigmatized in their communities.

Discussion

Causes of disability

Our study demonstrated that the majority of participants (76%, n=97) attributed disability to supernatural causes. Likewise, other authors studying different ethnic groups in PNG reported that supernatural causes of disability and sickness, such as sorcery, spirits violation of taboos and customary laws, constitute a greater proportion than any other category of perceived etiology (Byford & Veenstra, 2004; Gibbs, 2003; Macfarlane, 2009). These findings are in line with the Melanesian concept of causality of illness and disability. According to this concept the study in Sepik society concluded that there is no such thing as accidentally or randomly acquiring an illness or impairment. On the contrary, each illness or disability has a spiritual cause and the care for the sick always take place in the cultural context (Lewis, 1975). Strathem's (1968) study of Melpa believes (in Enga) listed such supernatural causes of sickness as "attacks by ghosts, enemies using poison or menstrual fluids, wild spirits, by other spirits sacrificed to in cults, sorcerers who live in the fringe areas surrounding the Melpa, and by a group of totem which works in conjunction with ancestors spirits." In the same study, Wiru, another ethnic group in Enga, have many parallel believes to Melpa, while they added to the causes of sickness a class of "bad things" that embrace stick insects, some lizards and moths. Likewise, traditional health beliefs of Aboriginal people are interconnected with many aspects of their life and place emphasis on social and spiritual offences causing illness (Maher, 1999).

In particular, sorcery was perceived as one of the commonest causes of illness and disability in traditional societies (Lindenbaum, 1979; Macfarlane, 2009; Maher, 1999; Mitchell & de Lissovoy, 1997). Similarly to Melanesian believes, in many other traditional societies chronic disease of disability is perceived as a form of punishment by offended gods or spirits incurred on those who violated customary taboos or social obligations, or discordant family or social relationships (Koka, 2004; Macfarlane, 2009; Maher, 1999; Monk & Wee, 2008). In many instances, these causes of illness or disability are mediated by spirits whose role is to preserve traditions and social harmony. While there are different kinds of taboos such as dietary, geographic or protecting social harmony, a commonly breached one is to trespass in a sacred place or on land belonging to someone else (Macfarlane, 2009).

According to Macfarlane (2009), in PNG there is the common classification system into minor diseases caused by natural causes and serious diseases in

which supernatural sources are involved. In all provinces there is a prevalent belief that all kinds of spirit can cause disease or disability. In the same vein, Gibbs (2003) study on causality of disability in different parts of PNG recorded 3 categories: biomedical, supernatural and not known causes. In addition, he noted that often a natural cause coexisted with the supernatural. In many instances, even if participants of Gibbs' study (2003) admitted that a particular disability was caused by the accident, the underlying cause of the accident was believed to be sorcery. A possible explanation to a large proportion of respondents choosing "I don't know" could be, that this answer was a way of avoiding answering the question (Gibbs, 2003). The Aboriginal system of health beliefs also categorized illness according to the cause into natural, environmental, direct supernatural, indirect supernatural and emergent or Western causes. It is essential to recognize that similar to the Melanesian view these categories are not mutually exclusive; indeed they accept multiple causes of illness or disability (Maher, 1999).

Traditional medicine

Consistent with other studies we have shown that the most common practice for a person with disability was to seek first help from the traditional medicine. In a case when the traditional medicine has not worked, they would try Western medicine. Although Byford and Veenstra (2004) noted widespread acceptance of Western medicine, help was more likely to be sought from traditional medicine for disabilities believed to have a supernatural origin. A recent review on traditional medicine in PNG further explained that illness, which was caused by supernatural forces or caused by some cultural practices required traditional medicine in order to be cured (Macfarlane, 2009). In the anthropological analysis of biomedical relations in Madang hospital, Street (2014, p. 5) has shown reverse order of seeking first help with Western medicine, and when this fails, turning back to traditional methods. She has described a case when patient's experience of "white people medicine" was disappointing, when he was not cured of the sickness in the expected time, he resorted to a glassman services and when that did not work, he placed his hope in praying to God. In Bougainville (Hamnett & Connell, 1981) and Madang (Lipuma, 1988) it has been reported that people see Western and traditional medicine as being compatible and part of one medical system. In rural PNG the modern medical system co-exists alongside traditional medical practices. When one method fails to treat the sickness, the condition is re-evaluated and different methods of treatment are tried (Koczberski & Curry, 1999). An interesting distinction is that in case of "sick of the place" (*sik bilong ples*), Western medicine is seen as good for alleviating symptoms whereas traditional treatment is seen as a cure for the cause of the illness (Hamnett & Connell, 1981; Lipuma, 1988). Our study found that approximately half of the disabled would try traditional herbs. Similarly others pointed out herbs as most commonly used in traditional medicine; however it was likely that some kind of ritual might be conducted by a traditional healer or a sorcerer (Macfarlane, 2009). In most ethnic groups sorcerers are believed to possess the power both to cause and cure illness, although understanding of the specific relations between illness and sorcery vary across provinces (Macfarlane, 2009).

Stigma and low priority in health policy

We found that most respondents felt stigmatized in their communities. Our findings are in agreement with studies on other societies which revealed that generally attitudes toward people with disability were negative resulting with some exclusion from the social activities (Kleintjes et al., 2013; Staniland, 2009). In addition, the degree of stigma and marginalization depends on the type of disability. For instance, acceptance for people with disability caused by diabetes or arthritis was much higher than for people with mental retardation or psychiatric illness (Westbrook, Legge, & Pennay, 1993). This marginalization extends to exclusion from meaningful opportunities to transform policy directions which impact on their lives (Kleintjes et al., 2013). Our findings contrast with other studies which reported there was little or no stigma associated with disability, however disabled individuals and their families identified a range of outstanding needs including need for better rehabilitation, provision of mobility aids and social support for caregivers (Byford et al., 2003).

In many cultures disability is seen as a form of punishment by God or spirits for sin, violation of taboos or social obligations. In this view, it is understandable that support for the individual with disability might be half-hearted or lacking (Monk & Wee, 2008). Other study implies that cultural beliefs are a hindrance to developing better care for persons with disabilities (Van Amstel et al., 1993).

Recently there has been growing interest in understanding disability in a socio-cultural context. The knowledge of traditional beliefs and practices towards disability are of vital importance when we plan to construct and implement culturally relevant services (Capstick et al., 2009; Mallory et al., 1993; Samu & Suaalii-Sauni, 2009). Incorporating cultural beliefs into health programs for individuals with disability is necessary if these programs were going to make a real difference in their lives (Mallory et al., 1993; Samu & Suaalii-Sauni, 2009).

In addition, it was found that perceptions about causes of disability formed attitudes towards disability and facilitated the integration between the people with disability and the community (Monk & Wee, 2008). In the same vein, Groce (1999) postulated that deeper comprehension of traditional system of beliefs about disability is fundamental to our understanding of how to approach the health care system and how to foster productive change, e.g. reduction of stigmatization of the disabled.

Limitations of the study

There were several limitations in our study. Non-probability sampling with likely sampling bias, a relatively small sample size and rural locations in only two provinces together with the rich cultural diversity in PNG indicate that our results cannot be fully extrapolated to the whole rural population. Finally, the

study was not designed explore the depth of cultural believes related to disability which would require a longer exposure to a particular ethnic group and building trust between the researcher and participants.

Conclusion and recommendations

Recently there is an increasing awareness of the importance of understanding of traditional belief models and attitudes towards disability and the significance of this understanding on the construction of culturally sensitive and thus effective health policies. This study contributes to comprehension of the common belief model in Melanesian society connected with disability which is essential in planning and implementing rehabilitation services for people with disability. We must find effective and efficient ways to bridge the communication gap between medical and traditional perception of disabilities and culturally held beliefs of the supernatural causes of disabilities. Providing a detailed explanation to the cause to disability as well as combining traditional and spiritual approach with physiotherapy and Western medicine could be the best way to fulfill the health expectations of disabled people in Melanesian society. We concur that understanding Melanesian concepts and beliefs about disability are fundamental to the way we approach the health care system in order to foster productive change. A health care system that is congruent with concepts of illness, illness causation and treatment preferences may be better utilized and thus eventually leads to better health for Papua New Guineans.

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