

'A picture is worth a thousand words' – using photovoice to unravel the caregiving experiences of parents of children with special education needs during the COVID-19 pandemic

Principal investigator: Dr Cho Lee Wong¹ (Contact: jojowong@cuhk.edu.hk)

Co-investigators: Dr Dorothy Fung Ying Chan², Dr Yuen Yu Chong¹

Affiliations: ¹The Nethersole School of Nursing, Faculty of Medicine, CUHK

²Department of Paediatrics, Faculty of Medicine, CUHK

Introduction

- ❖ Parenting is challenging but raising a child with special education needs (SEN) poses additional hardships to parents.
- ❖ The unprecedented Coronavirus disease 2019 (COVID-19) inevitably posing additional difficulties for parents of children with SEN.
- ❖ However, no photovoice study has been carried out on this topic during the COVID-19 pandemic and its aftermath, thereby warranting further research.

Aims of the study

- ❖ The present study, using a Photovoice approach, aims to explore the experiences and perceptions of parents raising children with SEN, with a particular focus on the impact of the COVID-19 pandemic and its aftermath.

Methods

- ❖ A descriptive qualitative design using Photovoice approach to explore the participants' experience through photos, narratives, and interviews.
- ❖ Purposive sampling was used to recruit interested parents with children of different ages and years of diagnosis.
- ❖ Parents were asked to take at least 10 photographs reflecting their caring experiences for children with SEN and needs during COVID-19, and then to write a narrative for each photo.¹
- ❖ Interview was conducted with parents after they had taken the photos.

Findings

- ❖ 17 parents of children with SEN participated in this study from May 2023 to December 2023.
- ❖ Thematic analysis was performed on 188 photographs submitted with 4 themes emerged.

Theme 1: Flashbacks of COVID-19 memories

- ❖ This theme described the lasting memories of parents of children with SEN related to the COVID-19 pandemic.



P12: It seems we were trapped in prison. We only had four walls and a television... and there was nothing you could do about it.

Theme 2: Impacts that last beyond the pandemic

- ❖ Many parents have experienced lasting consequences that continue to persist even as the pandemic situation improves.

P13: I thought there were more conflicts. I was very unhappy. The more time we spent together, the more trouble it caused.



Theme 3: Lessons learnt

- ❖ Parents and children with SEN have experienced many challenges during the pandemic. They overcame these difficulties and shared valuable lessons learnt from the experiences, such lessons were important to them and the impacts lasted after the pandemic



P3: We made a ball pit like those in the game centre for my child so that he could have some childhood memories.

Theme 4: Services needed

- ❖ This theme described parents' views on how service provision for families with children with SEN can be improved.

P10: It was us parents who needed the most support. We should have been able to ventilate and receive consultations.

Conclusions and Implications

- ❖ This study sheds light on the unique caregiving experiences of parents raising children with SEN. It revealed both the positive and negative aspects of their experiences, offering a new perspective on their caregiving journeys and highlighting their ongoing needs.
- ❖ Insights gained from this study serve as a foundation for developing interventions that recognise the unique needs of parents with children with SEN.

References

1. Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. Health Educ Behav. 1997;24(3):369-387.