"We Were Absolutely in the Dark": Manifest Content Analysis of Developmental Disability Nurses' Experiences During the Early COVID-19 Pandemic

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Abstract

People with developmental disabilities (DD) are devastatingly impacted by COVID-19, yet no studies have explored the experiences of developmental disability nurses during the pandemic. In April 2020, as part of a multiple method study, we used manifest content analysis to evaluate nurses' 287 open-ended responses to our online survey question: "What is the *experience* of being a developmental disability nurse while encountering challenges to meeting basic care needs during the early COVID-19 pandemic?" We identified four themes: living with fear and stress, helping others to understand and cope, navigating a changing landscape, and being left out. Findings reinforce the need for accessible health information for people with developmental disability, guidelines relevant to developmental disability nursing settings, emotional support for developmental disability nurses, and education of health care professionals about the contribution of the developmental disability nurse in supporting the holistic well-being of people with DD.

People with developmental disabilities (DD), who represent approximately 1–2% of the USA population (Larson et al., 2001), are disproportionately impacted by COVID-19. It is estimated that 4.5 million people in the USA have DD (National Council on Disability, 2009). DD is an umbrella term for a range of conditions that arise during the developmental period, impair physical ability, intellectual ability, or both, and are expected to last a lifetime (National Institute of Child Health and Human Development, 2016). Examples of DD include intellectual disability, cerebral palsy, and autism spectrum disorder. A study of health insurance claims data for 467,773 people who received COVID-19 diagnoses between April and August of 2020 in the USA revealed that people with DD were more than three times as likely to die of COVID-19 than people without disability (FAIR Health, 2020). The presence of intellectual disability was the strongest independent risk factor for contracting COVID-19 and the strongest independent risk factor for COVID-19 mortality aside from age in a separate study of 547 USA health organizations'

electronic health data (Gleason et al., 2021). Many factors contribute to these increased risks and poor outcomes among people with DD including the inability to socially distance due to support needs, difficulty accessing COVID-19 testing and health care, challenges with communication in the limitation of face-to-face appointments, and increased prevalence of comorbid health conditions (Constantino et al., 2020).

Due to the complex health conditions that often accompany DD, nurses are an important member of the

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multidisciplinary support team for people with DD. Prior to the deinstitutionalization movement beginning in the 1960s, nurses who specialized in the care of people with DD primarily practiced in large, state-run institutions. The role and practice settings of the DD nurse in the USA are now as diverse as the many environments where people with DD live, work, and choose to spend their time (Auberry, 2018). The role of the DD nurse has been described as ambiguous (Auberry, 2018), as a DD nurse may support both children or adults or both, may provide direct care or may supervise care, and may practice in residential, day, or school settings. These settings range from care and support of an individual in their own home, to a small group home, to an intermediate care facility, and to an institutional setting. The Developmental Disabilities Nurses Association (DDNA) was established in 1992 in the USA as an international nursing organization with a mission to "educate, empower, and advocate for nurses practicing in the specialty of developmental disability nursing" (DDNA, 2021). The developmental disability nursing specialty is relatively small; there are, as of this writing, 924 members of DDNA (DDNA, 2021), compared with approximately 8000 members of the Academy of Medical Surgical Nurses (Academy of Medical Surgical Nurses, *personal communication*). These numbers are not representative of the total number of nurses practicing in these specialties, but it does provide a useful point of comparison in the absence of absolute numbers of DD nurses. Most DDNA members are from the United States and Canada (DDNA, *personal communication*). The Practice Standards of Developmental Disability Nursing, first developed in 2004 and revised in 2020 (DDNA, 2020), and certification in DD nursing offered since 1995 define the role and expectations for DD nurses in the USA. DD nursing is built on strong, trusted relationships with people with DD and focused on bridging the disparate disability support and health care systems (Wilson et al., 2019).

As COVID-19 expanded from an epidemic in China to a global pandemic in early 2020, the experiences and sacrifices of nurses captured an outpouring of media attention (Bagnasco et al., 2020). We, as developmental disability nurses, sought to capture the experience of the COVID-19 pandemic through the lens of the DD nurse, as we found no representation of this lesser-known nursing role in the public media or health care research at the March–April 2020 onset of the COVID-19 pandemic. In fact, our search at that time yielded zero research studies related to the impact of COVID-19 on people with DD. While many studies on the impact of COVID-19 on people with DD have since been published (Doody & Keenan, 2021; Kim et al., 2021; Lake et al., 2021; Rosencrans et al., 2021; Totsika et al., 2021), as of July 2021, we have found no other empirical research studies related to the impact of COVID-19 from the lens of the DD nurse. Furthermore, we have found no empirical research studies of DD nurses' experiences during other public health crises, including SARS, H1N1 or other influenza outbreaks, or during major disasters such as Hurricane Katrina.

Following Institutional Review Approval from the University of Massachusetts Dartmouth [approved exempt study 21.014], we commenced this multiple method project. We conducted an online survey of all 954 members of DDNA to assess the impacts of the COVID-19 pandemic on the lives of people with DD through the examination of challenges faced by DD nurses. The survey was open from April 6 to April 20, 2020, following a stay-at-home order for most states. Nurses were eligible to participate in this study if they were currently providing, directing, consulting, or managing the care of people with DD. Nationwide, 556 nurses completed the survey for a response rate of approximately 58%. The survey included 35 questions which asked the nurses to rate the degree of challenge faced in meeting the health, social service, and COVID-19 specific needs of people with DD during the pandemic. One open-ended question asked nurses "What other challenges, if any, have you faced or anticipate facing in supporting people with DD during the COVID-19 pandemic?" Due to concerns related to participant burden during the pandemic, we collected only basic demographic characteristics related to the nurses' practice and geographic settings, and whether nurses had yet had a case of COVID-19 at their organizations. Written statements were received from 287 nurses. We applied descriptive and inferential statistics for the quantitative data and manifest content analysis for the open-ended responses, which stays close to the text and focuses on describing what was said (Bengtsson, 2016). We categorized the challenges that nurses identified according to socioecologic levels of individual, interpersonal, organizational, community, and society. Results of these analyses have already been published (Desroches et al., 2021).

In this study, rather than focus on identifying nurses' challenges associated with meeting the care needs of people with DD, we seek to further analyze the data to answer a separate, but related research question: What is the *experience* of being a DD nurse while encountering challenges to meeting basic care needs during the early COVID-19 pandemic?

Methods

We used a qualitative descriptive design for this study as Sandelowski (2000) described it. Qualitative description is a naturalistic approach to inquiry, in which the researcher studies and interprets people's experiences in their natural societal and cultural context (Armstrong, 2010). The purpose of qualitative description is to produce a descriptive summary of an event comprehensively and accurately in the everyday language of the event (Sandelowski, 2000). Although less interpretive than other qualitative methods, descriptions are influenced by the describer; that is, the researchers choose what to describe and how to represent its details (Sandelowski, 2000). In this manner, we acknowledge our positionality as researchers who are influenced by our experiences as developmental disability nurses and engaged members of the DDNA, and for one of us, as a mother of a

person with DD. As researchers who collectively focus on nurses' and emotions attitudes toward people with intellectual disability, nursing ethics related to the care of people with DD, disability education in healthcare, and problem solving in people with DD's group homes, it is impossible to separate our interpretation of the data from our own experiences. Our goal, however, was not to interpret the meaning between the events and scenes described by the nurses through a particular lens, but rather to produce an account of the nurses' experiences that they would agree was accurate, and for which other researchers analyzing the data would reach the same conclusions.

Sample

The sample was comprised of the DD nurses' 287 responses to the open-ended survey question. Responses were recorded using Qualtrics survey software and exported verbatim to a Microsoft Excel data file yielding 12,607 words. Data were analyzed after all survey responses were collected; all responses were analyzed thus data saturation was not relevant to this study.

Data Analysis

Because we wanted to understand the experiences of DD nurses in meeting the care needs of people with DD early in the COVID-19 pandemic, we utilized an inductive approach for this study, focusing on analyzing the responses using manifest qualitative content analysis. Qualitative content analysis is the analysis method of choice for qualitative descriptive research (Sandelowski, 2000). Manifest content analysis focuses on describing what is observable in a text, rather than interpretation of meaning (Bengtsson, 2016). Two qualitative nurse researchers independently evaluated the textual data following repeated readings and review of the DD nurses' responses. We coded data into meaningful categories according to concepts and themes that were recurrent throughout the data using the following four stages as identified by Bengtsson (2016): (1) decontextualization where inductive coding identifies meaning units in the data, (2) recontextualization, where meaning units are compared with the textual data to ensure that all content has been covered in relation to the study goals and questions, (3) categorization, where homogeneous groups are condensed into categories or themes, and (4) compilation where realistic conclusions and results can be drawn from the data (Bengtsson, 2016).

These primary patterns of codes, categories, and themes were further developed through an iterative effort and three consensus building meetings by these researchers. Member checking, which is a method of validating the credibility of data through discussions and debriefings with participants (Polit & Beck, 2016), was not possible as the survey was anonymous; however, we completed an external review with

DD nurses and maintained an audit trail reflecting decisions regarding data and analysis.

Qualitative Rigor

Qualitative research uses methods that are consistent with the paradigm of naturalistic inquiry, and "*trustworthiness*" is the measure of evaluation used for qualitative analyses (Morse, 2018; Lincoln & Guba, 1985; Polit & Beck, 2016). Trustworthiness occurs when the following criteria of credibility, transferability, dependability, and confirmability are met. In this paradigm, *credibility* is the equivalent of internal validity, indicating the degree to which data analysis is realistically reflected. *Transferability* is the equivalent of external validity, meaning the extent to which study findings are applicable in other settings or groups, *dependability* is the equivalent of reliability, and *confirmability* is the equivalent of objectivity (Morse, 2018; Lincoln & Guba, 1985; Polit & Beck, 2016). These measures to ensure rigor in qualitative research were applied to the current study and trustworthiness was achieved by using (1) coding with the same two coders, (2) additional review by members of the research team, with familiarity of the data affirmed findings, (3) consensus building between investigators, (4) external member checking with DD nurses, and (5) maintenance of an audit trail. Member checking was performed through the presentation of study themes by the first author to a group of DD nurses at a virtual regional training conference in the Northeast. Participants were asked to provide verbal feedback on the fittingness of the themes to their experiences. Participants who responded agreed that the themes resonated with their experiences, and one nurse emphasized that stress related to the amount of time spent on tasks related to COVID-19 be included in the findings.

Results

Table 1 presents the demographic data of participants involved in this study (*n* = 282). The largest group of respondents were nurses who were from the Northeast (42%) and worked in a group home setting (33%). The majority of nurses worked in organizations that had not yet had a positive case of COVID-19 among their clients with DD.

Four themes were identified that characterized the experience of being a DD nurse at the start of the COVID-19 pandemic in the United States. The themes include living with fear and stress, helping others to understand and cope, navigating a changing landscape, and being left out.

Theme 1. Living with Fear and Stress

Our analysis revealed that most nurses experienced a variety of negative emotions at the beginning of the pandemic, including stress, anxiety, frustration, sadness, depression, and burnout. Many nurses described increased stress and mental fatigue as the COVID-19 pandemic increased their

Table 1. Demographic Characteristics of DD Nurses (*n* = 287).

Practice setting	Percent, %
Hospital or medical center	2.1
Ambulatory clinic	2.1
Public residential institution	10.6
Private residential institution	14.5
Community-based group home	33
Adult foster care/shared living	1.8
Private duty	1.1
More than one type of setting	18.1
Other	16.3
Region of USA	
Northeast	42.2
South	13.1
Midwest	31.6
West	13.1
Has a client at your organization experienced COVID-19?	
Yes	26.2
No	73.7

workloads. While some support providers including clinical psychology and rehabilitative therapies were shifted to remote services or services were temporarily halted, one nurse stated, "Nursing...has had to pick up for all the other disciplines and continues to do their own much needed jobs." Some nurses described how answering the frustratingly large number of calls and questions about COVID-19 detracted from the nurse's time and ability to perform regular nursing duties. Keeping up with the constant changes to policies and procedures related to COVID-19 also contributed to nurses' stress and emotional burnout. In the words of one nurse, "I spend every waking hour on COVID."

In some cases, nurses were physically distanced by the provider agencies from the people with DD whom they supported unless face-to-face care was absolutely necessary. This affected some nurses emotionally, as described by one nurse, "[I] have experienced sadness and the want to serve and see the individuals in this time of quarantine." Other nurses continued to provide face-to-face care, but many were fearful of contracting COVID-19. One nurse described:

> Concerns our residents do not know social distancing and the risk to nursing staff. Cannot count how many times a shift I have to "back up individuals from myself the nurse", most of us are 45 years or older...very concerned.

Some nurses were also concerned that they would contract COVID-19 and spread the virus to family members at home.

The fear of inadequate staffing, deeply exacerbated during the COVID-19 pandemic, was also commonly reported by the nurses, who feared that there would not be enough nurses and direct support staff to provide essential care and supports. One nurse described the fear "that there will be no staff willing to care for COVID positive individuals, that this will fall on the nurse and if the nurse falls ill that there will be nobody to care."

Nurses' fears were also related to legal and financial concerns. A few nurses articulated fear that their nursing licenses could be jeopardized on the basis of not being able to do enough to provide needed care to people with DD being supported during the pandemic due to staffing shortages. Many nurses described worry and fear about the finances of the non-profit organizations in which they were employed, with one nurse stating, "With the fiscal outlay during this crisis, we can anticipate cutbacks in funds for health care the likes of which we've never seen."

Many nurses also were fearful of possible discrimination of people with DD from needed healthcare during the pandemic. As stated by one nurse,

> We are afraid that a person would not get the care or service they need due to their disability– hospitalization, ventilators, tests, etc. If an individual becomes really sick with COVID-19 and would require a ventilator- will they be bumped for someone else due to disabilities?

Finally, as nurses were experiencing these overwhelming stresses and fears, some nurses were challenged to hide these emotions from the people with DD they supported. One nurse described the challenge of "Keeping some sense of normalcy for our folks since they pick up on our stress." In some cases, nurses were also impacted by the fact that some agencies employed only a single nurse, as one nurse stated "I am the only RN, so I feel very responsible for the welfare of these clients. I am worried about how long this will go on and the effect on the clients in the future."

Theme 2. Helping Others to Understand and Cope

Many of the nurses used the word "understand" as they described challenges related to the COVID-19 pandemic. Nearly all of the nurses described helping people with DD, their families, and agency staff to understand the need for the many changes brought forth by the pandemic, including use of personal protective equipment, need for social distancing, and changes to daily routine as a result of stay-at-home orders. Helping people to understand was closely linked with helping people to positively cope with these changes, as well as their emotional reactions to these changes. One nurse said:

> Some of the most difficult challenges have been related to emotional support to both individuals and staff. Helping the individuals understand the changes in their routine, their usual staff, their usual activities, social distancing, helping communicate needs, missing their families, etc. Although difficult dealing with concrete issues as in cleaning and infection control, I feel that the emotional side has been the most difficult. Even with staff.

The nurse's ability to help people with DD understand and cope with changes was influential in helping to reduce the challenging behaviors of people with DD that occurred as a result of pandemic-related changes, including agitation, aggression, and elopement. Many nurses described how many people with DD, because of their varying cognitive abilities and limited accessible information available to them, "don't understand and are really starting to act out." "Quelling inaccurate fears of the folks we support (ex. 'it's floating in the air, I can't go outside or I'll get it')" was an important role of the nurse to support people with DD.

Likewise, many nurses similarly reported helping direct support staff and other non-healthcare agency staff understand and cope with pandemic-related changes. For both people with DD and their support staff, the influence of media misinformation was described as problematic. Many nurses detailed the need for constant education and reassurance of staff, particularly related to infection control. For some staff, this education was intended to reduce excessive fears, for other staff it was to promote adherence to COVID-19 guidelines and recommendations. One nurse stated, "Infection control is not easily understood by a lot of DSPs [direct support professionals]. There is also a lot of fear related to lack of understanding." Another nurse described the opposite challenge of "Getting staff to understand the need to keep their masks on."

Theme 3. Navigating a Changing Landscape

Many nurses expressed how they felt challenged to provide guidance and support to people with DD, agency staff, and families while not having a sense of when the pandemic will end. One nurse stated, "Without seeing a light at the end of the tunnel, it's difficult to keep reassuring people and encouraging people to hang in there." Some nurses were also stressed by the constant policy and guideline changes, none of which the nurses felt directly applied to the settings where nurses were employed. One nurse described the challenge of "Keeping up with the almost daily changes in federal/state/local guidance and ensuring that staff understand the ever-changing environment in which we are practicing."

The "uncertainty of transition to a 'new normal'" was also described by some of the nurses. One nurse detailed many aspects of uncertainty about re-opening of a day habilitation program:

> I don't know how many of our furloughed staff will return when we reopen. I don't know if we can continue to provide programs to the high level we have been once we reopen. I don't know how many of our clients will even return. I don't know how many other day programs will be able to reopen once this subsides. This will affect the daily lives of adults with DD for years to come.

Theme 4. Being Left Out

Many nurses described the experience of being left out, from planning within their employing agencies, from the health care system, and from society. Some nurses reported being excluded from their employing organizations related to pandemic planning and decision making. One nurse stated, "Our agency did not consult with their nursing team when decisions were made and plans were put in place. We were absolutely in the dark," and another, "The executive team has excluded the nursing team from all planning, discussions, implementation related to COVID-19." One nurse described a particularly challenging situation in which he/she was excluded:

> There was a staff that had an exposure, that I as the RN asked her to call the public health nurse as stated in the guidelines that were put in place. Instead, the employee was told to call her immediate manager in which has no medical experience, was not familiar with the guidelines that were set forth in the house, and decided the said employee did not have an exposure. That employee had a 102.5 fever at 1pm and had to take acetaminophen. I was called by my immediate boss to tell me I had to stay out of staff business, as I had asked the employee to follow the guidelines placed.

Some nurses also expressed concern about being left out of the healthcare setting support team due to visitor restrictions when people with DD would require hospital admission. In the words of one nurse "If individual hospitalized and nonverbal or unable to consent for themselves who will be with them?" Several nurses felt that people with DD and the nursing care and support provided to them were not seen as important in society, and this was magnified during the pandemic. Nurses stated that "Our supported people are not seen as valuable in our society and they are placed at the end of the line" and that

> The big concern I see is that this population is not considered as important. Our PPE and supplies were confiscated and sent elsewhere by the government and we still remain very low on certain necessities. We were asked by our local health department what we will do when the hospital turns one of the individuals away due to their disability?

Another nurse described how "We are low on the priority list but provide 24/7 care. How do we keep consumers and staff safe?... We are at the front lines trying to keep consumers and staff safe, and feel alone."

Discussion

In this study, we explored in-depth the experience of encountering challenges to meeting basic care needs of people with DD through the lens of nurses working in the specialty of DD nursing at the start of the COVID-19 pandemic in the United States, April 2020. We used manifest content analysis (Bengtsson, 2016) of 287 open-ended responses from an online survey to all members of the DDNA. We identified

four themes: living with fear and stress, helping others to understand and cope, navigating a changing landscape, and being left out.

Living with Fear and Stress: Need for Emotional Support for DD Nurses

Nurses described high levels of fear, stress, mental fatigue, and burnout during the COVID-19 pandemic. While the negative impact of the COVID-19 pandemic on the mental health of health care workers is well documented (Mental Health America, 2021), DD nurses have experienced emotional distress even prior to the pandemic (Desroches, 2020). Findings of an integrative review of nurses' attitudes and emotions toward caring for people with intellectual disability internationally support the idea that DD nurses are emotionally invested in their work, bringing passion and enthusiasm to their practice (Desroches, 2020). Stress, guilt about not being able to do more to alleviate some of the difficulties faced by people with DD and feeling devalued and misunderstood in their role, contributes to emotional conflict and depletion (Desroches, 2020). In the same way that the COVID-19 pandemic has exacerbated health disparities experienced by vulnerable groups, so too has the pandemic exacerbated the emotional distress faced by DD nurses. These findings are similar to the experiences of nursing home staff during the COVID-19 pandemic, who reported stress and burnout due to staffing shortages, the emotional toll of caring for residents who were significantly isolated, ill, or dying, and feeling devalued in their roles due to negative media attention of nursing homes (White et al., 2020).

While there have been large-scale initiatives to address nurse mental health during the pandemic (American Nurses Association, n.d.), these initiatives may not reach all nurses who practice DD nursing, especially nurses who are the only nurse in their community-based organizations and agencies. Also, given that DD nurses in this study expressed how the COVID-19 public health guidelines were not relevant to settings where people with DD receive care, DD nurses may similarly perceive that COVID-19 nurse mental health supports also may not apply to the DD nursing role. Further research is needed to elucidate factors that contribute to the mental well-being and resilience of DD nurses to design interventions specific to the emotional needs of DD nurses.

Helping People to Understand and Cope: Need for Accurate, Accessible Health Information

Nurses repeatedly identified that a major responsibility during this time was helping people with DD, families, and staff understand and cope with pandemic-related changes. It was particularly challenging for nurses to help people with DD of varying intellectual abilities to understand the social changes

necessitated by the pandemic, including social distancing and changes in daily routine such as staying home from day programs and not having visitors. Television news and social media were problematic sources of information, especially in the absence of public health information and guidelines relevant and accessible to people with DD. Misconceptions of the general public and health care professionals about the ability of people with DD to understand basic health information may have resulted in little attention paid to accessible COVID-19 information for people with DD. Focht-New (2012) describes an underestimation of the abilities of people with DD related to health teaching, and the surprising capacity of many people with DD to learn health concepts. While nursing has been historically associated within a "medical model" of disability (Auberry, 2018) which represents disability as a medical condition to be treated and cured, our study results support that DD nurses were more concerned with the mental and social effects of the pandemic than meeting medical needs. Ongoing, effective education on health and safety is needed for people with DD, and future research should investigate effective educational strategies using universal design for learning so that public health information is accessible to all (Hewitt et al., 2021).

Navigating a Changing Landscape: Need for Relevant Public Health Guidelines and Support for Nurses in Non-Traditional Settings

Frequently changing public health policies and guidelines were reported as a source of stress for many of the nurses, as was the lack of specificity of the policies and guidelines to settings where many of the nurses were employed. Not having a clear sense of what to do, who to turn to for DD-specific guidance, and when to plan for re-opening left many nurses feeling uncertain as they navigated an unfamiliar and changing landscape. These findings are similar to those of a qualitative study of school nurses' experiences in Hong Kong; one of the four major themes was "navigating the school through the pandemic," which included finding relevant COVID-19 information and staying up to date and developing guidelines for the school (Lee et al., 2020). This theme also captured nurses' experiences with limitations of the guidelines in terms of the contextual realities of the school, that is, small classrooms and social distancing, and students, including those with intellectual disabilities, who had difficulty wearing masks and keeping their hands away from their faces (Lee at al., 2020). To overcome a lack of useful COVID-19 information, the school nurses found support through virtual informal networking with other school nurses, using the WhatsApp app (Lee at al., 2020). Together, the findings of these studies support the need for public health guidelines that are timely, clear, and relevant to non-traditional nursing settings. Interprofessional collaboration

and education are major functions of DD nursing practice (DDNA, 2020) and thus DD nurses are well positioned to offer leadership in the development of accessible, relevant public health guidelines. There is also a need for mechanisms that promote connection of nurses in non-traditional settings to reduce feelings of isolation and share best practices in interpreting and adapting guidelines to these settings.

Being Left Out: Strengthening and Articulating the Value of the DD Nurse

Some nurses in this study reported being excluded from COVID-19 planning and policy implementation in their employing agencies, despite being health care professionals with knowledge of infection control principles and the unique health needs of people with DD. Lee et al. (2020) described how not all schools included nurses in planning and the shortfalls in the guidelines that resulted from the lack of nursing perspective; however, more nurses reported increased involvement of the school nurse that resulted in a rise in profile of the role of the school nurse. This rise in profile was not mirrored in DD nurses in our study. This may be related to the ambiguous role of the DD nurse after deinstitutional-ization with diverse practice settings and differing models of care delivery and policies (Auberry, 2018). This also may reflect a cautiousness by disability providers to include nurses, fearing that DD nurses would medicalize the everyday lives of people with DD, as nurses have historically been situated within a medical model of care (Auberry, 2018). DD nursing has been described as a "shy discipline" and "lacking a strong voice to articulate and explain their role fully" (Martin et al., 2012). Yet, as other members of the multi-disciplinary team were suspended from face-to-face care due to pandemic restrictions, nurses were valuable in either pro-viding the care themselves or coordinating care to meet basic needs in the face of severe disruptions. Our findings support the need to clarify and strengthen the voice of DD nurses in terms of the philosophical approach of DD nursing and the value that DD nurses offer to supporting the holistic well-being of people with DD, extending the perception of the role of the nurse beyond physicians' orders and medical treatments.

There has been recent momentum in articulating the role and necessary preparation for DD nursing practice. In 2018, the Golisano Institute for Developmental Disability Nursing was founded at St. John Fisher College in Rochester, NY, the first institute or center in the United States devoted to ad-vancing the specialty of developmental disability nursing. The Institute has recently accepted its inaugural class of 15 fellows for its 1-year Fellowship program to produce leaders in developmental disability nursing (St John Fisher College, n.d.) In 2020, the third edition of the Scope and Standards of Developmental Disability Nursing was published, which in-cludes the first Professional Practice Model of Developmental Disability Nursing (DDNA, 2020). The model identifies four key aspects of the nursing role: expertise in primary and chronic nursing care interventions, comprehensive person-centered care coordination, advocacy and leadership, and interprofessional collaboration. These four aspects of the role are centered around a relationship-based, lifespan approach. International interest is also advancing as the publication of the findings of our parent study gained international attention and resulted in the expansion of a follow-up study to Canada, the United Kingdom, Ireland, Australia, and New Zealand. Further international work is underway to articulate the value of the DD nurse internationally in reducing health inequities faced by people with DD.

One major barrier to inclusion of DD nurses in public health planning is the lack of knowledge and understanding of health care professionals related to the health care needs and community-based supports system for people with DD. Physicians and nurses receive very little training, if any, related to care of people with DD in the absence of accreditation-required curriculum in DD in the USA. In-clusion of basic concepts related to care of people with DD and their systems of support in medical school and under-graduate nursing curricula is needed. Partnership between DD nurses and public health professionals is not possible if public health professionals are not aware of the role and expertise of DD nurses.

Strengths and Limitations

This study was a qualitative content analysis of nurses' re-sponses to one open-ended item of an online survey. Pro-viding a venue for nurses to provide more in-depth responses, such as through qualitative interviews, may have yielded thicker description taking into consideration the context of nurses' responses. As a cross-sectional study with data collection occurring during the early pandemic in April 2020, only 26% of nurses reported having a positive case of COVID-19 in their organization; thus, the findings may not be transferable to time points later in the pandemic. Also, to limit participant burden during a public health crisis, we also did not collect demographic characteristics including nurse age, gender, or racial/ethnic background, and so we are unable to ascertain sample representativeness. Our high re-sponse rate (58%) from invitations sent to the entire mem-bership of the DDNA helps offset sampling bias. However, as the USA and Canadian nursing workforce is predominantly female, we would expect that our sample would reflect a female gender bias. As of July 2021, we are aware of no other studies that explore the impact of COVID-19 on people with DD and their support staff including nurses, from the lens of the DD nurse.

Conclusion

Issues existing prior to the COVID-19 pandemic have been exacerbated in the area of DD nursing, including lack of accessible health information for health teaching with people

with DD and the marginalization of DD nursing as a specialty. This has contributed to greater nurse emotional distress than already existed prior to the pandemic. Findings of this study reveal that there is still much work to be done to support DD nurses in their ability to support the holistic health of people with DD. It is more important now than ever to advance the public perception of DD nursing beyond administering medications and applying bandages to supporting the physical, mental, and social well-being of people with DD throughout the lifespan.

Declaration of Conflicting Interests

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References

American Nurses Association. (n.d.). *Well-being initiative*. https://www.nursingworld.org/practice-policy/work-environment/health-safety/disaster-preparedness/coronavirus/what-you-need-to-know/the-well-being-initiative/.

Armstrong, J. (2010). Naturalistic inquiry. In N. J. Salkind (Ed.), *Encyclopedia of research design* (pp. 881–886). SAGE. https://doi.org/10.1037/0000119-012.

Auberry, K. (2018). Intellectual and developmental disability nursing: Current challenges in the USA. *Nursing: Research and Reviews*, 55(8), 23–28. https://doi.org/10.2147/NRR.S154511.

Bagnasco, A., Catania, G., Gallagher, A., & Morley, G. (2020). Media representations of nurses in the pandemic: Just doing our job? *Nursing Ethics*, 27(4), 901–905. https://doi.org/10.1177/0969733020926352.

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, 2, 8-14. https://doi.org/10.1016/j.npls.2016.01.001.

Constantino, J. N., Sahin, M., Piven, J., Rodgers, R., & Tschida, J. (2020). The impact of COVID-19 on individuals with intellectual and developmental disabilities: Clinical and scientific priorities. *American Journal of Psychiatry*, 177(11), 1091–1093. https://doi.org/10.1176/appi.ajp.2020.20060780.

Desroches, M. L. (2020). Nurses' attitudes, beliefs, and emotions toward caring for adults with intellectual disabilities: An integrative review. *Nursing Forum*, 55(2), 211–222. https://doi.org/10.1111/nuf.12418.

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/j.dhjo.2020.101015.

Developmental Disabilities Nurses Association. (2020). *Practice standards of developmental disability nursing* (3d ed.). High Tide Press.

Developmental Disabilities Nurses Association. (2021, May 19). President's address *[Conference session]*. Developmental Disabilities Nurses Association Annual Meeting of Members, virtual.

Doody, O., & Keenan, P. M. (2021). The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: A scoping review. *Annals of Medicine*, 53(1), 786–804. https://doi.org/10.1080/07853890.2021.1922743.

FAIR Health. (2020). *Risk factors for covid-19 mortality among privately insured patients: A claims data analysis*. https://www.fairhealth.org/publications/whitepapers.

Focht-New, G. (2012). Transformation through health teaching for adults with intellectual and developmental disabilities: A qualitative study. *Intellectual and Developmental Disabilities*, 50(2), 129–139. https://doi.org/10.1352/1934-9556-50.02.129.

Foundation for People with Learning Disabilities. (2021). *Social model of disability*. https://www.learningdisabilities.org.uk/learning-disabilities/a-to-z/s/social-model-disability.

Friedman, C. (2021). The COVID-19 pandemic and quality of life outcomes of people with intellectual and developmental disabilities. *Disability and Health Journal*. Advance online publication. https://doi.org/10.1016/j.dhjo.2021.101117.

Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States. *NEJM Catalyst*. https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051.

Hewitt, A., Pettingell, S., Kramme, J., Smith, J., Dean, K., Kleist, B., Sanders, M., & Bershadsky, J. (2021). *Direct support workforce and COVID-19 national report: Six-month follow-up*. Institute on Community Integration, University of Minnesota. https://publications.ici.umn.edu/community-living/covid19-survey-6-month-followup/main.

Kim, M. A., Yi, J., Sung, J., Hwang, S., Howey, W., & Jung, S. (2021). Changes in life experiences of adults with intellectual disabilities in the COVID-19 pandemics in South Korea. *Disability and Health Journal*. Advance online publication. https://doi.org/10.1016/j.dhjo.2021.101120.

Lake, J., Jachyra, P., Volpe, T., Lunsky, Y., Magnacca, C., Marcinkiewicz, A., & Hamdani, Y. (2021). The wellbeing and mental health care experiences of adults with intellectual and developmental disabilities during COVID-19. *Journal of Mental Health Research in Intellectual Disabilities*. Advance online publication. https://doi.org/10.1080/19315864.2021.1892890.

Larson, S. A., Lakin, C., Anderson, L., Nohoon, K. L., Lee, J. H., & Anderson, D. (2001). Prevalence of mental retardation at developmental disabilities: Estimates from the 1994/1995 national health interview survey disability supplements. *American Journal of Mental Retardation*, 106(3), 231–252. https://doi.org/10.1352/0895-8017(2001)106<0231:POMRAD>2.0.CO;2.

Lee, R. T. L., West, S., Tang, A. C. Y., Cheng, H. Y., Chong, C. Y. Y., Chien, W. T., & Chan, S.W. C. (2021 May-Jun). A qualitative

exploration of the experiences of school nurses during COVID-19 pandemic as the frontline primary health care professionals. *Nursing Outlook*, *69*(3), 399–408. https://doi.org/10.1016/j.outlook.2020.12.003.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

Martin, A., O'Connor-Fenelon, M., & Lyons, R. (2012). Nonverbal communication between registered nurses intellectual disability and people with intellectual disability: An exploratory study of the nurse's experiences. Part 2. *Journal of Intellectual Disabilities*, *16*(2), 97–108. https://doi.org/10.1177/1744629512442033.

Mental Health America. (2021). *The mental health of health care workers during COVID-19*. https://mhanational.org/mental-health-healthcare-workers-covid-19.

Morse, J. (2018). Reframing rigor in qualitative inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (5th ed., pp. 796–817). SAGE.

National Council on Disability. (2009). *The current state of health care for people with disabilities*. https://www.ncd.gov/publications/2009/Sept302009.

National Institute of Child Health and Human Development. (2016). *Intellectual and developmental disabilities (IDD): Condition information*. https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default#f3.

Polit, D. F., & Beck, C. T. (2016). *Nursing research generating and assessing evidence for nursing practice* (10th ed.). Wolters Kluwer.

Rosencrans, M., Arango, P., Sabat, C., Buck, A., Brown, C., Tenorio, M., & Witwer, A. (2021). The impact of the COVID-19 pandemic on the health, wellbeing, and access to services of people with intellectual and developmental disabilities. *Research in Developmental Disabilities*, *114*, 103985. https://doi.org/10.1016/j.ridd.2021.103985.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, *23*(4), 334–340. https://doi.org/10.1002/1098-240X.

St. John Fisher College. (n.d.). *Golisano Fellowship in developmental disability nursing*. https://www.sjfc.edu/institutes/golisano-institute/fellowship/fellowship-overview/.

Totsika, V., Emerson, E., Hastings, R. P., & Hatton, C. (2021). The impact of the COVID-19 pandemic on the health of adults with intellectual impairment: Evidence from two longitudinal UK surveys. *Journal of Intellectual Disability Research*. Advance online publication. https://doi.org/10.1111/jir.12866.

White, E. M., Wetle, T. F., Reddy, A., & Baier, R. R. (2020). Frontline nursing home staff experiences during the COVID-19 pandemic. *Journal of Post-Acute and Long-Term Care Medicine*, *22*(1), 199–203. https://www.jamda.com/article/S1525-8610(20)30987-7/fulltext.

Wilson, N. J., Wiese, M., Lewis, P., Jaques, H., & O'Reilly, K. (2019). Nurses working in intellectual disability–specific settings talk about the uniqueness of their role: A qualitative study. *Journal of Advanced Nursing*, *75*(4), 812–822. https://doi.org/10.1111/jan.13898.

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