OPEN ACCESS Freely available online

ISSN 2737-5315
Volume 5, Issue 1
https://eiet.iikii.com.sg/
Educational Innovations and Emerging Technologies

Article

Deafblindness and Coping Strategies Related to Social Connectedness Theory in Ethiopia: The Case of Three Women with Acquired Deafblindness

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Received: Apr 22, 2024; **Revised:** Jun 16, 2024; **Accepted:** Jun 22, 2024; **Published:** Mar 30, 2025

Abstract: Deafblindness is the least understood and the most neglected disability in Ethiopia. Women with disability in developing countries are disadvantaged and neglected even with double jeopardy. The main objective of this study was to investigate women with acquired deafblindness (adult Ethiopian women who are not congenitally deafblind) who have been struggling in Ethiopia, a patriarchal country based on the social connectedness theory their coping strategy (ways of communication and their method of solving problems in their social connectedness). Social connectedness is an ongoing, momentary, and affective experience of belonging based on awareness and appraisals of social relationships and interactions. In this study, three women with acquired deafblindness were selected using snowball and purposive sampling techniques and they were interviewed using a tactile sign language interpreter. The participants are coping with their disability by distancing themselves from the public and staying at home, which causes a lack of two components in social awareness; the sense of being in touch and involvement and sharing. Such a lack is not appropriate for the family and their future. The participants had less or no social connectedness with their neighbors and the community. Young deafblind people need role models to be self-dependent. The government, associations, professionals, and other stakeholders must collaborate to let women with acquired deafblindnessbe integrate into society and benefit from their human rights in the country.

Keywords: Acquired deafblindness, Social connectedness, Social connectedness theory, Coping strategy

1. Introduction

Social connection is the subjective experience of feeling close to and belongingness with others. It improves physical health and mental and emotional well-being. Seppala (2014) showed that a lack of social connection is more detrimental to health than obesity, smoking, and high blood pressure. On the other hand, a strong social connection increases a chance of longevity by 50%, strengthens one`s immune system, and helps to recover from disease faster. People who feel connected to others have lower levels of anxiety and depression. Moreover, they also have higher self-esteem and greater empathy for others being trusting and cooperative. As a consequence, others also tend to trust and cooperate with them. In other words, social connectedness generates positive feedback in terms of social, emotional, and physical well-being. Low levels of social connection are associated with declines in physical and psychological health as well as a likelihood of antisocial behavior that leads to further isolation (Seppala, 2014). Ambady et al. (1995) stated that social connectedness is the measure of how people interact. At an individual level, social connectedness involves the quality and quantity of connections with others in a circle of family, friends, and acquaintances. Beyond these individual-level concepts, relationships with people in other communities are necessary. This connectedness is one of the components of community cohesion and benefits individuals and society.

Social scientists have studied distinct features of social connectedness in terms of relationships. Social isolation refers to the relative absence of social relationships. Social integration refers to the level of involvement with informal and formal social relationships, which are exemplified by a relationship with a spouse and with religious institutions and volunteer organizations, respectively. The quality of relationships is determined by emotional support provided by significant others, conflict, and stress. Social networks offer social relationships surrounding an individual with structural features. Each aspect of social relationships affects health. The effects of the features of relationships on health can be discussed from the perspective of “social relationships” and “social ties” interchangeably (Smith and Christakis 2008).

In Ethiopia, deafblindness has been considered a rare disability. As a result, much attention has never been paid to it. Deafblindness in Ethiopia is thus less understood and more neglected than other disabilities. Deafblindness in the country was researched by the World Deafblindness Congress in Bucharest for a baseline survey on the situation of deafblindness in Ethiopia (Sewalem, et al., 2015). Among 58 participants, 25.86% had congenital deafblindness, 3.45% had unknown onset, 70.69 % had acquired deafblindness and 48.28% of them were females. Most participants had acquired deafblindness after being born. Women with disability in developing countries are disadvantaged and neglected (Sewalem, 2012).

In this study, three women with acquired deafblindness (adult Ethiopian women who are not congenitally deafblind) in Ethiopia have been researched to understand their loneliness, coping strategies in their community, social connectedness, and their suggestions. The results serve as a reference for the authorities to be aware of the situation of deafblind women and support women with deafblindness to develop their social connectedness which was neglected. The results of this study also provide a basis for further studies on women with acquired deafblindness.

2. Methodology

The number of people with deafblindness in Ethiopia has not yet been known. Therefore, we selected three women from 58 participants in the study of Sewalem et al. (2015).To select them, the snowball sampling method was used for chain referral or respondent-driven sampling. Berg (2007) argued that snowballing is the best way to locate subjects with certain attributes or characteristics. He further stated that snowball samples are useful in studying deviance, sensitive topics, or difficult-to-reach populations. The basic strategy of snowballing sampling involves identifying people with relevant characteristics and interviewing them. Participants are then asked to recommend others who possess the same attributes as theirs. The Ethiopian National Association of Deafblindness (ENADB) recommended the first participant who recommended the other two participants. To interview the participants, a tactile sign language interpreter and human assistants were used for data collection. For ethical reasons, all the participants were asked for informed consent. Qualitative data analysis was employed to thematize and analyze the obtained interview data.

3. Results and Discussion

3.1. Background of Participants

Three participants were coded as M1, K1, and R1. K1 and R1 lost their sense of vision before their sense of hearing. The onset of sensory impairment occurred at the age of 6, 32, and 9 years old for hearing and 20, 32, and 4.5 years old for vision for M1, K1, and R1 (Table 1). For M1 and R1, mobility limitations were a factor affecting their social ties. Hughes and Waite (2009), Zhang and Hayward (2006), and Umberson and Karas (2011) stated that marriage is important in the social ties of the disabled, and marital history shapes health outcomes, including cardiovascular disease, chronic conditions, mobility limitations, self-rated health, and depressive symptoms.

Table 1. Background of Participants

Participants	Age	Onset		Marital status
		Deafness	Blindness	
Case M1	34	6years old	20 years old	Not married
Case K1	51	6 months after blindness	32 years old	Married before onset (3 children and 3 grandchildren)
Case R1	55	9 years	4.5 years old	Not married

The participants were asked if they had felt lonely and had social connectedness. The results are summarized in Table 2.K1 felt that she was the only woman in Ethiopia with such a problem until she saw others with similar problems. She felt that 늦 was detached and had less social connectedness.

Table 2. Social Connectedness of Participants.

Participants	Responses			
	loneliness	Little social connected-ness	No social connectedness	Better social connectedness
Case M1	v		v	
Case K1		v		
Case R1				v

Many study results show an increase in loneliness for people. Despite its importance for health and survival, social connectedness has declined at an alarming rate. The modal number of close others (i.e., people with whom one feels comfortable sharing a personal problem) in the USA in 1985 was only three. In 2004, it decreased to zero, and 25% of Americans felt that they had no one to confide in. The decline in social connectedness explains reported increases in loneliness, isolation, and alienation which are leading reasons for psychological counseling. People with less social connection are vulnerable to anxiety, depression, antisocial behavior, and even suicidal behaviors, which further increase their isolation. Most poignantly, a lack of social connectedness leads to vulnerability to disease and death beyond traditional risk factors such as smoking, blood pressure, and physical activity. Thus, psychologists recommend a green diet and exercise (Sappala, 2014). Social support refers to the emotionally sustaining qualities of relationships (e.g., a sense that one is loved, cared for, and listened to). Studies showed that social support benefits mental and physical health (Cohen, 2004; Unicho, 2004; Umberson & Karaz Montez, 2011). Social support can be obtained when people are connected socially. The participants were less socially connected except one who had the opportunity to participate in meetings and had human assistants.

3.2. Coping Strategy

M1 and K1 reported that they have distanced themselves from the public and stayed at home. This is not good for their family and their future. Regarding a coping strategy, M1 said, "I cope with my problem by distancing myself from the social arena, extended family, and by avoiding my former friends. I even do not have a spouse or a boyfriend. I sometimes try to cope with suicidal attempts especially when I feel very unhappy."

Distancing oneself from the social arena leads to social isolation which can cause mental health problems such as depression. Although M1 had no depression, her suicidal attempt indicated that she might have had it. The relative absence of social relationships led her to social isolation and social integration. There are distinct features of social connection offered by relationships (Smith and Christakis, 2008). Social isolation refers to the relative absence of social relationships. Social integration refers to the level of involvement with informal and formal social relationships such as family and religious institutions and volunteer organizations, respectively.K1 said, "I sometimes cope with my problem by distancing myself from people. I am lucky to get married before my deafblindness. I am lucky to have grandkids too. Thanks to God."The supportive husband of K1 let her have a relatively better social relationship and social integration.

3.3 Impact of Deafblindness on Social Connectedness

Except for R1 who had a better social connection with her employed human assistant, M1 and R1 said that being a woman with acquired deafblindness in a developing country has had an immense impact on social connectedness. They mentioned they lack the courage to go out alone as they could not have any orientation and mobility training for self-movement. M1, K1, and R1 agreed that deafblindness impacts their social connectedness. They face problems with social support, too. Social support refers to the emotionally sustaining qualities of relationships If their deafblindness impacts their social connectedness, it also impacts social support and the quality of their relationship without family support.

3.4Suggestions for Improving Social Connectedness

Participants recommended women with deafblindness to improve social connectedness as shown in Table 3.

Table 3. Perceived Suggestions for improving social connectedness.

Suggestions	Responses
M1	No idea
K1	Not sure but teaching family members tactile sign language benefits both
R1	Step-by-step awareness raising on deafblindness, collaborative work among professionals, the government,and associations of persons with a disability such as ENADB is mandatory. Family members must develop their tactile sign language more as well. They need to take their deafblind family members to all social services including churches, mosques, recreational centers, birthday parties, wedding ceremonies, and other social issues with them. Using adaptive technology, i.e., computer (with Braille reader and converter) training is very important.

R1 had a better exposure as compared to the others and for improving social connectedness, suggested the following:

I think vocational training or handcraft will improve social connectedness and in the meantime can help women with deafblindness make a living. On top of that, she added, family members and friends as well as neighbors including the community

should be able to accept people with deafblindness. Family members should be able to take them shopping, to wedding ceremonies, and to local associations like Idir to improve their social connectedness. I thank the National Association for Deafblindness by saying, that my association is trying its level best in taking out of children with deafblindness to the public who were otherwise locked indoors for a long time which caused them to develop a third disability, mobility problems, as they sit always at home. Women with acquired deafblindness themselves should be empowered through empowerment training, orientation and mobility training and awareness raising on deafblindness to the community are vital in improving the social connectedness of women with acquired deafblindness in the country. Technology is also helping people with disability and if it is imported to our country, she said, we will improve a lot.

4. Conclusions and Recommendations

Social relationships have significant effects on health through behavioral, psychosocial, and physiological pathways. Social relationships also lead to health outcomes throughout life and have a cumulative impact on health over time. However, the costs and benefits of social relationships are not given equally to people. Women with acquired deafblindness had limited social connectedness. To improve their social connectedness, family members need to learn tactile sign language as a means of communication was found to benefit both the family members and women with acquired deafblindness. The participants felt loneliness. However, their coping strategies varied from their experiences and distancing themselves from the public. Social awareness for deafblindness and collaboration with stakeholders for related problems is recommended. In doing so, the involvement of women with acquired deafblindness in social activities will improve their coping and social connectedness. Using Adaptive technology and training also helps them overcome loneliness and improve their social connectedness. The government, associations, professionals, and other stakeholders must collaborate to help women with acquired deafblindness integrate into society and benefit from their human rights.

In this study, only women with deafblindness were involved. For further studies, it is necessary to increase the number of participants and include people with other disabilities.

Funding: This research did not receive any external funding.

Data Availability Statement: The data of this study are available from the corresponding author upon reasonable request.

Acknowledgments: The author would like to acknowledge the participants, their families, and the tactile sign language interpreter. The author would also like to thank the Ethiopian National Association for Deafblindness which was a bridge between the participants and the author. The author would finally like to acknowledge the Educational Innovations and Emerging Technologies Journal team for the constructive comments from the reviewers which made the article to the standard and let it get published to reach the world.

Conflicts of Interest: The author declares no conflict of interest.

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