

Disability and Grief: Lived Experiences of Social Support in Polio Survivors in Punjab, Pakistan

Saheem Nasif

Lecturer, Sociology, Govt. Graduate College for Women
Kahna, Nau, Lahore

Email: saheemnasif@gmail.com

Muhammad Rizwan Safdar

Assistant Professor, Sociology, University of the Punjab, Lahore
Email: drrizwansafdar.iscs@pu.edu.pk

Abstract

This study explores polio survivors' experiences of coping with disability grief, focusing on the role of social support. In this phenomenological study, 20 participants were selected through purposive sampling from the ten divisions of Punjab Province of Pakistan. The process of data collection consisted of in-depth interviews. The obtained data were analyzed by utilizing thematic analysis technique. The results of the data yielded four major themes: 1) Coping mechanism and resilience 2) Struggle with body image 3) Personal growth and emotional fulfillment and 4) Social support in shaping social relationships. The findings indicate the multifaceted nature of social support among polio survivors. These findings contribute to understanding the importance of social support in empowering polio survivors with physical disabilities.

Keywords: polio survivors, disability, social support, coping with grief

Introduction

Disability encompasses a profound and complex process that brings unforeseen situations for individuals, such as acquisition of disability results changes in individuals' self-perception and societal expectations (Lutz & Bowers, 2005). Learning to adapt to unfamiliar changes that are brought by disability is the one of the most stressful events that an individual can undergo in a lifetime. This process may have the potential to disrupt the expected stages of development (Falvo & Holland, 2017). People with disabilities often face discrimination, the same as experienced by racial and minority groups. As a result, they often suffer social marginalization and similar disadvantages (Omansky Gordon & Rosenblum, 2001). It is sadly true that people whose bodies are different from society's established norms, even when these differences do not produce physical or practical difficulty, are still regarded as social disabilities (Wendell, 1996).

The concept of physical disability has evolved over a long period of time and is a physical or mental challenge that lasts for six or more months

and impedes a person's physical functioning (Statistics South Africa, 2014). Any deformity limits body functioning (Ross & Deverille, 2010) and they need coping strategies to manage their disability. Meanwhile, the role of coping is to organize the response of stressful situations to overcome the loss. The purpose of this organized response is to produce satisfactory results for a long period (Folkman & Moskowitz, 2004).

Polio is a viral disease, which affects the motor nerve cells in the spinal cord. According to Global Polio Eradication Initiative, polio remains endemic in two countries Afghanistan and Pakistan (GPEI-Endemic Countries). Illiteracy, conflicts and internal threats in these regions have hampered vaccination efforts and have been directly linked to increased transmission of poliovirus (Steel Fisher et al., 2015). Pakistan faces all these challenges as well as a difficult geography that contributes to poor healthcare services (O'Reilly et al., 2012).

Furthermore, parents' hesitancy to the immunization is a significant reason to transmit polio in Pakistan. They have misconceptions about immunization such as vaccination can harm the child or that they contain products made from monkeys or pigs that are forbidden in Islam (Khan & Sahibzada, 2016).

The eradication of polio in Pakistan is a difficult process; sociocultural factors have made it complicated. It is not that lack of medical resources caused polio in Pakistan. Rather the proliferation of conspiracy theories negatively targeted the working organizations and vaccinators working to eradicate poliovirus (Andrade & Hussain, 2018). This theory claims that the polio eradication programs within Pakistan deliberate plan by America and Israel to sterilize the Muslim population. This theory is traced back to the 1988 World Health Organization campaign, "Kick" Polio out of Africa" (Letore, 1998).

Polio survivors complained of greater deterioration of their physical and psychological condition that also had negatively affected their ability to participate in social activities (Grimby & Jönsson, 1994). Polio, mostly contracted in early childhood, has a definite impact on polio survivors. Polio survivors often have early childhood memories of their differences with other children: necessity to wear orthotic devices or braces, inability to play sports like other kids. If the symptoms were acute, they had to stay at hospital.

These experiences were traumatizing as they had stayed away from their homes for hospitalization. The agony is that growing with the fear of abandonment, anxiety and sometimes-physical abuse were awful daily companions for these children (Yelnik & Laffont, 2010). In such circumstances, social support helps to cope with situational stress, anxiety attacks, and traumas, and reduce morbidity (Ozbay et al., 2007). Social support can be defined as a support accessible to an individual through social connections with other individuals, groups and the community (Jukić et al., 2022).

Recently, public health has focused on the importance of social capital in seeking better healthcare – that is, people with restricted networks have poorer health indicators while higher social support has a positive effect on mental health (Ferlander, 2007).

Research Questions

- 1) How do polio survivors perceive social support in response to their phenomenological experience of grief?
- 2) How does social support contribute to providing meaning to life among polio survivors?
- 3) What role does social support play in the lived experiences of disability and grief?

Literature Review

The grief of disability, particularly when experienced in isolation, can have profound emotional and psychological consequences. Social support from significant others serves as a protective buffer against stress, fulfills individuals' need for connection and helps reinforce their sense of identity (Kim et al., 210). A study was conducted by Li et al. (2021) during the Covid 19 pandemic, and found that social support from family members, friends, partners and colleagues positively affected mental health by reducing stress and depression.

Literature highlights that social support is an important factor in reducing stress and providing meaning to life. For example, in a study of post traumatic growth (PTG) after burns, survival rates were higher among Iranian individuals who received social support. The results of this study showed that PTG would be higher for burn survivors who perceived more social support (Ajoudani et al., 2019).

On the contrary, low social support is associated with a high level of distress. In contrast to low social support, high levels of social support and good mental and physical health are positively associated. The higher level of social support has been shown to be an important factor in reducing the effect of physical impairment (Ozbay et al., 2007).

Social support can increase an individual's resilience to stress, acting as a protective shield against the harmful effects of unfavorable circumstances (Ozbay, 2007). A strong support system is important for an individual's well-being because it directly influences their psychological well-being and mental health (Tindle et al., 2022). Research has shown that people who received social support tend to be healthier and happier. Strong social support helps reduce depression and anxiety among cancer patients by accelerating the coping process (Zamanian et al., 2021).

Methodology

This study used a qualitative research design, specifically based on phenomenology. This approach is appropriate for this study as it allows for an exploration of the individual experiences of polio survivors and how

they make sense of these experiences with social support. The present study was conducted in ten divisions of Punjab province of Pakistan. The population of the study consisted of polio survivors who had experienced social support in their survival journey after getting infected with polio virus. 20 participants were recruited from the ten divisions using pre-defined inclusion and exclusion criteria with purposive sampling.

Inclusion Criteria

- Individuals who have experienced polio
- Participants aged 18 years and above
- Both men and women who have survived polio will be part of this study
- Polio survivors who received social support as a coping strategy

Exclusion Criteria

- Participants who live in other provinces of Pakistan
- Individuals who have not received social support as coping strategy
- Participants who cannot communicate effectively
- People who have other disabilities rather than polio

Data Collection Methods

In-depth interviews were conducted to collect data from the participants using a semi-structured interview guide. During the interviews, some inductive codes emerged which helped to make the research more fruitful. The interviews were conducted in Urdu and were then transcribed in English. Thematic analysis was carried out to analyze the data. Reflexivity was maintained throughout the research to ensure minimal research biases. This study adheres to the ethical guidelines and standards of research. For this purpose, informed consent was obtained from all participants. Participants were not asked to share their personal information that could identify them or put them in any harmful situation.

Results

Four major themes emerged during data analysis: 1) Coping mechanism and resilience 2) Struggle with body image 3) Personal growth and emotional fulfillment and 4) Social support in shaping social relationships.

Coping mechanism and resilience

Many of the participants discussed that social support helped them to cope with grief of disability and accepting the disability. It was observed that social support increased resilience against grief.

As one of the participants narrated:

“Just as it is very important to have social support for normal people, in the same way social support is important for us - disabled people. Positive attitude and words from other made me want to move forward in my life.”

Another participant mentioned:

“As I had been living with polio since my childhood, my grandmother’s stories of hope never made me realize that I would not be able to walk. However, I am always grateful that her positive behavior instilled a sense of gratefulness in me. Therefore, I always remained motivated and maintain positive outlook to face the challenges of my disability.”

This shows how social support foster resilience and serves as a coping mechanism. Some participants narrated that they accept their disability that their body has limited functions. It was interesting to find that most of the participants were not living in denial because of social support.

A participant stated:

“Social support plays an important role in my life. Due to my disability, it is not possible to survive without it. If I don’t have the social support of my family and friends, I can neither see the outside world nor see life behind the walls of my home.”

This reflects that polio survivors are aware of their disability and the restrictions that come with it.

Struggle with body image

During interviews, it was reflected that many participants struggle with low self-esteem and body image due to societal perceptions due to disability. Many participants discussed how social support helped them cope with and deal with negative perceptions of body. One respondent stated:

“My grandmother used to tell me that disability cannot limit my inner beauty. What matters most is how I see myself and how I feel about myself. We all have disabilities, some visible and some hidden.”

The data showed that social support helped many participants on their journey to body positivity. Social support serves as an invaluable asset to polio survivors.

Such as a participant stated:

“People around me especially my friends and family have been supportive. They help me to understand that I should focus on my abilities rather than limitations.”

Some respondents said that social support and positive reinforcement from friends and family made them more confident. It was said that confidence helped them internalize their self-worth and ability to overcome their limitations. As one respondent stated:

“When I joined my college, my friends never made me realize that I am a disabled person. They always made efforts to include me in their activities. I love painting. They always focused on my painting skills rather than wheelchair. The positive responses from them encourage me to embrace myself.”

Similarly, another respondent stated:

“My wife always reassures me that my body is perfect just the way

it is. She always validates my efforts and small milestones. Her support and pride make me feel strong and positive about my body.”

These responses demonstrate the profound impact of social support on the body image of polio survivors. This indicates that positive social support and an inclusive environment helped respondents develop a positive body image.

Personal growth and emotional fulfillment

An overwhelming majority of respondents highlighted the importance of social support. They discussed their career and personal achievements made possible by supportive friends and family.

One participant stated:

“My family helped me pursue my dreams with my mobility issues. They never stopped me dreaming. They always helped dream and make them come true. Their support helped me advance my career and I am an activist today. I contribute to facilitate many polio survivors and disabled people.”

Social support helped many respondents to be inclusive and contributed to finding life purpose. It was discussed that instead of isolating themselves they participated in social activities with the help of social support.

One of the participants stated:

“The support of my teachers and family helped me discover myself. When I was in university, my teachers helped me to participate in extracurricular activities. They have always been encouraging.

That is why I am working in government organization and handling matters with confidence.”

Another participant stated:

“I was worried about my disability, but my support system helped me to cope. My family and friends are educated people. They are aware of the susceptibility of polio and its effects. They always create an inclusive environment for me. They helped me become a teacher and made me realize that my disability does not define me.”

Social support encouraged participants to pursue their dreams and goals. It helped them find purpose in life and empowered them to overcome challenges of their physical disability.

Social support in shaping social relationships

During the interviews, participants discussed how social support helped them in the formation of social relationships. Polio survivors explained that their disability helps them to connect with people. One participant said:

“Joining online polio survivors’ community helped me to understand how our experiences are different. I feel less isolated and more confident while sharing my experience and struggle.”

One of the most important findings highlighted by polio survivors was that social support helps them to boost their confidence which helps

them to build social relationships. This formation of social relationship allowed them to connect with others. One participant stated:

“The role of social support was mixed. I have social support from my family and friends. My siblings help me with mobility and daily activities. However, school is tough because of bullying. I also have some friends who make my school life better with understanding and support.”

Along with this, some participants mentioned that sometimes they felt isolated in gatherings when could not participate in activities. At that time social interaction became difficult because they were not accessible.

One participant stated:

“Because of polio, I faced obstacles in social interaction but mostly I felt isolated whenever I went to a function like a party or a wedding. Because of my disability, I cannot move much the way a normal person does. My family helped me in socialization, particularly my mother’s encouragement was crucial. However, the support I expect from my community is not encouraging.”

Another participant stated:

“My lived experience of polio has been a roller coaster of emotions. At times, I have seen social support as a blessing to cope with grief but sometimes I have felt like a curse to my family. The role of my mother has been supportive, and then followed by my father and siblings. However, over time I realized it was important to maintain my inner chaos is. Now I have many friends from my online community as well as from my neighborhood.”

The role of social support in shaping social relationships is mixed. However, social support is crucial to foster social connections and aids in coping with their challenges of disability.

Discussion

According to the present study, it was revealed that social support played an important role in the grief management of polio survivors. Social support was defined as a strategy to cope with the grief of disability with emotional, physical and instrumental support. It helped polio survivors to accept their disability instead of denying it. Social support made polio survivors do things with ease and were not felt excluded most of the time. However, their mobility problem sometimes made them feel isolated from others, but the help and support of family and friends mitigated the negative effects.

The role of online social support is also noteworthy, validation from others who understand challenges living with polio. In the findings, some participants discussed online community helped reduce their sense of isolation as they shared their lived experiences of polio and validate each other. Furthermore, online support is accessible and available anytime from online forums and communities that make it easy for polio survivors to communicate.

The findings of this study showed that social support helps polio survivors in building social relationships. Polio survivors who felt low self-esteem because of their disability reported that positive attitudes and support from others helped them rebuild social relationships. The role of parents, grandmother, friends and teachers has been important in helping to make social relationships. However, some polio survivors were bullied by their peers or school.

Despite disability, social support helped polio survivors to find their purpose in life. According to Frankl (1984) finding meaning in life is a fundamental need of humans. Social support and relationships play an important role in finding the meaning of life, especially in difficult times.

Conclusion

This study observed that social support plays an important role in empowering polio survivors as well as reducing the grieving process. It helps them to get motivated to move forward in life. Based on the findings of this study, it is concluded that the social support and positive environment of polio survivors makes them productive and helps them cope with the grief of disability. This study also concluded that social support from not only family but also peers, friends, relatives and neighbors help build social relationships and find meaning in life.

References

- Ajoudani, F., Jafarizadeh, H., & Kazamzadeh, J. (2019). Social support and posttraumatic growth in Iranian burn survivors: The mediating role of spirituality. *Burns*, 45(3), 732-740.
- Andrade, G. E., & Hussain, A. (2018). Polio in Pakistan: Political, sociological, and epidemiological factors. *Cureus*, 10(10), e3502.
- Falvo, D. R., & Holland, B. (2017). *Medical and psychosocial aspects of chronic illness and disability*. Jones & Bartlett Learning.
- Ferlander, S. (2007). The importance of different forms of social capital for health. *Acta Sociologica*, 50(2), 115-128.
- Folkman, S., & Moskowitz, J. T. (2004). Coping: Pitfalls and promise. *Annual Review of Psychology*, 55(1), 745-774.
<https://doi.org/10.1146/annurev.psych.55.090902.141456>
- Frankl, V. E. (1984). *Man's search for meaning*. Washington Square Press.
- Grimby, G., & Jönsson, A.-L. T. (1994). Disability in poliomyelitis sequelae. *Physical Therapy*, 74(5), 415-424. <https://doi.org/10.1093/ptj/74.5.415>
- Heriot, C. S. (1992). Spirituality and aging. *Holistic Nursing Practice*, 7(1), 22-31.
- Horstmann, D. M. (1982). Control of poliomyelitis: A continuing paradox. *The Journal of Infectious Diseases*, 146(4), 540-551.
- Jukić, M., Talapko, J., Škrlec, I., Čičak, P., Jukić, M., Lukinac, J., & Požgain, I. (2022). A cross-sectional study of psychiatric comorbidity in Croatian homeland war veterans who were held as prisoners of war and are affected. *Psychiatria Danubina*, 34(3), 464-474. <https://doi.org/10.24869/psyd.2022.464>
- Khan, T. M., & Sahibzada, M. U. (2016). Challenges to health workers and their opinions about parents' refusal of oral polio vaccination in the Khyber Pakhtoon Khawa

- (KPK) province, Pakistan. Vaccine, 34(18), 2074–2081. <https://doi.org/10.1016/j.vaccine.2016.03.008>
- Kim, J., Jeong Yeob Han, Shaw, B., McTavish, F., & Gustafson, D. (2010). The Roles of Social Support and Coping Strategies in Predicting Breast Cancer Patients' Emotional Well-being. *Journal of Health Psychology*, 15(4), 543–552. <https://doi.org/10.1177/1359105309355338>
- Letore, D. (1998). Campaign to kick polio out of Africa. *African Recovery*, 12(3), 18-19.
- Li, P. (2021, August 07). Resilience Theory in Psychology (Definition & Characteristics). Retrieved from Parenting for Brain: <https://www.parentingforbrain.com/resilience-theory/>
- Lutz, B. J., & Bowers, B. J. (2005). Disability in Everyday Life. *Qualitative Health Research*, 15(8), 1037–1054. <https://doi.org/10.1177/1049732305278631>
- O'Reilly, K. M., Durr, E., ul Islam, O., Quddus, A., Abid, N., Mir, T. P., Tangermann, R. H., Aylward, R. B., & Grassly, N. C. (2012). The effect of mass immunisation campaigns and new oral poliovirus vaccines on the incidence of poliomyelitis in Pakistan and Afghanistan, 2001–11: A retrospective analysis. *The Lancet*, 380(9840), 491–498. [https://doi.org/10.1016/s0140-6736\(12\)60648-5](https://doi.org/10.1016/s0140-6736(12)60648-5)
- Omansky Gordon, B., & Rosenblum, K. E. (2001). Bringing disability into the sociological frame: A comparison of disability with race, sex, and sexual orientation statuses. *Disability & Society*, 16(1), 5–19.
- Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: From neurobiology to clinical practice. *Psychiatry (Edgmont (Pa.: Township))*, 4(5), 35–40.
- Statistics South Africa. (2014). Census 2011: Profile of persons with disabilities in South Africa (Report No. 03-01-59). Pretoria, South Africa: Statistics South Africa. Retrieved from <http://www.statssa.gov.za/publications/Report-03-01-59/Report-03-01-592014.pdf>
- SteelFisher, G. K., Blendon, R. J., Guirguis, S., Brulé, A., Lasala-Blanco, N., Coleman, M., Petit, V., Ahmed, M., Mataruse, N., Corkum, M., Nisar, M., Ben-Porath, E. N., Gigli, S., & Sahm, C. (2015). Threats to polio eradication in high-conflict areas in Pakistan and Nigeria: A polling study of caregivers of children younger than 5 years. *The Lancet Infectious Diseases*, 15(10), 1183–1192. [https://doi.org/10.1016/S1473-3099\(15\)00178-4](https://doi.org/10.1016/S1473-3099(15)00178-4)
- Tindle, R., Hemi, A., & Moustafa, A. A. (2022). Social support, psychological flexibility and coping mediate the association between COVID-19 related stress exposure and psychological distress. *Scientific Reports*, 12(1), 8688.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. Routledge.
- Yelnik, A., & Laffont, I. (2010). The psychological aspects of polio survivors through their life experience. *Annals of Physical and Rehabilitation Medicine*, 53(1), 60–67. <https://doi.org/10.1016/j.rehab.2009.11.006>
- Zamanian, H., Amini-Tehrani, M., Jalali, Z., Daryaafzoon, M., Ala, S., Tabrizian, S., & Foroozanfar, S. (2021). Perceived social support, coping strategies, anxiety and depression among women with breast cancer: Evaluation of a mediation model. *European Journal of Oncology Nursing*, 50, 101892.