

Caring for People with Intellectual and Developmental Disabilities (PWIDD) during the COVID-19 pandemic: A Transcontinental Study

Trinity College The University of Dublin

Horan, P., (1), Desroches, M. L., (2) Marsden, D., (3) Fisher, K., (4) Stych, J., (5) Ailey, S. (6) McMillan, S., (7) Trip, H., (8) Wilson, N. (9)

1: Trinity College Dublin, Ireland 2: University of Massachusetts, USA (3) Canterbury Christ Church University, UK (4) Drexel University, USA (5) Wisconsin Department of Health Services, USA

(6) Rush University, USA (7) Surrey Place, Toronto, Canada (8) University of Otago, New Zealand (9) Western Sydney University, Australia

GATHERING A GLOBAL PERSPECTIVE ABOUT COVID 19 AND NURSING CARE FOR PWIDD

INTRODUCTION AND BACKGROUND

isproportionately PWIDD have been impacted internationally by COVID-19. As the largest public health crisis within a century, the COVID-19 pandemic has caused long-term disruption in the support systems of PWIDD across the globe. The purpose of this study was to investigate challenges and ameliorative strategies to supporting the basic care needs of people with IDD 1 year into the pandemic, as experienced by nurses who specialize in IDD nursing. We surveyed a convenience sample of 369 nurses from across North America, Europe, and Australasia using a 52-item online questionnaire (Desroches et al; 2022). Internationally Nurses played a key role in providing care to PWIDD during the pandemic. (Doody & Keenan, 2021).



STUDY PURPOSE AND KEY QUESTIONS

The COVID-19 pandemic highlighted the physical, mental, and social vulnerabilities of PWIDD and their carers.

The purpose of our study was to assess the experiences of nurses supporting PWIDD one year into the COVID-19 pandemic in order to compare IDD nurses' experiences across six English-speaking countries with differing disability nursing care systems and responses to COVID-19 in the hope of guiding collaborative recommendations for policymaking and nursing practice for future public health crises.

Our research questions

- 1) What are the greatest challenges to nurses across the globe in meeting the care needs of PWIDD 1 year into the COVID-19 pandemic?
- 2) How much and what types of support are nurses receiving within their organisations?
- 3) What challenges and strategies employed to overcome these challenges are reported by nurses related to enacting COVID -19 guidelines during the pandemic?

(Desroches et Al; 2022)



METHODOLOGY

his study set out examine the perceptions and experiences of IDD nurses 1 year into the global pandemic, "a convergent mixed methods design was utilized, where qualitative and quantitative data were collected simultaneously", (Creswell & Plano Clark, 2017). Data analysis occurred of two parts. For the first part, the quantitative data were analysed and "integrated" with statements from the qualitative data that exemplified findings from the quantitative data. We provide a joint display table, which is the visual representation of the integration of the two data sets (Creswell & Plano Clark, 2017). Research team members in the countries of the United States, Canada, Ireland, the United Kingdom, New Zealand, and Australia, recruited licensed or registered nurses currently providing, directing, consulting, or managing the care of PWIDD in their respective countries. Excluded from participation in this study were retired nurses, unlicensed student nurses or caregivers, and those not currently practising IDD nursing. Nurses were recruited via emails sent by the research team members through national or regional nursing networks. Snowball sampling was also employed as the email requested that the recipient share the study invitation with other IDD nurses in their personal or professional networks. This request served to reduce bias associated with belonging to a professional nursing organization, (Desroches et al; 2022).

FINDINGS

QUANTITATIVE RESULTS

Highest Ranked Challenges Across Global Regions



Socialization, meaningful activity, and mental/behavioral health

Understanding and complying with COVID-19 guidelines

Access to, quality of, and continuity of care COVID-19 fatigue and the influence of time

DISCUSSION

n this study it was found that PWIDD are most likely to be in re-Leipt of nursing care and support for often multiple and complex health problems. PWIDD continued to encounter entrenched and multiple disadvantages which were further exacerbated by the COVID-19 pandemic, (Desroches et al;2022).

Implications for Future Research

More research on nursing challenges and to caring for PWIDD during public health crises from an international perspective is needed, Research is needed that compares public health policy responses and outcomes for PWIDD internationally. Future research should explore how nurses and can employ person-centred strategies to reduce the trauma of public health crises for people with IDD and to clarify for whom and in what situations telehealth can be used safely and effectively for PWIDD. Intervention development is needed to support PWIDD to cope with pandemic-related changes and promote mental health and well-being, and to bridge the health care access gap within nursing care delivery models. The key outcome of this research has been the development of a new global international nursing research Collaboratory to explore nursing care issues for PWIDD. This has been enabled by Zoom and MSTEAMS advances during the pandemic making international in person research collaborations much more possible.



CONCLUSION

The COVID-19 pandemic exposed existing but often unrecognized inequities for PWIDD. This is especially tragic in a group already experiencing inequitable access to healthcare, compounding existing disadvantages across a multitude of life domains. These problems are accentuated by the stigma associated with disability, ableism, and a lack of understanding of the healthcare needs of this population. Nurses as health care providers, are central to the solutions to these problems and need to be included in healthcare and policy decision-making particularly during a global healthcare crisis

Strengths and Limitations

This study is one of very few research studies that the authors are aware of which explored the experiences of nurses caring for PWIDD during the COVID-19 pandemic. This study has limitations. We did not collect detailed demographic information from nurses, including gender or racial information. Our sample size from countries outside of the USA was small, limiting our ability to conduct statistical cross-country comparisons. The 3 months of data collection was also a potential limiting factor.

REFERENCES

- 1. Creswell, J. W., & Plano Clark, V. L. (2017). Designing and conducting mixed methods research (3rd ed.). SAGE Publications.
- 2. Doody, O., & Keenan, P. (2021). The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: A scoping review. Annals of Medicine, 53, 786–804. https://doi.org/10.1080/07853890.2021.1922743
- Desroches, M. L., Ailey, S., Fisher, K., & Stych, J. (2021). Impact of COVID-19: Nursing challenges to meeting the care needs of people with developmental disabilities. Disability and Health Journal, 14(1), 101015. https://doi.org/10.1016/
- Desroches, M. L., Fisher, K., Ailey, S., Stych, J., McMillan, S., Horan, P., Marsden, D., Trip, H., & Wilson, N. (in press). Supporting the needs of people with intellectual and developmental disabilities one year into the COVID-19 pandemic: An international, mixed methods study of nurses' perspectives. Journal of Policy and Practice in Intellectual Disabilities. DOI: 10.1111/jppi.12411

Acknowledgements

Participants: Nurses caring for PWIDD in North America, Europe, and Australasia during Covid 19. Supports: PWIDD their nurses and services without whom the study would not have been possible. Funding Bodies: This study was unfunded and a result of a new Collaboratory of IDD Nursing Academics globally!

Contact

Prof. Paul Horan

Assistant Professor in Intellectual Disability Nursing School of Nursing & Midwifery

Trinity College Dublin, Dublin 2 Ireland

Email: pahoran@tcd.ie

Phone: 353-1-8963110

Whatsapp: 35383636223