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Review Article

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An Integrative Review of the Attitudes of Acute Care Nurses towards Adults with Intellectual and Developmental Disabilities

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Abstract

Aim: The aim of this integrative review was to synthesize the research on attitudes of registered nurses caring for adults with I/DD in an acute care setting and discuss recommendations for nursing practice and future research.

Design: Integrative review

Methods: The Whittemore and Knafl's method was utilized to enhance the rigor of integrating experimental and non-experimental research. Authors followed PRISMA guidelines.

Results: Five themes emerged: caring for adults with intellectual disabilities was more difficult than caring for those with physical disabilities, lack of confidence influenced nurses' attitudes, time and staffing constraints contributed to negative attitudes, attitudes played a key role in the quality of care, and enhanced knowledge through education had the potential to improve attitudes.

Keywords: Education; Hospital; Intellectual disabilities; Nurses' attitudes; Older adults

Introduction

As of 2016, 7.37 million people in the United States had intellectual or developmental disabilities [1]. Furthermore, persons with Intellectual Disabilities (ID) are more likely to die from preventable illnesses and at an earlier age than their counterparts without ID [2]. Intellectual disability starts any time before a child turns 18 and is characterized by problems with both intellectual functioning and intelligence - including the ability to learn, reason, problem-solve, and manage social and life skills. The term "developmental disabilities" is a broader category of often lifelong disability that can be intellectual, physical, or both. "I/DD" is often used to describe situations in which ID and other disabilities are present.

Persons with ID experienced greater health disparities compared to the general population [3,4]. Incidence of post-surgical infections, hospital-acquired skin breakdowns, medication errors, falls, and deep vein thrombosis occur more frequently for patients with I/DD [4]. Nursing has often been deemed key in determining quality of patient care; therefore, health equity for these patients will lead to an examination of nursing practice. Studies have identified that nurses' attitudes have the potential to impact the quality of care delivered [5]. This is relevant as the [6] reported Healthcare Providers' (HCPs) attitudes factored in service delivery for patients with disabilities. Attitudes are expressed beliefs regarding what is normal, realistic, sustainable, or typical. They are formed from experiences, encompassing things learned through observations, reflections, or formal teaching; they are not innate [7]. To encourage positive behaviors it is important to understand their association with attitudes. While attitudes are important to patient care, nurses' perspectives on caring for these patients has hardly been studied.

Research has been conducted predominantly in community settings and from the patients' point of view. This review will focus on nurses' perspectives on their attitudes caring for this population in the acute care setting.

Background

Adults with intellectual and developmental disabilities (I/DD) are living longer, leading to increased hospitalizations and rehospitalizations due to multiple co-morbidities [8,9]. Odds for complications are higher for these adults [4]. Additionally, they are developing advanced progressive illnesses requiring palliative care [10]. I/DD involves physical, intellectual, and/or emotional development and many of these conditions affect multiple body parts or systems resulting in these patients needing specialized care [1].

Nursing care of this group requires extra time, communication skills, and specific knowledge and training on I/DD [11]. Nurses in the learning disabilities field have been shown to provide better care to these patients; however, they are not available in most acute care institutions. During hospitalization, patients with I/DD are primarily treated by generalist nurses [12]. Generalist nurses being more informed about I/DD has the potential to improve the care.

Healthcare professionals can facilitate or impede access to quality care [13]. Moreover, research on adults with I/DD and their loved ones indicated nursing as a major contributor towards receiving quality care [11]. Several barriers to quality care have been identified in the literature, notably, negative attitudes [11,14]. Negative attitudes and perceptions were attributed to deficiency in confidence and competence and had significant implications for patients [12]. Professional competence is the building block of nursing practice. How competence is executed may depend on attitudinal values.

Aim

The aim of this integrative review was to synthesize the research on attitudes of registered nurses caring for adults with I/DD in an acute care setting and discuss recommendations for nursing practice and future research. The research question was Do nurses' attitudes affect nursing care for patients with I/DD?

The Study Design

Integrative reviews incorporate experimental and non-experimental research, and in this case, results might contribute to improving nursing practice for patients with I/DD. Since an integrative review is a compilation of primary research it should undergo the same standards of rigour as its original components. Combining different types of research is complex and may result in a lack of rigour, inaccuracies, and biases [15]. To enhance the rigour of this review, the analysis, synthesis, and deduction processes were based on the format presented by [15]. The format is comprised of identifying a problem, conducting a literature search, evaluating quality, analyzing the data, and presenting the results.

Method

The literature search was conducted using at least two strategies to yield the maximum number of relevant primary sources. Electronic databases CINAHL, Medline, Psych Info, Academic Search Premier, and PubMed were searched for full-text articles in English published between 2000 and 2020. The following Mesh terms were utilized: attitudes, perceptions, nurses, intellectual disability, developmental disability, acute care, and hospitals. Reviewing reference lists of articles was another search strategy. Unpublished articles and dissertations were excluded. Inclusion and exclusion criteria were established to increase the likelihood of producing reliable and reproducible results. Articles were screened by the following inclusion criteria: Participants were registered nurses caring for adults with intellectual and developmental disabilities in acute care settings and if other healthcare practitioners were included in the research, information regarding registered nurses was reported separately; primary research articles published between 2000 and 2020; and peer reviewed. Exclusion criteria were: articles not published in English; research published before 2000; articles not reporting on primary research. Seven articles were eligible from the database search and three articles from reference list searches (Figure 1). Authors followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines to conduct the search. Eligible studies were then categorized into subdivisions.

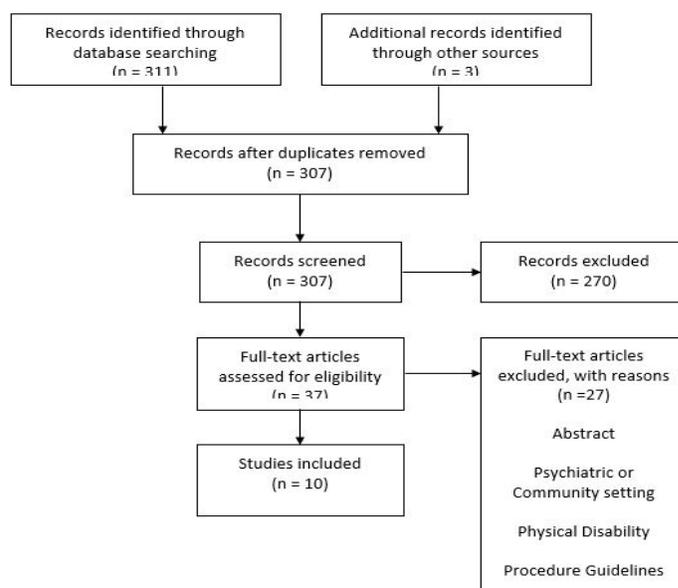


Figure 1: PRISMA Flow Diagram. From: Moher D, et al. [16].

Analysis

Whittemore, et al. [15] recommend several approaches to appraising the quality of the research used in an integrative review. They suggest utilizing a tool that analyzes multiple methods and specific ones for exceptions. This review included quantitative, qualitative, mixed method, and cross-sectional studies. The Mixed Methods Appraisal Tool (MMAT) was used for analyzing the quantitative, qualitative, and mixed method studies. The MMAT consists of five categories of study designs: qualitative, quantitative randomized controlled trials, quantitative non-randomized, quantitative descriptive, and mixed methods, with five questions each. The questions address topics such as appropriateness of data collection and measurement methods, risk of bias, and interpretation of results [17]. Answers ranged from yes, no, can't tell, and comments. The Joanna Briggs Institute Checklist for Analytical Cross-Sectional Studies was used to appraise the cross-sectional research. It is composed of eight questions regarding some of the following criteria: sample description, measurement reliability and validity, and statistical analysis. Answers to these questions were yes, no, unclear, and not applicable [18]. Ten studies were included in the integrative review. The authors critiqued the studies independently to corroborate findings of the appraisals and ensure credibility and validity. Discussion led to a consensus regarding the ratings of the studies. Overall, the quality of these studies was moderate.

Data abstraction followed the content comparison method described by Whittemore and Knaff [15]. This approach is recommended for analyzing different methods. Initially, the authors extracted data from the articles including author, purpose, design, measures, and key findings, which were displayed in a table to facilitate comparison of multiple primary sources (Table 1). Data was then classified by categories relevant to the attitudes of nurses caring for patients with I/DD. This step assisted in recognizing patterns, relationships, and discrepancies in the data and identifying emerging themes. Deductions and conclusions were verified for accuracy and confirmability. Themes were summarized and narratives were developed.

Author	Purpose	Design	Sample	Measures	Key Findings
[10]	To assess confidence levels of palliative care RNs.	Qualitative	33 nurses	Postal questionnaire	Nurses reported more discomfort caring for patients with LD than physical, secondary to inadequate skills, education, and resources. Confidence and experience were related. Difficulties addressing psychosocial and spiritual needs with LD. Easier caring for end-of-life than general care. Nurses wanted additional training, specific tools, and health action plans.
[2]	To explore the attitudes and emotions of nurses.	Cross-sectional, descriptive, exploratory study	248 nurses	Adapted Caring for Adults with Disabilities Questionnaire	Nurses had neutral to positive attitudes. Preferred caring for physical than intellectual physical disability. Experience/exposure correlated to emotions. Nurses beliefs predicted attitudes and emotions. Education increased positive attitudes.
[19]	To explore the experiences of registered intellectual disability nurses.	Qualitative Heideggerian phenomenological approach	7 registered ID nurses.	Semi-structured interviews.	Three themes: care delivery, inclusiveness and client-focused care. Importance of seeing person rather than disability. Insufficient time to care for or understand clients. Specialized support in a seamless plan needed. Positive attitudes part of solution.

[20]	To investigate the perception of oncology nurses about care for patients with and without an ID.	Quantitative Descriptive	83 nurses	Questionnaires	Nurses felt less positive and confident when caring for patients with ID. Less relevant knowledge, training, and experience. Experience influenced confidence and attitudes. Communication issues. Increased stress and burnout levels caring for ID patients.
[5]	To compare differences between caring for intellectual and physical disability.	Cross-sectional	160 RNs, 16 Student Nurses, and 86 Nursing Assistants	Vignette style questionnaire	Nurses preferred caring for patients with physical disabilities than with ID. Fewer positive attitudes and negative emotions towards patients with ID. Segregating patients with ID, delaying tasks like performing blood pressures and administering medication, communicating, and expecting challenging behavior. Required additional nursing time, training, and skills. Attitudes and emotions affect quality of care.
[21]	To explore nurses and therapists interactions with people with LD.	Quantitative	269 RNs nurses, 169 therapists, 270 LD staff, 261 students	Self-completion questionnaire.	Nurses and therapists reported less confidence as well as communication issues when encountering learning versus physical disability. They felt unprepared and requested more education. Supervised placement opportunities and education recommended. Inadequate preparation and past contact with LD patients influenced future willingness to treat. Attitudes, skills, and knowledge impact quality of care.
[3]	To examine Healthcare Professionals pro-inclusion attitudes toward people with ID	Quantitative	367 (119 physicians, 141 psychiatrists and 107 nurses)	Attitudes Toward Intellectual Disability Questionnaire	Examining attitudes help determine if they align with health policies. Generally, healthcare professionals with inclusive attitudes will provide tailored care and services. Knowledge increased positive attitudes. Attitudes impact accessibility and quality. Inclusivity was a key factor in behavioral attitude scores.
[22]	To explore nurses representation caring for people with ID.	Qualitative descriptive study	18 Nurses	Semi-structured interview	Caring for patients with ID more complex and challenges staff competency. Issues include managing patient behavior. Continuity of care, staff training, and resources require multiple interventions. Improvements in care delivery are needed.
[23]	To identify factors that promote and compromise adjustments to services for patients with ID.	Mixed method	1251 participants	Questionnaires and interviews	Adjustments in services are necessary. In the acute care setting, adjustments were not always reliable or consistent. Knowledge and attitude of staff, ward culture, staff attitudes, and staff knowledge were crucial determinants of accessibility. Systematic identification of patients with ID recommended.
[13]	Instrument development and validation measuring attitudes of healthcare professionals toward persons with disabilities.	Quantitative	993 healthcare professionals	Delphi survey consensus.	Education/training improved attitudes and knowledge/skills, clinical experience increased scores in emotions, knowledge/skills.

Table 1: Characteristics of reviewed articles.

Ethics

Ethical approval was not required.

Results

Five themes emerged from the synthesis of the literature. They were: caring for adults with ID was more difficult than caring for those with physical disabilities; lack of confidence influenced nurses' attitudes; time and staffing constraints contributed to negative attitudes; attitudes impacted quality of care; and knowledge through education had the potential to improve attitudes.

Intellectual Vs Physical Disabilities

Nurses responded differently when caring for patients with intellectual versus physical disabilities [2,5,20]. Some nurses expressed beliefs these patients might be easily distressed, aggressive, or less cooperative [5]. Nurses surmised patients with I/DD were less capable of making decisions or living independently [2]. Segregating patients, avoiding performing invasive procedures, allocating less time to explain treatments, and expecting caregivers' assistance were behaviors exhibited by nurses [5].

Lacking Confidence

At times, knowledge deficits were associated with a lack of confidence [5]. Several studies reported nurses believed these patients might not be able to understand treatment plans or report pain [5,11]. Communicating was challenging for some nurses, who reported not knowing what to say upon meeting persons with ID, resulting in nurses expressing feelings of nervousness, hopelessness, and fright [5,21].

Nurses in oncology and palliative care reported feeling less confident caring for these patients due to lack of exposure; however, studies indicate prior experience correlated to more confidence [10,20]. Nurses reported being more confident caring for physical rather than psychosocial needs. Flynn and colleagues [20] suggested informing these patients they were nearing the end of life was extremely difficult for these nurses because of less relevant knowledge. According to Cooper, et al. [10] nurses lacked education on dealing with the outcomes of such conversations.

Time and Staffing Constraints

Some nurses viewed these patients as complex and requiring more time [3,5,11,22]. Nurses were less likely to perform tasks such as taking blood pressures or administering medications [5,11]. Oncology nurses expressed that caring for patients with ID would be more burdensome and time consuming [20]. Nevertheless, learning disability nurses reiterated the importance of allocating time to care for these patients [19]. Challenges related to staffing include patient handling difficulties, delay in service because staff needed help, and interference from or dependence on caregivers [11,13]. Institutional factors, increased workload, and inexperience were related to staffing dynamics [13]. A recurring theme was that patients with complex problems may receive substandard care [3,5,14].

Attitudes

Studies have found that exploring HCPs' attitudes might help with understanding whether their behaviors were in alignment with standards of practice [3,23]. HCPs reported feeling unwelcomed, apprehensive, burdensome, and fearful when encountering these patients [13]. In comparison, the general population had better attitudes towards persons with ID. Morin D, et al. [3] reported this difference may be due to the general population usually interacting with this group in a social context, unlike HCPs' whose contacts predominantly involve illness. Increased contact and positive attitudes were related [2,21]. Adults with I/DD represented an exceedingly small portion of acute care patients resulting in staff feeling unfamiliar, uncomfortable, and reluctant to treat them [3,24].

Knowledge

Patients with ID reported that negative staff attitudes originated from lack of understanding of disabilities [13]. Knowledge deficits were associated with decreased quality of care due to perceived patients' behavioral and communication challenges [22]. Increased knowledge led to more objective assessments of patients' capacities, causing less pity or overprotectiveness [3]. Nevertheless, knowledge of rights and capacities did not always transfer to good practice [3]. Some palliative care nurses requested training to provide general care for this group [10]. Education increased HCPs' positive behaviors, knowledge, skills, and their ability to provide care tailored to these patients [13]. Some studies indicated nurses desired to provide quality care and were receptive to learning [22]. Education significantly improved attitudes [13].

Discussion

Care for adults with I/DD in the acute care setting is usually provided by nurses who have had little exposure or experience with this group [3,12,21]. How nurses ultimately deliver care is based on how they understand themselves and interpret others' behaviors. Such behaviors and perceptions are interrelated with attitudes [7]. Furthermore, attitudes towards persons with I/DD may reflect beliefs about inclusion for this group as well as their capacity. Inclusion consists of beliefs about similarities between persons with ID and those without, their ability to participate in decision-making, and how much they should be segregated from society [25]. Negative or positive attitudes impact the quality of patient care. Factors such as nurses' perceptions of intellectual versus physical disabilities, lack of confidence, time, staffing and organizational culture, as well as knowledge influenced nurses' attitudes [2,5,14,20,24]. Studies indicated nurses made assumptions about patients' capacities based on stigmas and stereotypes [2,23]. Often, stereotypes affected nurses' willingness to deliver care, and prevented them from implementing improvement strategies [2]. Themes of infantilization, sheltering, and paternalization were evident in the literature. Pelleboer-Gunnink, et al. [26] reported that stigmatization sometimes can result from indecisiveness about wanting to shelter or empower these patients. Nevertheless, these conflicting feelings may manifest as negative attitudes; thereby, affecting patient care.

Additionally, nurses lacking skills and confidence, feeling intimidated, or frightened were common threads in the literature [5]. Overall, nurses reported caring for these patients as daunting. Frequently, these sentiments led to behaviors, such as sequestering patients, which could negatively affect patient safety and quality of care. This is particularly concerning as multiple co-morbidities and communication impairments render these patients more vulnerable and susceptible to unanticipated occurrences than the general population.

Many of the studies implied nurses caring for patients with I/DD in acute care settings could benefit from education at the prelicensure and practice levels because of the potential to increase skills, confidence, and improve attitudes [11,13,19]. Since patients with I/DD represent a small number of patients admitted to hospitals; therefore, generalist nurses have less contact with them leading to feelings of inadequacy. Exposure builds confidence and consequently, disability nurses expressed feeling more confident caring for this population [19,21]. Of note, clinical experience caring for patients with I/DD was associated with positive emotional responses [13].

Several factors such as age and education influence attitudes. However, education primarily was found to have a significant effect. In a study on residential staff and patients with ID in the community setting, age and education were associated with attitudes; whereby older staff were more likely to encourage sheltering and/or paternalism [25]. Additionally, older staff were less likely to view patients with ID as similar to themselves, while staff with more education demonstrated less sheltering and more empowering attitudes [25]. The correlation between attitudes and education was also established by Yi et al. [13]. They reported participation in an I/DD education module designed to improve understanding and awareness of disability resulted in improved knowledge, skills, behavior, and attitudes [13].

The results of this integrative review revealed nurses' attitudes affected care for patients with I/DD. The findings support a need to investigate how to elicit positive attitudes towards this population. Price, et al. [7] reported that in healthcare, certain attitudes are deemed positive while others are viewed as negative. Standards of nursing practice established by the American Nurses Association Code of Ethics [27] require that nurses practice with "compassion, and respect for the inherent dignity, worth, and unique attributes of every person". Accordingly, professional attitudes supersede individual attitudes because they affect decisions and behaviors towards patients [7]. Training can facilitate nurses learning desired attitudes. A change in attitudes involves considerable persuasion and introspection since challenging deep-seated attitudes requires extensive retraining [7]. Ites several methods to bring about change: role modelling and imitating others, involvement in interactive exercises, information, and exposure.

Adults with I/DD are living longer with multiple comorbidities; therefore, will require specialized care from nurses. Future research should explore nurses' perspectives on how to equip them to care for these patients in the hospital setting. Furthermore, research into organizational structure is warranted as it was identified as one of the factors impacting the care. Research into nursing care and organizational structure related to patient with I/DD will transform education, policy, and practice.

Limitations

The limitations of this review included a dearth of previous research. The search yielded ten studies. Sample size was small which could affect generalizability of findings. Focusing primarily on the acute care setting limited retrieval of articles and decreased generalizability. Excluding non-English articles could have left out important research findings. Additionally, some articles regarding HCPs attitudes were excluded because they did not distinguish participants' professions. Pertinent information in these articles about nurses might have been omitted.

Conclusion

The literature on nurses' attitudes caring for adult patients with I/DD in an acute care setting was scarce. Most of the current studies have been from the patients' perspective. Several of the studies in this integrative review revealed positive attitudes impacted patient outcomes. Some studies concluded that attitudes can be learned through targeted education and practice. Furthermore, nurses who had prior exposure to patients with I/DD demonstrated positive attitudes. Thus, incorporating contact opportunities into nursing curricula and continuing education has the potential to improve patient care outcomes.

Increased contact will result in increasing nurses' confidence in caring for this population. Patient satisfaction, comfort, and cooperation with staff would be enhanced by skilled nurses. In the absence of education and standardization of I/DD nursing care in acute care settings, nurses might have to utilize and develop their own strategies to ensure the best care for these patients. Findings can inform nurses, nurse educators, and change nursing practice.

Declaration of Interest

The authors report no known conflicts of interest associated with this manuscript.

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