

Participatory action research with adolescents with disabilities in Nepal (PARDAN) to understand their experience of COVID-19

Introduction

Adolescents with disabilities in low- and middle-income countries have been particularly vulnerable to the effects of

COVID-19¹. Despite this, there has been limited research to understand their experience of the pandemic².



Objectives

- To explore how adolescents with disabilities have experienced the pandemic in rural hilly areas of Nepal using participatory, inclusive research methods.
- To inform an inclusive pandemic response and provide an exemplar of how to conduct research with adolescents with disabilities in low-income settings.

Participants

- Twelve adolescents with moderate to severe disabilities (five girls, seven boys) between the ages of 11 and 17 years old. Seven had physical impairments (three had multiple impairments), two had visual impairments, three had speaking impairments, two had hearing impairments.
- Eleven caregivers (ten mothers, one grandmother)

Methods

In September 2021 we conducted qualitative interviews with adolescents with disabilities and with caregivers about their experience of the pandemic in Udaypur and Myagdi.

We used interactive tools to help the discussion: pictures, a family of dolls,

illustrated story sequences, an emotions chart (where children could put a thumb print to indicate an emotion), a large soft dice with buttons to indicate numbers, numbered pencils, and coloured pencils and paper.

Results

Fear and experience of debt and poverty

Despite most participants having access to social protection (government allowances), many families struggled financially. This caused stress and worry in the household. An

adolescent with a hearing-impairment said: “There is a huge debt that needs to be paid at the shop. I am fearful about how we will pay it back.”

Fear and experience of death and illness

Most participants, their families and/or close relatives and neighbours had been ill with COVID-19, and some had experience of death. A physically impaired adolescent said: “I thought we would all die.” Adolescents who went to school had received some information from their teachers about COVID-19, but most relied on information from caregivers.

Caregivers were particularly stressed about illness and death – if they relied on one earner, they worried what would happen if that person became ill. They worried about

who would take care of them if they became ill, and who would take care of their child with a disability if they died or were seriously ill. They often felt that their child was more vulnerable to COVID-19, and worried about transporting and staying in hospital facilities that were not adapted to the needs of their child. Lockdown restrictions and fear of discrimination and COVID-19 infection meant that some could not exercise and had limited access to essential support such as diapers.



Social isolation and stigma

Some adolescents and their families had experienced COVID-19 related stigma and discrimination. A physically impaired adolescent girl said: “I felt very bad. They treated me like I had corona. They didn't let me sit on the bench and in the vehicle.” Some

caregivers and adolescents felt isolated and unsupported. One adolescent with a physical impairment said: “No-one helped. They would run away instead, saying that we were ill.”



School and social life

Most adolescents felt bored and confined during lockdown and they missed their friends. Those in extended families and with access to internet had a better experience of the pandemic. Adolescents with hearing impairments felt particularly isolated as family and friends around their homes did not use sign language. Few adolescents accessed

online learning, and they missed learning, social contact and independence. One girl with visual impairment said: “I cannot play with my friends because school is closed. I cannot read and write. I feel bored staying here. I long for when I can go to school and feel free.”

Conclusion

COVID-19 and related control measures have exacerbated existing inequalities and resulted in increased social and economic deprivation which has been stressful for adolescents with disabilities and their families. Families who reported being socially isolated felt vulnerable and stressed. Robust social protection and wide community support networks are necessary in this context.

Contact with peers is particularly important for adolescent development and internet access was key to enabling social contact and access to education. Discrimination against adolescents with disabilities and their families has been exacerbated by COVID-19 and highlights the need to address harmful underlying social norms.

Adolescents and their families were fearful of not being able to access care if they became seriously ill and often relied on help from Organisations of People with Disabilities.



Access to health care and essential support should be guaranteed for those with disabilities.

Research with adolescents with disabilities is necessary to plan and implement an inclusive response to the pandemic. Our research tools were effective in facilitating communication about the experiences of adolescents with disabilities and can enable research about intersectional vulnerabilities in low- and middle-income countries.

References

- [1] United Nations. Policy Brief: Disability-inclusive response to COVID-19: United Nations; 2020 [Policy Brief].
- [2] Brigitte Rohwerder, Sara Wong, Shraddha Pokharel, et al. Adolescents with disabilities' experiences of COVID-19 and other humanitarian emergencies in low-and middle-income countries: a scoping review. Youth and Society forthcoming

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