ABSTRACT

Background: People with disabilities (PWDs) experience significant health disparities. The complex experience of disability requires that nurses are adequately and deliberately prepared to care for PWDs. However, there are no recognized nursing competencies to direct education and care.

Purpose: The purpose of this study was to develop a set of nursing competencies to better prepare prelicensure nursing students to provide competent care to PWDs.

Methods: A 2-round Delphi survey was administered to experts in the field of disabilities (n = 47, n = 35). Quantitative and qualitative methods were used to analyze data.

Results: Three major themes emerged: unique knowledge, volume and repetition, and distinct disability culture. Competencies were reduced with a focus on 4 dimensions: environment and care, communication, culture, and referral.

Conclusions: The 12 new competencies can serve as the foundation for the inclusion of disability content in nursing curricula.

Keywords: Delphi survey, disability care, nursing competencies, nursing education

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Because of the nature of the profession, nurses are expected to regularly care for people with disabilities (PWDs). As such, nursing students should be expected to develop a solid foundation on care of PWDs, along with an understanding of how PWDs navigate an increasingly complex health care environment. However, there are no established prelicensure nursing competencies on caring for PWDs. The absence of clear competencies may contribute to the findings that suggest that the relationship between health care providers and PWDs is often suboptimal and that attitudes of discrimination and disempowerment are prevalent.1,2

To improve the health and health care of PWDs and to address social inequities, the next generation of nurses must be equipped to care for individuals with disabilities across the world and across the lifespan.3 The purpose of this study was to develop a set of nursing competencies to care for PWDs via a Delphi survey, guided by input from experts and other stakeholders in the field.

Background

The World Health Organization (WHO) recognizes disability as a complex interaction between a person's health condition and environmental factors, resulting in impairments, activity limitations, and participation restrictions.2 People with disabilities represent a significant portion of the population and is expected to increase in the coming years. Globally, 15% of the population lives with a disability.4 In the United States, the average is 12.8%, although that number varies significantly by state; Utah's rate is 9.9%, whereas that of West Virginia is 20.1%.5 The 2016 Global Burden of Disease Study identified the combined effect of aging, population growth, and epidemiological changes as the 3 main factors increasing the number of years lived with disability.6
disabilities experience significant health disparities, both related and unrelated to their specific disability. Evidence also suggests that PWDs have poorer health outcomes, including higher rates of early death, chronic diseases, and disparities in preventive screenings. In comparison, a higher percentage of adults with disabilities (27% vs 12.1% of nondisabled peers) do not receive needed medical care due to health care costs. The Centers for Disease Control and Prevention reports that PWDs are 3 times more likely to develop heart disease, stroke, diabetes, and cancer; have higher rates of obesity (38.2% PWDs vs 26.2% of nondisabled peers); and are more likely to smoke (28.2% PWDs vs 13.4% of nondisabled peers).

The intersection of disability with other factors also contributes to increased vulnerability and need for specialized care. Persons with disabilities are some of the most disadvantaged; approximately 20% of the world's poorest people have a disability and are more likely to be unemployed, have greater health care costs, and limited opportunities to attend school. According to Krahn et al, adults with disabilities “fare poorly” on all measures of social determinants of health (eg, employment, education, and income). A double burden of disenfranchisement occurs if a person of racial or ethnic minority status also has a disability. A literature review by Peterson-Besse et al identified frequent barriers to health care for PWDs from underserved racial/ethnic groups, including type or lack of insurance, language barriers, low education, and no usual source of care.

In addition, PWDs are at significantly greater risk for violence and abuse. A meta-analysis by Jones et al reported that children with disabilities were 3.68 times more likely to be physically, sexually, or emotionally maltreated. Adults with disabilities experience similar rates of victimization. Understanding and responding to this increased vulnerability—and the factors that contribute to this alarming health disparity—are essential if nurses are to be in a position to intervene.

As early as 2007, the Institute of Medicine called on educators, practitioners, and consumers to develop curricula and competency standards to better prepare professionals to care for PWDs. In 2009, the National Council on Disability associated the lack of professional training on disability competency for health care providers to the lack of PWDs receiving appropriate and effective health care. In 2011, the WHO and World Bank made several recommendations to improve the lives of PWDs. One important recommendation was inclusion of relevant training on disability in the curriculum of health care providers.

Despite these efforts, along with the inclusion of disability-related objectives to Healthy People 2020, nursing programs have not consistently demonstrated a commitment to deliberate education in this area. In a 2005 study by Smeltzer et al, time constraints and the need for more important content limited the inclusion of disability content in nursing curricula. Faculty reported that the use of textbooks was the major teaching strategy to teach disability content. However, in 2010, Smeltzer et al reviewed 33 textbooks used in prelicensure nursing education and discovered an absence of disability-related content. Ilkhani et al conducted a literature review of nursing curricula relating to the care for children with disabilities from 1990 to 2015. Ten articles met inclusion criteria and revealed that “overloaded curricula,” lack of faculty expertise, problems with teaching methods, and a focus on the medical model were barriers to including disability content in nursing curricula.

Attitudes of nursing students toward PWDs have been investigated worldwide indicating that there are gaps in nursing curricula resulting in a need to strengthen students’ preparation to care for PWDs across cultures. In a qualitative study, Smeltzer et al interviewed PWDs and identified 4 major themes concerning their care by nursing staff when hospitalized: poor communication, lack of competence, negative attitudes of nurses, and a fear related to the quality of care received. A generic approach fails to recognize the unique needs of the population, heterogeneity of individuals, and complexity of their care, thus contributing to the unconscionable inequities in health and health care that exist between individuals with and without disabilities. A meaningful set of professional competencies related to care for PWDs could provide a structured guide for delineating the requisite knowledge, skills, and attitudes.

Initial Competency Development

Based on previous work in graduate nursing education related to care of PWDs, 2 of the coauthors drafted an initial set of competencies. Advisory Committees composed of key stakeholders validated the intent and content of that list. Despite strong response from the committee, the 43 competencies were never published or tested. They served as a preliminary draft for this study.

Methods

Design

Using the original 43 competencies as the starting point, this study used a 2-round Delphi survey design to further develop, revise, and validate the competencies for application to undergraduate education. The iterative process gathered both quantitative and qualitative data to reach expert consensus.

Sample

The authors identified experts in the field of disability health care known by their research, publications, organizational affiliations, or mutual contacts. The potential pool was 64 faculty, administrators, researchers, and advocates. The researchers invited people with and without disabilities to participate. Seventy-three percent of those invited chose to participate and completed round 1. Respondents were primarily white (95%), female (85%), and without a disability (73%). Their top 3 areas of expertise included nursing education (13.4%), adult health (10.2%), and advocacy (8.6%). For round 2, 39 of 64 of the original invitees were contacted. A total of 35 (59%) responded to round 2; this included 70% of the round 1 participants plus 2 additional
participants. Those 5 who were not invited to participate in round 2 either declined to participate in round 1 (4) or were not able to be contacted (1).

The university’s institutional review board approved the study. Participants were able to review the consent form embedded in the introductory email; clicking on the survey indicated consent to participate.

Procedure: Round 1
Beginning July 2017, experts were contacted via email, asking them to complete an online survey administered using electronic survey platform. A demographic profile asked participants about area of specialty, length of experience, professional role, whether they considered themselves to have a disability, gender, race, age category, highest degree, and organizational affiliation. The 43 competencies were presented in their original format, including domains and dimensions. Participants were asked to rate each competency on a 5-point Likert scale according to relevancy to prelicensure nursing education, from 1 (not relevant) to 5 (extremely relevant). After each dimension, the participants were also asked to provide comments and, at the end of the survey, to include an overall response to the domains, dimensions, and competencies as a whole. When data collection was complete, the first 2 authors met to discuss the quantitative and qualitative results and to revise the competencies for round 2.

Procedure: Round 2
Based on the quantitative and qualitative feedback from round 1, the researchers developed a revised list of 12 competencies, in 4 revised dimensions. A 4-point Likert scale assessed participants’ willingness to endorse each revised item, from 1 (do not endorse) to 5 (strongly endorse). The survey was again administered online using the electronic survey platform.

Analysis
Descriptive analyses were conducted on participant demographic data. As an indicator of endorsement in both rounds, analyses of Likert scales included the measures of central tendency, standard deviations, and consensus level. The literature provides no clear recommendation or scientific rationale for determination of consensus level; it can range from 51% to 100% depending on content of survey items. For example, Delphi studies completed to determine policy affecting life and death decisions would require a higher consensus level. Hsu and Sandford offered several sources of criterion, including a consensus of 70% on a 4-point Likert scale and a median greater than 3.25 or higher. A predetermined consensus level of 70% was chosen as acceptable; this translated into ratings of very and extremely relevant in items in the first round, then endorse and strongly endorse in the second round. To assess internal reliability in round 1, an analysis of variance (ANOVA) was performed to examine the variance within raters and between items.

Qualitative data were analyzed using content analysis. The brief responses were read by both researchers and coded into themes. Given the brevity of the responses and concise nature of the material, those themes were easily translatable into revisions of the competencies.

Results
Round 1 Quantitative Results
Internal consistency across all items was high, with a Cronbach’s α of .959. The mean values of the competencies ranged from 3.83 to 4.87 (within a potential range of 1-5); medians ranged from 4.00 to 5.00; and standard deviations ranged from 0.43 to 1.055. The mean standard deviation of all ratings for round 1 was 0.737. By combining very relevant and extremely relevant, all but 3 skill domain competencies reached the predetermined consensus of 70%. The 3 that did not reach consensus were: describes the difference between impairment and disability according to the WHO definitions (59.58%), verbalizes differences between primary and secondary conditions of PWDs (61.7%), and determines whether the PWD has advanced directive (68%). The 15 most highly endorsed items are available in the Table, Supplemental Digital Content, http://links.lww.com/NE/A655.

The ANOVA identified a significant difference within raters and between items ($F = 21.034, P < .01$), meaning that the raters approached the scale differently; although this is not uncommon for respondents from various experiences, it does suggest that the language is less precise than would be ideal.

Round 1 Qualitative Results
Themes were condensed into 3 focal points that guided competency development: unique knowledge, volume, and repetition, and omission of a distinct competency related to culture. There emerged a clear directive to differentiate the unique competencies needed to care for PWDs, above and beyond what would be expected in the provision of high-quality nursing care in general. According to participants, the number of competencies (43) was overwhelming and many items appeared repetitive. There was consensus that the major competencies were lost in the volume. This was further supported by the differences in scores between raters. Content specific to the culture of disability and culture as part of the care of PWDs appeared to be missing or lost. One participant noted that an “awareness of social/cultural limitations PWDs face within our health care system and society as a whole” was critical for nurses.

Revision Phase
Quantitative and qualitative results were analyzed concurrently. Guided by the need to isolate those competencies that specifically addressed what was required above and beyond the basic expectations of a nurse, the authors identified that critical information first. Although all but 3 individual items met the basic numerical threshold for inclusion, all items were systematically assessed in terms of fitting within the new, narrower vision of the intent. Although the threshold was set at 70%, items that did not reach 80% consensus were examined more closely.
using both quantitative and qualitative data. Competencies were combined and revised, whereas others were omitted completely (eg, the prelicensure student determines if the PWD has an advanced directive). Ultimately, 12 competences emerged within 4 dimensions: environment and care (6), communication (3), culture (2), and referral (1).

Based on the feedback from round 1, the authors decided that it was important to include some context in which the new revised competencies should be considered. Therefore, the introduction to round 2 emphasized to participants that the competencies were intended to specifically focus on the care of PWDs and would be complementary to the Nursing Professional Scope of Practice, Standards of Practice, Code of Ethics, and various specialty certifications.

Round 2 Quantitative and Qualitative Results
The reliability of the new competencies was high; the Cronbach’s α for round 2 survey items was .85. The mean values of the competencies ranged from 3.2 to 3.69 (with 3 being endorse and 4 strongly endorse); all but 1 item had a median of 4, and the remaining 1 item had a median of 3. The mean standard deviation of all ratings for round 2 was 0.715. All competencies reached an endorsement score well above the predetermined consensus of 70%. The researchers assessed quantitative and qualitative results and made very minor editorial revisions to the competencies in response. The Table provides the final list of revised competencies.

Discussion
Our study produced a set of 12 competencies that meet an important and acknowledged need. The flexibility and simplicity of these competencies could eliminate the barriers to include disability content in the nursing curricula as identified by Ilkhani et al.20 Once tested with students and shown to have an impact on care, the competencies could provide a framework for establishing focused learning outcomes across a prelicensure nursing program.

The strongest message that came from participants was the need to delineate the competencies for care within the context of what is considered to be universal high-quality nursing care. As such, the competencies were revised and presented with a clear statement about the intent of the document to complement those existing benchmarks. We should caution that often the most basic aspects of health care are overlooked in the care of PWDs,32 and we should be mindful to not compromise standards, thus contributing to the health disparities. In addition, these nurse-focused competencies could address concerns from faculty about disability education that is too focused on the medical model, as they focus on the holistic needs of the person.20

A list of competencies, however useful to organize concepts and delineate an area of specialization, is ultimately just a list. The more important step is turning the list into meaningful learning and measurable outcomes that demonstrate improved patient care. Based on the educational setting and program outcomes, each competency can be uniquely applied to include specific components of knowledge, skills, and attitude.

Limitations
There are limitations to this project and approach. First, there may be a selection bias with participants, including those who more explicitly value the content of the material, to the exclusion of those who are more grounded in the

Table. Competencies for Care of People With Disabilities for Prelicensure Nursing Students

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<tr>
<th>Environment and care</th>
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<tbody>
<tr>
<td>Integrate the full range of health care services (eg, primary nursing care, routine screenings, prevention) pertaining to the wellness and health promotion of the person with a disability.</td>
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<td>Apply legal and ethical principles to provide optimum health care to the person with a disability.</td>
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<tr>
<td>Determine the social, cultural, and biophysical constructs, individually and collectively, impacting the health of the person with a disability.</td>
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<tr>
<td>Identify potential barriers (eg, attitudinal, environmental) to optimum health care and functioning affecting the person with a disability and strategies to address the barriers.</td>
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<tr>
<td>Identify signs and symptoms of abuse and the increased risk for abuse, neglect, and exploitation in the person with a disability.</td>
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<tr>
<td>Demonstrate knowledge about the interaction of disability and other health states (eg, pregnancy and childbearing, transitions across the lifespan).</td>
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<th>Communication</th>
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<td>Demonstrate respect for the autonomy of the person with a disability using appropriate disability etiquette/language such as person first language.</td>
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<tr>
<td>Communicate directly with the person with a disability and family/surrogate.</td>
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<tr>
<td>Describe and use alternative communication strategies and technologies, as appropriate for the person with a disability and the situation.</td>
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<th>Culture</th>
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<td>Acknowledge the core cultural values of the person with a disability through communication and demonstrated interactions.</td>
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<td>Provide person-centered care that is culturally appropriate and informed by unique life experience of the person with a disability.</td>
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<th>Referral</th>
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<td>Refer to the complex system of interdisciplinary services and health care resources available to provide care for the person with a disability.</td>
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generalist or other specialty role. Although this could influence the findings, the intent was to amplify those voices, including participants with disabilities. In addition, this project was presented singularly and does not provide insight into how such competencies actually fit into existing curricula. As with many projects like this, this step likely represents an “ideal,” and we are now challenged to take this next more difficult step of implementation.

Conclusions

For too long, education about the care of individuals, families, and populations dealing with a disability have been considered to be inherent in nursing curricula. Research and advocacy efforts over the last 25 years have shown unequivocally that nurses who want to contribute to the health and well-being of the people they seek to serve must receive a deliberate and evidence-based set of learning objectives that is firmly grounded in the distinctive needs of PWDs. These revised competencies are an important first step in achieving those goals.

Acknowledgments

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References