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Attitudes of Registered Nurses caring for adults with intellectual and developmental disabilities in an acute care setting: A mixed method study

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Abstract

Adults with intellectual and developmental disabilities (I/DD) avoidable health disparities, which may be related to healthcare professionals' attitudes. To examine the attitudes and experiences of nurses caring for adults with I/DD in the acute care setting.Methods A mixed method approach was utilized. Data was collected from January to March 2021. Data collection consisted of the ATDP-B questionnaire completed by 31 RNs and Eight RNs interviewed via Zoom. ResultsQuantitative data from the ATDP-B questionnaire revealed most nurses had negative attitudes towards disabled persons. Four themes emerged from the qualitative data: Experience, setting, emotional responses, and education. DiscussionPractice implications include knowledge deficits and lack of confidence reported by the participants. Incorporating nursing care of adults with I/DD in the curriculum and in practice may improve patient safety and health equity for all individuals.

Keywords: Attitudes, acute care, nurses, nursing education, adults, intellectual disabilities, developmental disabilities

Background

By 2050, 30% of the world's population will be over the age of 65 (He, Goodkind, & Kowal, 2016). Persons with intellectual and developmental disabilities (I/DD), at times, exhibit signs of aging much earlier than the general population. They experience illnesses and hospitalizations at a higher rate (Ailey et al., 2015). Hospitalizations are a source of anxiety for patients and caregivers regardless of age, but for persons with I/DD, their anxiety is compounded by difficulties with communication, lack of participation in the plan of care, and decision-making (Sharkey et al., 2016). Integration of persons with I/DD into the community resulted in their receiving care from generalist nurses instead of nurse specialists (Desroches et al., 2019). Registered Nurses (RNs) caring for them require specific skills to meet these challenges.

Intellectual and Developmental Disability (I/DD) is defined as disability that is manifested before the person reaches twenty-two years of age and is attributable to neurological conditions affecting general intellectual functioning or adaptive behavior (http://www.arcadams.org/about_us/idddefinition.html). Interchangeable terms for I/DD include learning disabilities, intellectual disabilities, and developmental disabilities. There is a paucity of research regarding the hospital care of adults with I/DD. The few available studies identified the need for education for nurses at all levels. Care of individuals with I/DD is generally not part of nursing curricula (Hemsley et al., 2016). Practicing nurses in acute care do not encounter adult patients with I/DD on a regular basis and have acknowledged difficulty caring for this group (Hemm et al., 2015). Adults with I/DD are a growing population who often experience health disparities. This pilot study will add to the literature regarding attitudes and experiences of hospital nurses during their encounters with these patients. The results may be used to design nursing curricula and to guide educational interventions. The purpose of the study was to investigate Registered Nurses' attitudes and experiences caring for adults with I/DD in an acute care hospital setting using the Attitudes Towards Disabled Persons Form B (ATDP-B) questionnaire (Yuker et al., 1970) and semi-structured interviews. The research question guiding this study was: What are some factors influencing nurses' attitudes towards patients with I/DD?

Theoretical Framework

The Theory of Planned Behavior (TPB) was the framework for developing the semi-structured interview questions. TPB explains the relationship between attitudes, intentions, and behaviors. Behaviors or actions are based on intentions and perceived behavioral control (Ajzen, 1991). TPB proposes that behaviors are predictable given certain parameters, such as attitudes, social norms, resources, and context. Attitudes are formed when individuals ascribe positive or negative values to behaviors and are the primary predictors of behavior. Another factor to executing behavior relies on the availability of resources such as time, skills, and personnel.

Literature Review

Stigmas have affected every aspect of the lives of persons with I/DD including health status. Disparities exist in the utilization of preventative health screenings and may be related to providers' beliefs about quality of life and life expectancy for this population (Ditchman et al., 2016). Discriminatory practices have even led to fatalities for a number of patients with I/DD (Spassiani et al., 2020). The literature highlighted: (a) persons with I/DD experienced variations in the quality of care received, (b) healthcare providers and society at large shared negative perceptions regarding disabilities, (c) knowledge deficits and attitudes were related, (d) exposure to these patients led to positive attitudes, and (e) patients with I/DD and nurses could benefit from including disability teaching in the nursing curriculum (Appelgren et al., 2018; Desroches et al.,, 2019; Doyle et al., 2016; Louch 2021). Gaps in intellectual disability education resulted in inconsistencies in the preparation of nurses and quality-of-care for these patients (Appelgren et al., 2018). In a systematic review, researchers reported some findings as universal to all patient groups; meanwhile, themes like nurses *needing to work against negative attitudes and alienation* were specific to patients with I/DD (Appelgren 2018). Recommendations for improving attitudes included increasing exposure to these patients (Lewis, Gaffney, and Wilson, 2017). However, other researchers found benefits from personal and professional contact differed significantly; of the two, professional contact led to more positive attitudes (Desroches, et al., 2019). Increasing personal contact might not necessarily lead to improved attitudes. Desroches et al. (2019) reported that the number of patients cared for, beliefs about patients' capabilities and their quality of life were better predictors for positive attitudes. Consequently, implementing strategies to improve perceptions about the quality of life of patients with I/DD may prove more useful in changing attitudes than increasing personal contact (Desroches et al., 2019). Additionally, misconceptions about capacities caused some healthcare staff to assume these patients were incapable decision-making, notably giving consent (Doyle et al., 2016).

Knowledge deficits were found to be a predictor of negative attitudes and compounded patient safety issues. Failure to make reasonable adjustment to services placed these patients at increased risk (Tuffrey-Wilje et al., 2014). Another issue with safety was identifying these patients at points of entry to acute care, such as emergency departments and inpatient units. Not properly identifying these patients contributed to nurses failing to tailor care (Spassiani et al., 2020). Recommendations for improving patient safety and satisfaction were included in the literature. Adjustments such as stimuli reduction and pre-admission tours could decrease behavioral issues (Doyle et al., 2016; Tuffrey-Wijne et al., 2014). Organizational, systems level, designs, resources, or intra-agency communication problems could impede providing care (Desroches, 2020; Doyle, 2016; Tuffrey-Wijne et al., 2014). Many of the studies revealed staff attitudes were deciding elements leading to differential outcomes.

Methods

Quantitative methodologies were used to determine possible causes and patterns about nurses' attitudes. Qualitative methodologies were utilized to describe nurses' experiences (Fetters et al., 2013). Researchers employed a mixed method convergent design to analyze, merge, and compare the data. Mixed methods design can inform the development of interventions, training, and research. The study took place in an acute care hospital in the Northeastern United States, which was selected because it has an outpatient clinic servicing clients with I/DD.

Study Design

The university and hospital granted institutional review board approvals. Hospital nurse managers were requested to share recruitment and study information during staff meetings and huddles. An electronic mailing list was used to forward an e-mail, comprised of study details and a Web link to access associated forms. Inclusion criteria for the study was that participants be an RN with at least one year of experience and had cared of an adult patient with intellectual or developmental disabilities within the past three years. Nurses working in pediatrics, psychiatry, and obstetrics were excluded because the focus was on adults in acute care. An invitation letter, informed consent, the ADTP-B, and demographic questionnaire were uploaded on the hospital's Research Electronic Data Capture (**REDCap**) website. RNs interested in participating in the study were able to access the link from the informational email leading them to the informed consent which they were able to sign via DocuSign and upload. Upon signing the consent participants had access to the ADTP-B survey and demographic questionnaire. The demographic questionnaire included age, gender, ethnicity, and the following questions:

1. Do you consider yourself spiritual or practice a recognized religion?
2. What is level of education?
3. What is your nursing specialty?
4. Do you have any nursing certification?
5. How many years of nursing experience do you have?

Participants were requested to include their email address to the demographic questionnaire, should they wish to be contacted for interviews. The consent granted permission for interviews as well.

The survey questionnaire, Attitude Towards Disabled Persons Survey tool adapted from the ATDP-B by Yuker et al. (1970), consisted of 30 questions, on a 6-point Likert-type scale ranging from 1 (disagree very much) to 6 (agree very much). There is no neutral response; participants must either agree or disagree. The original ATDP tool was developed in 1960, versions A, B were also created. The tool is open domain. These are the most used and validated scales measuring attitudes of healthcare professionals towards individuals with disabilities (Lam et al., 2010). The ATDP-B assesses beliefs and perceptions about the capabilities of individuals with disabilities. The interpretation of the scores depends on the perception of respondents, that is, whether they perceive disabled persons the same as non-disabled persons. The ADTP-B survey took approximately 20 to 30 minutes to complete. Data collected from **REDCap** was stored on a password-protected information technology server then exported to Microsoft Excel. The Excel data were imported into the Statistical Package for the Social Sciences (SPSS®) version 17.0 software. Descriptive statistics, mean, standard deviation, and frequency percentages were utilized to analyze the responses. Age and years of experience and spirituality were analyzed to determine effects on attitudes.

Results

Quantitative Data

Initially, 105 RNs accessed the posting on the website; 40 replied to the questionnaire; however, nine were excluded because they did not complete the survey. The response rate was 38.1%, two males and 29 females, between 24 to 63 years of age (mean 35.97 ±12.77) with a minimum and maximum years of experience of 1 to 43. Table 1 displays a descriptive analysis of the categorical variables. Data indicated that the average study participant considered him/herself spiritual and practiced a religion (*n*=24, 77.4%), that his/her highest level of education was a bachelor's degree (*n*=25, 80.6%), and had a nursing certification (*n*=18, 58.1%). About one-third of the sample reported his/her years of nursing experience to be between 3-4 years (*n*=11, 35.5%). Lastly, the majority of study participants reported working on a Medical/Surgery unit (*n*=28, 90.3%). Bivariate analysis indicated that total scale scores were not correlated with study participant age at a statistically significant level, *r*(29)=-.10, *p*=.61, and did not vary at a statistically significant level by the items: *Does the Study Participant Consider him/herself Spiritual or Practice a Religion*?, t(29)=-.57, p=.58; *highest level of education*, t(29)=.93, p=.36; *Does the Study Participant Have a Nursing Certification*?, t(29)=-1.47, p=.15; *years of nursing experience*, F(3, 27)=.24, p=.87; and *unit where the study participant works*, t(2.08)=-.05, p=.96. The parametric and non-parametric tests produced the same findings in terms of statistical significance.

Table 1 Descriptive Analysis of Categorical Study Variables (n=31)

Variable	N	%
Does the Study Participant Consider him/herself Spiritual or Practice a Recognized Religion?		
Yes	24	77.4
No	7	22.6
Highest Level of Education		
Associate Degree	1	3.2
Bachelor's Degree	25	80.6
Master's Degree	5	16.1
Does the Study Participant Have a Nursing Certification?		
Yes	18	58.1

No	13	41.9
Years of Nursing Experience		
1-2	9	29.0
3-4	11	35.5
5-10	5	16.1
Greater than 10	6	19.4
Unit Where Study Participant Works		
Medical/Surgery	28	90.3
ED	3	9.7

The ATDP-B scores ranged from 52 to 144 with a mean score of 92.51. The mean score was low, indicative of perceiving disabled persons as dissimilar to non-disabled persons. A low score may correlate with negative attitudes (Yuker et al., 1970). The following is a breakdown of the responses showing nurses did not perceive disabled persons as similar to non-disabled persons. Question 2: 70.96% answered that disabled people should not have to pay income tax. Question 3: 64.52% of the nurses indicated that disabled people were more emotional; Question 8: 64.52% agreed to most people being uncomfortable associating with disabled people. 67.74% of the nurses disagreed to question 10, which stated that disabled people do not become more easily upset; Question 11: 70.97% nurses responded that disabled people are often less aggressive; 61.29% of the nurses disagreed with question 12, about whether disabled people get married and have children; Question 15: 61.29% expressed that disabled people were not as happy as non-disabled; Question 20: 67.74% agreed that the worst thing to happen a person would be for him to be severely injured; Question 21: 54.84% indicated disabled children should not have to compete with non-disabled children. Question 26: 74.19% reported that disabled persons want more affection and praise. Question 28: 70.97% indicated disabled people need special attention. Question 30: 64.52% described disabled persons as having different personalities than normal people.

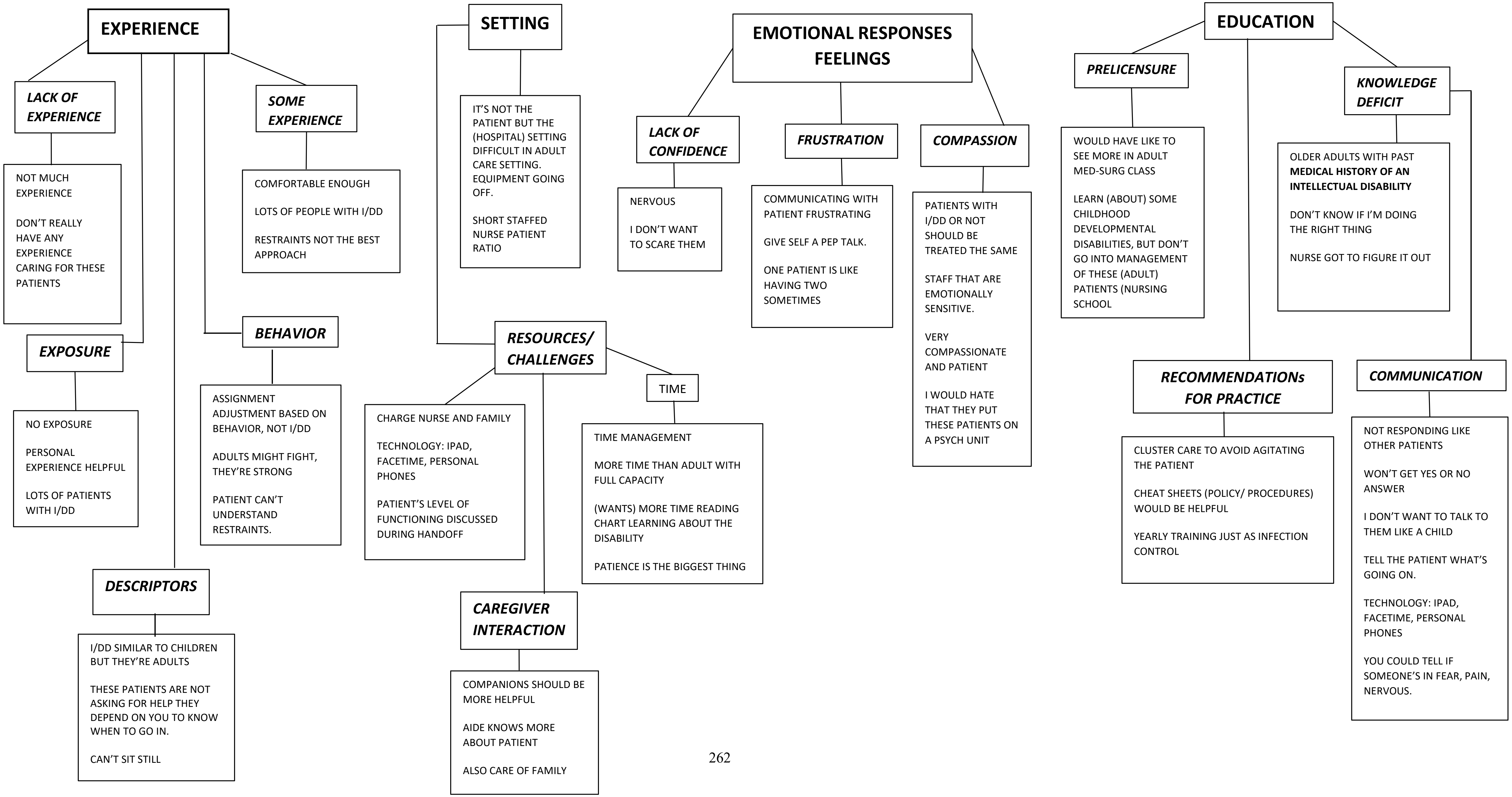
Qualitative Data

Eight face-to-face semi-structured interviews were conducted by the first author via Zoom from January to March 2021. Each interview lasted approximately 30 minutes and interviewees granted permission to be audio recorded. Interviews were conducted until saturation was reached. Recordings were transcribed by a professional transcriptionist. First and second authors read and re-read the transcripts and developed a code scheme using participants' quotes. Field notes, recordings, and transcripts were analyzed by the team who developed a display table (See Figure 1), resulting in emerging themes.

Four themes emerged from the data: Experience, setting, emotional responses, and education. The *experience* theme revealed that exposure to patients with I/DD was helpful. Some participants reported feeling comfortable, while others described their experiences as "…hard to …take care of these patients". Overall, participants reported having some experience, but not much, caring for this population. In the theme *setting*, participants reported organizational and systems level obstacles. For example, a participant stated, "If nurses feel that those patients are difficult it's because of the heavy load…They need to be watched more closely sometimes". Participants expressed hospital environment, time, and staffing issues impacted care; however, they also reported using technology and other staff members as resources. Statements reflecting relying on family and co-workers as resources included: "A coworker [who] has a family member with disability" and "[Asking] caregivers specifics about the patient".

In terms of *emotional responses*, participants voiced being nervous, upset, frustrated, and needing compassion to care for patients with I/DD. As a participant stated, "You are upset because now you have a heavier assignment". Another participant reflected that [these patients] "have the same feelings like us", require "the same amount of care as any other patient", and there's "no difference". The *education* theme indicated many felt ill-prepared to manage patients with I/DD. In several of the subthemes some participants' statements revealed knowledge deficits such as "I don't always know what to do", "nursing education mostly about kids with autism", and "even a quick education, a heads-up, could be helpful". Some participants described patients in terms of "like a baby or like a demented patient". Participants also reflected on the difficulty communicating with these patients. Some noted that "non-verbal patients cannot communicate" and nurses should "communicate with aide or family". Other participants stated patients with I/DD "communicate one way or another. [Nurses should] pick up on cues". Participants reported sometimes resorting to "trial and error".

Figure 1 Themes of Nurses' Attitudes Caring for Individuals with I/DD



- EXPERIENCE
  - *LACK OF EXPERIENCE*
    - NOT MUCH EXPERIENCE
    - DON'T REALLY HAVE ANY EXPERIENCE CARING FOR THESE PATIENTS
  - *SOME EXPERIENCE*
    - COMFORTABLE ENOUGH
    - LOTS OF PEOPLE WITH I/DD
    - RESTRAINTS NOT THE BEST APPROACH
  - *EXPOSURE*
    - NO EXPOSURE
    - PERSONAL EXPERIENCE HELPFUL
    - LOTS OF PATIENTS WITH I/DD
  - *BEHAVIOR*
    - ASSIGNMENT ADJUSTMENT BASED ON BEHAVIOR, NOT I/DD
    - ADULTS MIGHT FIGHT, THEY'RE STRONG
    - PATIENT CAN'T UNDERSTAND RESTRAINTS.
  - *DESCRIPTORS*
    - I/DD SIMILAR TO CHILDREN BUT THEY'RE ADULTS
    - THESE PATIENTS ARE NOT ASKING FOR HELP THEY DEPEND ON YOU TO KNOW WHEN TO GO IN.
    - CAN'T SIT STILL
- SETTING
  - IT'S NOT THE PATIENT BUT THE (HOSPITAL) SETTING DIFFICULT IN ADULT CARE SETTING. EQUIPMENT GOING OFF.
  - SHORT STAFFED NURSE PATIENT RATIO
  - *RESOURCES/ CHALLENGES*
    - CHARGE NURSE AND FAMILY
    - TECHNOLOGY: IPAD, FACETIME, PERSONAL PHONES
    - PATIENT'S LEVEL OF FUNCTIONING DISCUSSED DURING HANDOFF
    - TIME
      - TIME MANAGEMENT
      - MORE TIME THAN ADULT WITH FULL CAPACITY
      - (WANTS) MORE TIME READING CHART LEARNING ABOUT THE DISABILITY
      - PATIENCE IS THE BIGGEST THING
    - *CAREGIVER INTERACTION*
      - COMPANIONS SHOULD BE MORE HELPFUL
      - AIDE KNOWS MORE ABOUT PATIENT
      - ALSO CARE OF FAMILY
- EMOTIONAL RESPONSES FEELINGS
  - *LACK OF CONFIDENCE*
    - NERVOUS
    - I DON'T WANT TO SCARE THEM
  - *FRUSTRATION*
    - COMMUNICATING WITH PATIENT FRUSTRATING
    - GIVE SELF A PEP TALK.
    - ONE PATIENT IS LIKE HAVING TWO SOMETIMES
  - *COMPASSION*
    - PATIENTS WITH I/DD OR NOT SHOULD BE TREATED THE SAME
    - STAFF THAT ARE EMOTIONALLY SENSITIVE.
    - VERY COMPASSIONATE AND PATIENT
    - I WOULD HATE THAT THEY PUT THESE PATIENTS ON A PSYCH UNIT
- EDUCATION
  - *PRELICENSURE*
    - WOULD HAVE LIKE TO SEE MORE IN ADULT MED-SURG CLASS
    - LEARN (ABOUT) SOME CHILDHOOD DEVELOPMENTAL DISABILITIES, BUT DON'T GO INTO MANAGEMENT OF THESE (ADULT) PATIENTS (NURSING SCHOOL
  - *KNOWLEDGE DEFICIT*
    - OLDER ADULTS WITH PAST **MEDICAL HISTORY OF AN INTELLECTUAL DISABILITY**
    - DON'T KNOW IF I'M DOING THE RIGHT THING
    - NURSE GOT TO FIGURE IT OUT
    - *COMMUNICATION*
      - NOT RESPONDING LIKE OTHER PATIENTS
      - WON'T GET YES OR NO ANSWER
      - I DON'T WANT TO TALK TO THEM LIKE A CHILD
      - TELL THE PATIENT WHAT'S GOING ON.
      - TECHNOLOGY: IPAD, FACETIME, PERSONAL PHONES
      - YOU COULD TELL IF SOMEONE'S IN FEAR, PAIN, NERVOUS.
  - *RECOMMENDATIONs FOR PRACTICE*
    - CLUSTER CARE TO AVOID AGITATING THE PATIENT
    - CHEAT SHEETS (POLICY/ PROCEDURES) WOULD BE HELPFUL
    - YEARLY TRAINING JUST AS INFECTION CONTROL

Discussion

A narrative approach, known as weaving, describing the results of both methodologies based on similar themes was selected (Fetters et al., 2013). Weaving occurred because themes of both databases were connected. Quantitative data supported the themes. Quantitative survey data were compared with qualitative statements during the analysis phase to identify congruence of verbal and thought attitudes.

Similar to other studies, the qualitative component, revealed nurses have few opportunities to interact with patients with I/DD during clinicals nor is I/DD instruction a significant part of nursing curricula (Appelgren et al., 2018). Assessment problems led to nurses identifying these patients as demented or babies. With identification and assessment issues in mind, nurses would find it difficult to tailor care for this group (Louch, 2021; Spassiani, 2020). Nurses in this study reported organizational policies and systems obstacles to providing care, such as nurse-patient ratios and heavy workloads. Additionally, they recommended having "cheat sheets", a summary of policies and procedures to care for these patients. Similarly, Doyle et al. (2016) recommended summary sheets on communicating with this population. Notably, the hospital has an outpatient facility dedicated to the care of patients with I/DD, yet inpatient nurses did not mention these specialists or the clinic as a resource. This could represent issues with intra-agency communication, as well as nurses' knowledge deficits regarding resources within the institution and the community. Upon comparing the quantitative to the qualitative data several commonalities existed.

Quantitative findings indicated nurses perceived this patient population as significantly different from non-disabled groups. Beliefs about the quality of life was a key predictor for positive attitudes. Answers from the survey revealed the majority of nurses did not believe disabled persons got married and had children or should not be competing with non-disabled persons. Given, these measures examined quality of life values, it is possible nurses might not give equitable care based on these appraisals. The nurses' descriptors and perceptions that assignments with these patients were more difficult and would warrant having to give themselves "pep-talks" implied negative attitudes towards these patients. From survey results, the majority of nurses expressed envisioning disabled persons as not normal, assumed most people were uncomfortable associating with disabled persons, or considered becoming disabled as the worst thing to happen to a person, these beliefs could negatively impact attitudes and ultimately care delivery.

This study exposed the toll on nurses caring for patients with I/DD without adequate skills and knowledge. The findings suggest a beginning framework in disability curriculum by identifying parameters to address education, professional practice, and research. Educational interventions at the undergraduate and practice levels could begin through clinical and simulation experiences tailored to this population. During the interviews, it became clear, nurses do not encounter this population on a regular basis, instituting continuing education programs has the potential to enhance practice skills and confidence.

Limitations

Limitations within the study included small sample size and not having information about I/DD training nurses received. The ATDP-B is a self-report questionnaire, where nurses may respond based on expectations.

Conclusions

This study concurs with the literature in that negative attitudes may be the result of lack of exposure to I/DD-specific education. Disability curricula define the competencies nurses require to care for this population holistically. To integrate disability into education and practice it is important that contributions of people with disabilities and organizations supporting them be acknowledged. Their expertise can inform education and practice. Educators and national nursing leadership should foster relationships with individuals with disabilities and their service organizations to support the inclusion of disability education. Further research on the nursing care of this population would advance health equity and social justice.

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