Perspectives of community health workers and women's leaders regarding people with disabilities and their recognition of their roles and functions in rural Kenya

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Introduction

Health and quality of life (QOL) of people with disabilities (PWD) were recognized as important matters of global concern by the World Health Organization (WHO) and the World Bank in 2011 [1] and the United Nations Children's Fund (UNICEF) in 2013 [2]. The Global Burden of Disease 2004 estimated that 15.3% of the world's population, i.e., about 978 million people, have moderate or severe disability [3]. Within this population, around 93 million are children 14 years old or younger, i.e., approximately 1 in 20 children have a disability. Children with disabilities are often poorly accepted and placed at a disadvantage in the community regardless of resource-rich and poor settings. In addition, children with disabilities are more likely to be victims of abuse and violence [4]. In the UNICEF Multi Indicator Cluster Survey (MICS) 2005-2006, a median of 23% of children aged 2-9 years old were screened as positive for disability using the Ten Questions screen in 18 countries [5]. MICS also demonstrated associations between disability and not having been breastfed, not receiving vitamin A supplementation, stunting and/or underweight, and attending school [5]. However, previous studies regarding childhood disability did not appropriately represent not only identification, but also intervention, service utilization, and legislation from low- and middle-income countries [5-7]. In addition, previous studies used various methodologies to identify PWD, including household surveys, rapid rural appraisal (RPA), key informant interviews, and others in rural communities [8,9].

PWD and their families have extra expenditure for health care services, transportation, assistance devices, personal assistance, etc., regardless of whether they live in resource-rich or -poor settings [10]. Low household socioeconomic status (SES) and households with PWD may be both cause and consequence in low- and middle-income countries [11]. PWD are often discriminated against and socially excluded, e.g., less access to school and health care services, and more vulnerable to abuse and harassment in their community and society [1, 2].

Community-based rehabilitation (CBR) provided by non-healthcare professionals, including family, neighbors, community health workers (CHWs), and others, is an effective strategy in resource-poor settings, which was recommended and implemented in the 1970s by the WHO [12,13]. However, there is limited evidence regarding the effectiveness of non-specialist health worker intervention for care of PWD, especially in low- and middle-income countries, although their roles may be key factors to fill the disparity between the needs of disabled people and care provision in resource-limited settings [13]. A study from South Africa demonstrated a positive impact of CBR by community rehabilitation facilitators (CRF), although there was poor recognition of the scope of CRFs' performance and complex interactions [14]. Community-based care

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addressing comprehensive components of support by CHW was also effective for people living with schizophrenia and their families in India [15,16]. In Zimbabwe, community-based mental health care as part of routine primary health care provided by CHW showed positive effects for people with depression and mental disorders [17]. On the other hand, CBR approaches were suggested to address the whole family of PWD, not only focusing on services for the individual with a disability, e.g., supporting opportunities for fathers' involvement and respite care for female caregivers, because the burden of caregiving principally falls on the mother in Uganda [18].

The WHO defines universal health coverage (UHC) as follows: "the goal of universal health coverage is to ensure that all people obtain the health services they need without suffering financial hardship when paying for them" [19]. This concept of UHC encompasses not only financing coverage but also equity of health service coverage based on the concept of Health for All and Primary Health Care (PHC) by the Alma-Ata declaration. Therefore, UHC also incorporates PWD as a target population. The world's population is aging rapidly, not only in high-income countries, but also in less developed countries, including sub-Saharan Africa [20]. Therefore, the roles and functions of CHWs and community participation may be reconsidered as a community resource to guarantee health of the whole population, including those at a disadvantage [21,22].

A study conducted in rural Kenya reported a prevalence rate of moderate or severe neurological disability of 61 in 1000 [23]. There were commonly identified physical health problems among caregivers of children with physical disabilities [24]. On the other hand, caregivers of children with physical disabilities attempted to adjust to their children's conditions and sought internal and external support, including spiritual and emotional support, in rural Kenya [25]. In addition, recommendations were made for culturally acceptable approaches to PWD, which were adopted by women's groups [26].

This report summarizes the perspectives of CHWs and women's leaders with regard to PWD and their recognition of the roles and functions of CHWs and women's leaders in rural Kenya through interviews conducted in 2012 as part of a feasibility study of collaboration between the School of Health Sciences and School of Engineering, Nagasaki University, to contribute to improving the QOL of people within the community in resource-poor settings.

Methods

Eight CHWs from Mbita district and six women's leaders from Saro district were invited to participate in two interviews in February 2012. In addition, community leaders from both areas were also invited to participate in a series of in-depth interviews. The interviews were conducted using a structured interview, which was prepared in English and Luo, the common local language in the study area. Interview guides were prepared for CHWs, women's leaders, and community leaders. Before commencement of the interviews, a stakeholder meeting was held and the local communities were informed about the interviews through the district health officers. Verbal explanations regarding interview participation, including ethical considerations, were provided to the interviewees at each interview.

Results

Table 1 shows sociodemographic characteristics of interviewees, who are CHWs and women's leaders. Table 2 shows the results from CHWs and women's leaders with regard to perspectives of disability and/or PWD. Interviewees recognized not only physical handicaps, including deafness and blindness, but also mental handicaps and inabilities due to age in the community as disabilities. In addition, interviewees mentioned orphans due to AIDS and stigma as social problems. They also reported a relationship between disability and/or PWD and poverty.

The roles/functions of CHWs and women's leaders are shown in Table 3. Both CHWs and women's leaders mentioned supporting and fulfilling basic needs for livelihood of people in the community as their roles and functions. Although they did not express much regarding disability and PWD, they recognized visiting households and caring for sick people and orphans as important activities.

Women's leaders reported that looking for food and cooking, fetching water for bathing, farming, and bathing children were socially accepted gender roles for women in the family and the community. They also reported that mothers have a tender heart, women have the feeling of being a mother, and women have blessings from god that provide advantages for caring for disabled people.

One of the community leaders suggested that "disability" and "inability" are different, because the former represents a lack of function that is originally present, while "inability" is not fully demonstrating

one's capacity despite having the capability of doing so. He also mentioned that the provision of substantial support, including food, clothing, health care services, and education, were necessary for disabled people, and encouragement and empowerment for unable people were important. In addition, a representative of PWD in the community reported feeling that PWD were a forgotten class within society, and he appreciated focusing on PWD in the interviews.

Table1. Sociodemographic information of interviewees

	Role	Sex	Age	Marital status	Religion	Education	Occupation
1	CHW	F	38	Married-polygamous	Christian-not Catholic	Secondary not completed	Farmer
2	CHW	F	25	Married-polygamous	Christian-not Catholic	Secondary not completed	Farmer
3	CHW	F	38	Divorced/separated/widowed	Christian-not Catholic	Secondary not completed	Self-employed
4	CHW	F	31	Married-monogamous	Christian-not Catholic	Secondary not completed	Self-employed (Hair Salon)
5	CHW	F	26	Married-monogamous	Christian-not Catholic	Secondary not completed	Farmer, Housewife
6	CHW	M	41	Married-monogamous	Christian-not Catholic	Secondary completed	Farmer
7	CHW	M	43	Married-monogamous	Christian-not Catholic	Secondary completed	Bike taxi driver, Farmer
8	CHW	F	38	Married-polygamous	Christian-not Catholic	Secondary completed	Farmer, Grocery business
9	WL	F	35	Married-polygamous	Christian-not Catholic	Primary not completed	Farmer
10	WL	F	63	Married-polygamous	Christian-not Catholic	Primary not completed	Farmer business
11	WL	F	59	Married-polygamous	Christian-not Catholic	Primary completed	Farmer selling firewood
12	WL	F	40	Married-polygamous	Christian-not Catholic	Primary not completed	Business
13	WL	F	42	Married-polygamous	Christian-not Catholic	Primary completed	Business
14	WL	F	62	Married-polygamous	Christian-not Catholic	Primary not completed	Business making ballast

CHW: community health worker, WL: women's leader
M: Male, F: Female

Table2. Perspectives of people with disabilities

What do you think about "disability" and/or disabled people?	
CHW	・Disease that affects the limbs, hands, and sight making people unable to fend for their families. ・Relying on others for help. ・Mental impairment on capacity to judge. ・Incapacity to reach where others can reach or where others are.
Women's leader	・Disability is a problem as one is not functioning normally. ・Disability is a disease. ・Incomplete body tissues or malfunctioning of some organs, e.g., blindness, lack of both or limping, inability to speak, mental disability, deafness. ・Incapacitation of physical or mental type that hinders a person from fending for their family. ・Impairment. ・People with no clear mind.
Are you aware of any disabled people in your community? If yes, do you know what kind of disability they have?	
CHW	・Inability to talk. ・People who cannot walk or move. ・People who walk with one limb supported by a walking stick. ・Walks with the support of crutches. ・People who are mentally affected. ・Deaf. ・"Short hand people" (an expression made by an interviewee referring to people missing part or all of an arm/hand due to accident, disease, or congenital anomalies). ・People who are blind and have tremors of the hands.
Women's leader	・Those who are unable to walk, stand, lame, blind, and unable to speak. ・Being too old and unable to do normal duties due to complications. ・A child born and unable to walk. ・Abnormal discharge of saliva from the mouth or mental problems. ・Disability due to accidents, such as limb amputation. ・Diseases, such as polio, cause disability. ・Severe arthritis causes disability in the elderly. ・Down's syndrome. ・Harelip and cleft palate.

Are you aware of any disabled and/or elderly people with problems/difficulties in their life? If yes, do you know what kind of problem/difficulties they have?	
Women's leader	・Developing depression. ・Elderly people take care of their family, especially orphans, including HIV/AIDS orphans. Orphans who are cared for by elder people have a high likelihood of dropping out of school, because of not only poverty but also elderly people have health and livelihood problems. ・Severe arthritis making elderly people unable to walk and backache problems. ・Loss of sight due to old age. ・Lack of adequate food in old age. ・Dropping out of school among disabled persons due to poor performance. ・Community stigma toward people living with disability, perception of curse, punishment, witchcraft, etc. ・Inability to perform tasks due to effects of disability leading to dependency on others. ・High rate of poverty among disabled households leads to financial problems. ・Families do not bring disabled child/person out in public.
What kind of help/support is necessary for disabled people and their families mentioned in the above question?	
Women's leader	・Provision of food and clothing for the elderly. ・Formation of support organizations for disabled and elderly persons in the community. ・Medical care and attention for the elderly and disabled persons in the community. ・Special education for disabled children. ・Counseling services offered to the disabled persons and their family members. ・Sustainable livelihood programs (income generating activities) for disabled persons to be initiated in the community. ・Community sensitization through education on disability among persons in the community. ・Government census of all persons with disability and provision of food relief support to them and their household members ・Establishing a center for disabled persons in the community consisting of a school, health facility, and other care for the disabled.
If there is a disabled child in a family, does he/she usually go to school?	
Women's leader	・The majority of disabled children do not go to school because it is a burden for their parents. ・There is a notion that disabled children will perform poorly in school, so most stay at home. ・Some children fear interacting freely with others who are not disabled. ・Some disabled children are hidden from the public because of their disability and are not able to access education. ・Some go to school but they are enrolled late in education and they are sometimes late due their disability. ・Lack of availability of special schools to cater to their needs within the local area.
Who usually makes decisions regarding schooling of children, including disabled children, in a family?	
Women's leader	・It is the mother because they are the ones who take care of children most of the time, but mother's decision making is reversed by father's decision if he has the reverse opinion. ・Mothers usually make decisions but lack financial support for education of their children. ・Fathers are always the decision makers because of their financial influence as the sole family breadwinners. ・Both mothers and fathers decide.
What kind of role/function can you take to help/support disabled people and their family as women's leader?	
Women's leader	・Formation of groups and other organizations to help disabled persons with income generating activities to promote their lives. ・Provide counseling to disabled persons in the community. ・Involve disabled persons in development matters in the community. ・Referral of disabled persons for medical attention. ・Government to provide direct support to disabled persons in the community. ・Initiating special institutions to address the needs of disabled persons in society.

Table3. Recognition of the roles/functions of community health workers

What kind of people become CHW?	
CHW	・CHW must be trusted and respected members in the community. ・CHW should be members of the community with no criminal record. ・CHW should be residents in that given community. ・CHW should be role models in the community. ・CHW must be literate. ・CHW should be organized members of the community（married in that community）. ・CHW should know how to communicate well with community members. ・CHW must be capable to initiate health changes through innovations.
What do you think are the roles/functions of community health workers or women's leaders?	
CHW	・Link the community and the health facility. ・Conduct monthly household visits. ・Collect data from households for submission to the community health extension worker（leader of CHW）monthly. ・Deliver Kenya Essential Package for Health（KEPH）to the community. ・Health education on awareness and taking action to improve health matters in the community. ・Help the community to know health and sanitation as a basic right. ・Refer community members to the health facility. ・Trace immunization and TB defaulters in the community.
Women's leader	・Caring for orphans through groups by initiating economic activities, such as goat rearing（fund raising）. ・Giving advice to community members on good health through advocacy. ・Information dissemination to the community on new developments. ・Promoting health in the community. ・Home visits for sick people in the community and providing them with food and spiritual needs through prayers. ・Supporting the less privileged in the community. ・Participation in community meetings with several stakeholders（standpoint/position）for empowerment of women in the community. ・Counseling women in the community. ・Support and counseling mothers who are HIV-positive. ・Peace promotion through conflict resolution. ・Offering spiritual support through prayers.
What is the principal health problem in your community?	
CHW	・Malaria. ・Diarrheal diseases. ・Coughs among children and adults. ・Lack of safe drinking water（during drought）. Water should be taken from far away water sources. Contaminated water causes diarrhea. ・Cases of disability. ・Illiteracy about health（poor health seeking behavior）.
What kind of challenges and/or difficulties regarding child rearing are you aware of in your community?	
Women's leader	・Lack of food and clothing. ・Responsibility for child rearing is mainly left to women. ・Lack of special schools to cater for the needs of both physically and mentally challenged children in the community. ・Lack of financial support for children to access basic education.
What occasion/situation do you feel satisfaction with your work as a CHW?	
CHW	・When community members ask for my assistance to help refer pregnant mothers to the health facility for antenatal care（ANC）or delivery. ・When health personnel at the health facilities and community members recognize my work as a CHW. ・When mothers complete ANC visits and take their children to complete immunization schedules. ・When the community refers to me as a doctor even when I am not trained or qualified as health personnel. ・When I am motivated after meetings.
What occasion/situation do you feel challenged as a CHW?	
CHW	・Visiting households and members do not appreciate and cooperate to make my work easier. ・Community high expectation on drug kit distribution or supply. They want me to provide them with drugs at home. ・Distance between households when collecting data.
Have you ever experienced refusal of your help/support by people in the community? If so, could you elaborate on the occasion?	
CHW	・In the case of adverse effects following immunization, the community members blame that on CHWs. ・Strong religious beliefs where some church members refuse to be referred to the health facility because of their religion. ・Myths and misconceptions from community members that taking your child to the health facility for immunization will cause death.

Future perspectives

The promotion of social inclusion of PWD is needed, from policy making to grass roots and community-based activities. The millennium development goals, which will be evaluated in 2015, included the establishment of sustainable development goals (SDGs) in a global society. SDGs focus not only on health issues, but also on comprehensive social and economic development, peace keeping, and sustainable protection of the environment. Based on the concept of SDGs targeting the most vulnerable people in society, including PWD, UHC and reconsideration of PHC will be promoted at both global and local levels regardless of the resource-rich or -poor nature of the settings. There have been insufficient reports regarding the situation of PWD in resource-poor settings, such as rural Kenya, to establish a support system. Discussions with people from rural communities in Kenya indicated that not only special care and education for PWD, but also general social and economic support, including mitigation of stigma and discrimination, as well as substantial support, such as food and clothing, may improve the QOL of PWD and their families.

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