

PREPARING FOR THE NEXT HEALTHCARE CRISIS: AN EXPLORATION OF
STUDENT-PERCEIVED PREPAREDNESS TO CARE
FOR PEOPLE WITH DEMENTIA

By

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Abstract

Dementia-specific education is invaluable for improving student nurses' care for a person with dementia and equipping them with a more complete understanding of each person with dementia. The purpose was to explore student perceptions and ideas of their preparedness to provide care for people with dementia in the hospital. This study was a qualitative design consisting of multiple focus groups facilitated by the student investigator. Four focus groups were conducted with students in their final semester of an undergraduate nursing school. Analysis brought forth the following themes: (1) Dementia knowledge, (2) desire for more dementia-specific education, (3) clinical relevancy, (4) poor care for people with dementia observed, and (5) perceived low preparedness by students. Recommendation includes the incorporation of key dementia-specific education such as the Virtual Dementia Tour® into the nursing curriculum to improve perceived preparedness by students and fulfill the students' desire for a more complete education on dementia.

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Improving Dementia-Specific Nurse Education:
An Exploration of Student Perceptions and Ideas

Student nurses generally express fear and apprehension when caring for patients with dementia (Kimzey, Mastel-Smith, & Alfred, 2016). Dementia alters an individual's ability to think, communicate, focus, reason, and perform everyday activities (Alzheimer's Association, 2016). In an effort to better prepare student nurses to provide quality care for this population, the Texas Board of Nursing has extended education on dementia to two different semesters. However, this education is limited and may be inadequate to prepare students to care for people with dementia.

Dementia-specific education is invaluable for improving student nurses' care for a person with dementia (PWD) and equipping them with a more complete understanding of each PWD. Incorporating innovative learning activities, such as the Virtual Dementia Tour® (VDT), with nursing students may further improve upon students' care for a PWD. This research will answer the clinical question: How prepared are students to understand and meet the healthcare needs of PWD? To answer this, the student researcher conducted focus groups to explore the perceptions of nursing students in their final semester about their confidence and competency of caring for a PWD. The purposes of these focus groups were to (1) explore the students' knowledge and attitudes about dementia, (2) explore the students' perceptions of their ability to care for a PWD, (3) explore students' thoughts and feelings about the level of dementia-specific education they received, and (4) explore ideas students may have to improve dementia specific education for the coming students. The findings provide insight into how well universities are preparing graduating nursing students to care for this growing patient population and will be used to further the development of the dementia-specific education used at this campus.

Theoretical framework

Social cognitive theory (SCT; Bandura, 1977) served as the foundation for the study. Bandura (1986) bases SCT upon the reciprocal determinism model of causation as shown in Appendix A. The social cognitive theory is an appropriate framework for the project because it suggests that students may adopt a new behavior through a change in personal and environmental determinants. This framework accounts for many of the different methods of education that may be used in nursing curriculum including clinical experience, lecture, and the VDT. The SCT, rather than personal instincts, served as a guide for this research as it has stood as a valid theory for decades.

Theoretical Definitions

The social cognitive theory (SCT; Bandura, 1977), previously called social learning theory, emphasizes mediational processes as critical components of human learned behavior. This theory defines learning as the process which occurs in a social context with a dynamic and reciprocal interaction of the person, environment, and behavioral determinants. Bandura (1986) uses SCT to explain human learned behavior in terms of triadic reciprocal determinism. Personal, behavioral, and environmental factors make up this triad and are explained below.

Personal determinants are considered the biological, cognitive, and emotional processes unique to each individual. Self-efficacy and empathy fall under the category of personal determinants. To address personal determinants, one factor of the triad, focus group questions were aimed to explore students' personal connection to dementia. Environmental determinants refer to external factors such as social influences and observed experiences. Questions inquired about students' clinical experiences address this triadic factor. Behavioral determinants are considered one's actions and behaviors. Questions pertained to actions students take to incorporate this factor into the study. The student researcher looked specifically at how students feel they would be able to provide care for a PWD as a graduate nurse and how they felt their

personal experiences compared to their dementia-specific education in preparing them to provide care for a PWD.

Operational Definitions

Dementia specific education is defined as education pertaining only to dementia. This can include education on how to care for a person with dementia and the pathophysiology behind dementia. The Virtual Dementia Tour® is a learning activity designed to simulate dementia. The components of the simulation will be addressed in this project by exploring participants' thoughts on how to improve dementia-specific education. Gaining insight into students' perceptions may serve as invaluable information to improve the outcomes associated with dementia-specific education. Bandura's model of reciprocal determinism (1986) will guide the initial focus group questions.

Literature Review

CINAHL, ERIC, Medline, and PubMed were searched using the following terms: *dementia, Alzheimer's disease, nurs* student*, nurs*, educat*, memory loss, and dementia train**. Searches were limited to articles published within the past seven years and in English. Reference lists were reviewed for additional evidence pertinent to nursing education and memory loss. The most frequently measured outcomes included attitudes toward PWD and dementia knowledge. Instruments used to measure were inconsistent across studies as most authors created instruments to assess outcomes. Because few studies were located that specifically discussed dementia education outcomes in nursing, evidence representing dementia education among other health professional disciplines is included in the following review. The student researcher aims to address the deficiency in nursing specific studies by exploring ways to improve future dementia education programs via this research study.

Dementia Learning Activities: Quantitative Studies

Researchers used various tools and instruments to measure the impact of different learning activities on students' dementia knowledge and attitudes of PWD. Shin, Seo, Kim, Kim, and Lee (2015) found coupling lecture with clinical experience to have a significant positive effect on nursing students' knowledge about a PWD. Likewise, Kimzey, Mastel-Smith, and Alfred (2016) reported significantly improved knowledge and attitudes toward PWD in nursing students with dementia-specific clinical experiences than in nursing students equipped only with online training modules or nursing students who received no dementia-specific training. Maharaj (2017) further reported students who cared for a simulation patient with dementia had significantly improved Alzheimer's disease knowledge compared to students who cared for patients which did not suffer from cognitive impairment. These researchers' findings support Bandura's social cognitive theory and suggest observational learning, such as clinical experience, can significantly improve nursing students' knowledge and attitudes about PWD.

Dementia Learning Activities: Qualitative Studies

There is a huge gap in literature regarding strategies to improve dementia learning activities in nursing education. Qualitative research studies have been done exploring students' response to dementia specific education including: clinical placements with PWD (Baillie, Cox, & Merritt, 2012a; Baillie, Merritt, & Cox, 2012b; Baillie, Merritt, Cox, & Crichton, 2015; Jordan & Church, 2013; Lea et al., 2015; McKenzie & Brown, 2014) simulation clinical experiences with PWD (Donahoe, Moon, & VanCleave, 2014), and multi-modal learning activities (Lorio, Gore, Warthen, Housley, & Burgess, 2016). Students reported that staff often lacked knowledge and had poor attitudes toward dementia care (Baillie et al., 2012a) which negatively affected their experience (Baillie et al., 2015). Research indicates that students feared the unknown (Kimzey et al., 2016) and aggressive patients (Baillie et al., 2015). Overall, qualitative studies reported students' observations of people with dementia and feelings toward PWD and the

efficacy of dementia specific education, but there were no reports on improvements to interventions. Although there are no apparent data on how to further advance dementia learning activities, the student researcher acknowledges these findings as useful to the project as findings assist in developing more pertinent focus group questions.

Virtual Dementia Tour

Digby (2016) demonstrated nurse empathy to be a vital element to provide quality care to PWD in the hospital. The Virtual Dementia Tour[®] (VDT) was developed to enhance understanding of what it is like to experience memory loss and ultimately improve care for PWD (Beville, 2002). The simulation uses sensory tools to simulate dementia, and trained facilitators guide participants through a series of tasks followed by a debriefing. There is mixed evidence suggesting VDT's effectiveness on students' knowledge of dementia and emotional responses to PWD. Physical therapy students experienced significantly improved knowledge and attitudes of caring for PWD (Lorio et al., 2016); social work students (Donahoe, Moon, & VanCleave, 2014) reported greater understanding of PWD's emotional needs. In contrast, Brown et al. (2014) found VDT to have no significant effect on students' interactions with PWD or recognition of personhood in PWD. Nursing students who participated in the VDT plus a dementia lecture did not report greater empathy compared to the control group who received only the dementia lecture (Kimzey, Mastel-Smith, & Seale, 2018). Because of the conflicting evidence on the efficacy of VDT, further investigation is necessary to demonstrate the efficacy of VDT as a successful educational tool. The student researcher's findings add important knowledge of how prepared nursing students are to care for a PWD and identifies potential growing points for nursing curriculum.

Nursing Curriculum

According to standardized nursing curriculum, dementia falls under the “cognition” concept. While “cognition” is addressed as a concept in multiple courses, dementia is specifically addressed only in Foundations of Nursing Care Concepts and Behavioral Health Concepts. (American Psychiatric Nursing Association, 2019) However, both courses have dementia grouped together with other alterations. The exemplar for the Foundations of Nursing Care Concepts course reads, “management of patient with altered mental status-dementia vs. delirium”. After reviewing the PowerPoint that corresponded with that lecture, it was clear that the focus was on differentiating between dementia and delirium rather than caring for a person with dementia. The exemplar for the Behavioral Health Concepts course reads, “Dementia, Delirium, Depression.”

Methods

Design

This study was a qualitative design consisting of multiple focus groups facilitated by the student investigator.

Sample and Setting

The inclusion criteria were: (a) students enrolled in a baccalaureate nursing program and (b) currently enrolled in the program’s final semester simulation course. Qualitative data was collected from fourteen (14) students who participated in an audio taped focus group. The focus group lasted approximately 60 minutes. Focus group data was collected in a private quiet location on campus.

Ethical Considerations

The study was approved by the university Institutional Review Board where the student investigator was enrolled. Students provided written informed consent and informed that there is no penalty for refusal to participate. To ensure data remained confidential names were not used in focus group discussions and students were reminded to keep information shared private. Data was stored in faculty investigator's password protected laptop.

Procedure

The student investigator recruited participants from the intervention group to explore their perspectives of their growth and their ideas to improve the simulation experience to better support student learning and understanding of people with dementia. Four focus groups were conducted with two to five participants each ($N=14$).

Recruitment

The student investigator recruited participants via word of mouth and flyers to explore their perspectives of their growth and their ideas to improve the simulation experience to better support student learning and understanding of people with dementia. On the day of the focus group, the student researcher explained the purpose of the study, that all data will be confidential, and asked participants not reveal information shared in the focus group with others. The student researcher also explained that participants can stop at any time without penalty. Signed informed consent was obtained on the day of the focus groups (Appendix B).

Data Collection

Following informed consent, the student investigator facilitated focus groups at a time mutually convenient for the participants and themselves. Focus groups were initially structured around Bandura's (1989) model of triadic reciprocal determinism. After the research questions had been addressed, the student researcher allowed the conversation to flow naturally as to let the participants discuss their thoughts and feelings as they arise. Research questions aimed to

explore how confident and competent students feel about caring for people with dementia, how well prepared they are to care for a PWD, and what did or did not work well for them (Appendix C). Focus groups were audio recorded and data transcribed verbatim by the faculty investigator.

Data analysis

Following professional transcription, the student and faculty investigator individually analyzed the focus group transcriptions. The investigators used content analysis. After completion of the individual data analysis, the student and faculty investigator compared findings to assure reliability. The researchers did not find a discrepancy in their findings and no further analysis was necessary to continue from there. The investigators also identified ongoing and repeated words, ideas, or phrases by the participants to capture the overarching themes of each focus group. Line by line coding identified the smallest units of meaning which were categorized and themes identified as they emerge from the data.

Results

There were fourteen students in four different focus groups. Analysis brought forth the following themes: (1) dementia knowledge, (2) desire for more dementia-specific education, (3) clinical relevancy, (4) poor care for a PWD observed, and (5) perceived low preparedness by students. While quotes are included in this section, an exemplar quote has been chosen for each of the themes (Appendix D).

Dementia knowledge

Most all participants demonstrated some dementia knowledge during the focus group. Participants identified the need to, “be patient and give [the patient] the time they need to calm down,” and to, “be compassionate,” when caring for a PWD. Additionally, participants emphasized that, “the family is a really good resource to use” and that, “the better you know a person with dementia, the more you are able to understand what they are feeling”. Finally,

participants were able to identify the importance of not reorienting a PWD, which is essential in caring for a person with dementia.

Desire for more dementia specific education

Another theme brought forward was the desire for more dementia-specific education. Participants insisted that this is, “something that just needs a lot more attention.” Students identified many different opportunities they would like to see more dementia specific education added into their classes such as Health Assessment, Behavioral Health, and Foundations of Nursing. Essentially, participants described a desire to see dementia introduced earlier in the nursing curriculum. One student summed up the participants’ overall desire for more dementia-specific education saying, “nurses should be caring for people, so teach us how to care for them.” The desire to learn more is important because it shows that students may be receptive to additional dementia education.

Clinical relevancy

Participants acknowledged the likelihood that they would care for people with dementia at some point in their nursing career. Clinical relevancy was established early on in each focus group. Participants noted that the population of people with dementia is growing and is, “inevitable for any nurse in just about any situation.” Some participants were extremely passionate and begged the question, “How can we throw out the statistic that the majority of the people using hospice is because of dementia but we covered it in four slides?” Although this patient population is less, “fun” to take care of, the aging Baby Boomers will lead to a further increase in the population of people with dementia.

Poor care for people with dementia observed

Unfortunately, participants noted poor quality of care for people with dementia by the nursing staff they were paired with in clinical. Participants observed nurses refusing to change the patient's soiled clothes, ignoring the patient, and overall providing subpar care to people with dementia. One participant noted that, "It's just so easy [for nurses] to neglect [people with dementia] and you're like: Wow you just dehumanize them because you don't think they remember". Others expressed that the care they had observed, "made me so mad." The desire for better care for people with dementia is uplifting and shows a brighter outlook for future patients.

Perceived low preparedness by students

The final – and arguably the most important – theme that arose was a perceived low preparedness by participants. Participants expressed feelings of uncertainty and apprehension to caring for people with dementia. Quotes that support this theme vastly outnumber the other themes and vary from acknowledgements that caring for this patient population will be, "overwhelming" and "challenging" to admissions that nursing school, "hasn't taught me anything more than what I've already known." As mentioned above, participants expressed a lack of exposure to dementia in the clinical setting. The participants linked this limited exposure to their feelings of low preparedness. Participants want to provide quality care to their patients, but fear they are unable to do so. One participant exemplifies this by saying, "People, in general, aren't educated. Not that we're really educated on this, but people that just don't really know how to deal with that might not deal with it in the best way possible." This perceived low preparedness by students is alarming and hopefully prompts administration to consider adding dementia-specific education into nursing curriculum.

Discussion

The researcher believes each identified theme is present due to specific reasons. Further exploration may be beneficial in determining where exactly each of these themes originated. Themes, along with their background and believed reasoning, are discussed in detail below.

Basic dementia knowledge was demonstrated at some point by each student in the focus group. This basic dementia knowledge is believed to arise from the limited dementia specific education that currently exists in nursing curriculum. Although participants accurately identified elemental principals of dementia care, they still expressed a desire for more dementia specific education to improve their understanding of this patient population. Lecture coupled with clinical experience could be the most effective way to increase students' perceived preparedness to people with dementia. Additionally, the researcher believes that incorporating the VDT into nursing curriculum would be beneficial for student understanding of dementia.

Many participants asked the student researcher why more dementia-specific education is not included more heavily in the nursing curriculum. In a personal interview (E. Muensterman, March 20,2019), a representative from a large regional hospital in North Texas stated that approximately 25% of their patients have a diagnosis of dementia and estimates that number would be much higher if it considered the patients who have dementia but not a formal diagnosis. Additionally, dementia is a growing topic on the National Council Licensure Examination (NCLEX) – the accrediting exam that nurses must pass to be licensed (National Council of State Boards of Nursing). Currently, up to 9% of a student's NCLEX questions may pertain to dementia (S. Evans, personal communication, April 10, 2019).

Because of the increased prevalence in dementia and apparent lack of confidence in caring for people with dementia, students need more dementia-specific education. Some students proposed dementia-specific education be introduced as early and as frequently as diabetes. Others rallied behind the idea of structured clinical exposure to dementia. Many students leave

nursing school with little to no interaction with a PWD. The fact that students are requesting more education on a patient population that they are, “not particularly ... head over heels about” is evidence that they understand the importance of dementia specific education and truly have a desire to properly care for a person with dementia. It is clear that students feel they need more exposure to dementia to adequately provide care to these patients.

Recommendations

In conclusion, the student researcher recommends an increase in dementia specific education in nursing curriculum. Currently, dementia is mentioned only twice in the Texas Board of Nursing Curriculum Crosswalk Table (APNA, 2019). This low exposure leads to inadequately prepared students. To better prepare students to care for people with dementia, the researcher recommends coupling of lecture and clinical experience along with participation in the VDT.

As much of the literature shows, lecture should be combined with clinical experiences to provide the best learning outcomes for students. To accomplish the lecture half of this, dementia should be introduced earlier and more frequently in nursing coursework. To address the clinical piece, instructors should encourage students to seek out encounters with people with dementia rather than avoiding them and address such encounters in daily debriefing. Further inclusion of dementia-specific education could be considered to include a clinical piece, such as clinical time at a memory care facility.

Participants who participated in the Virtual Dementia Tour® expressed how paramount this was to their education. One even stated: “Without the VDT, I would be completely inept”. The evidence showing how the virtual dementia tour improves student self-efficacy and empathy is astounding. Therefore, it is recommended that the VDT be incorporated into the nursing curriculum.

Limitations

While the researchers were diligent in this research, no study is without limitations. Limitations for this study include convenience sampling, small sample size, and use of self-reported data. Convenience sampling was used in this study. To improve on future research, a probability sampling could be used. The sample size ($N=14$) should be expanded in future research to make findings applicable to greater populations. Finally, the use of self-reported data poses as a limitation because it cannot be independently verified. Participants may exaggerate experiences or may have selective memories pertaining to questions the researcher posed in focus groups. Taking these limitations into account when reviewing this paper is crucial for a better understanding of the results.

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Appendix A

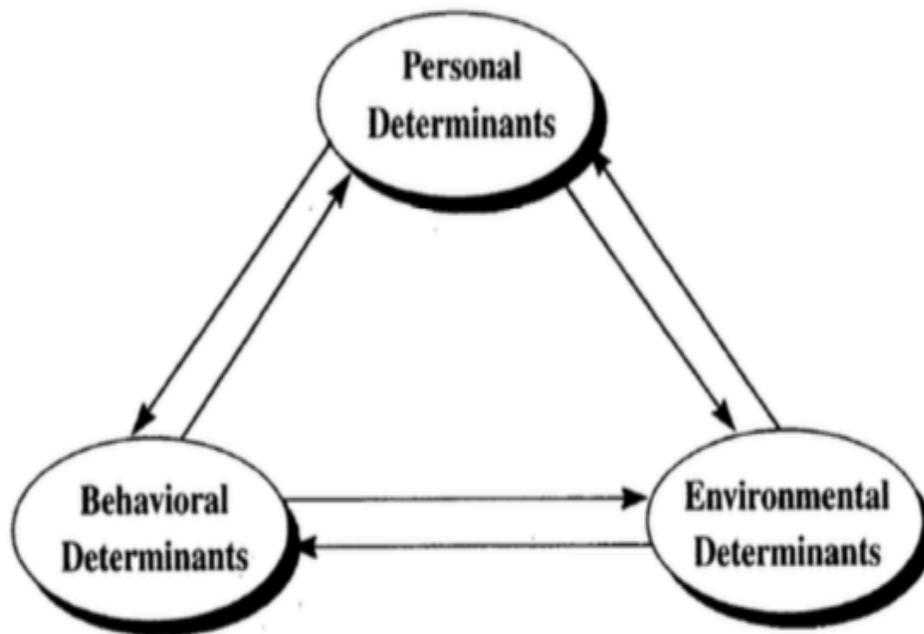


Fig. 1. Interplay of determinants in the causal model of social cognitive theory (Bandura, 1986).

Appendix B

Focus Group Consent
Texas Christian University
Informed Consent to Participate in Research
Institutional Review Board #
Approval Date:

1. **Project Title:** *Preparing for the Next Healthcare Crisis: An Exploration of Student-perceived Preparedness to Care for People with Dementia*
2. **Student Investigator:** *Kayla Pair*
3. **Participant's Name:**

To the Participant:

You are being asked to take part in this study at Texas Christian University (TCU). This permission form explains:

- Why this research study is being done.
- What you will be doing if you take part in the study.
- Any risks and benefits you can expect if you take part in this study.

After talking with the person who asks you to take part in the study, you should be able to:

- Understand what the study is about.
- Choose to take part in this study because you understand what will happen.

4. **Description of Project:** The purpose of this study is to explore ways to improve dementia specific learning and to learn about the effect of learning activities that you experienced in CRiS III, your understanding of memory loss, and perceived ability to take care of someone with dementia.
5. **Research Procedures:** If you agree to be in this study, you will:
Meet with a research team member along with other students. Together you and the other students will share your perceptions of the dementia learning activities you had this semester in CRiS III. Your answers will be recorded and written out later. This session should not last more than 45 minutes to an hour.
6. **Potential Risks:** A potential risk is the loss of privacy. The research team member will make every effort to keep all of your information private. A code number will be used to identify your answers not your name, your answers will be entered into a computer that is password protected and the paper copies will be kept in a locked file cabinet that only the researchers can open. You will not be identified by name.
7. **Potential Benefits:** Sharing your experiences with dementia learning activities will help to improve future nursing education.

Understanding of Participants:

8. I have been given a chance to ask any questions about this research study. The researcher has answered my questions.
9. If I sign this consent form I know it means that:
 - I am taking part in this study because I want to. I chose to take part in this study after having been told about the study and how it will affect me.
 - I know that I am free to not be in this study. If I choose to not take part in the study, then nothing will happen to me as a result of my choice.
 - I know that I have been told that if I choose to be in the study, then I can stop at any time. I know that if I do stop being a part of the study, then nothing will happen to me.

- I will be told about any new information that may affect my wanting to continue to be part of this study.
 - The study may be changed or stopped at any time by the researcher or by Texas Christian University.
 - The researcher will get my written permission for any changes that may affect me.
10. I have been promised that that my name will not be in any reports about this study unless I give my permission.
11. I also understand that any information collected during this study may be shared as long as no identifying information such as my name, address, or other contact information is provided). This information can include health information. Information may be shared with:
- Organization giving money to be able to conduct this study
 - Other researchers interested in putting together your information with information from other studies
 - Information shared through presentations or publications
12. I understand Texas Christian University Institutional Review Board (the group that makes sure that research is done correctly and that procedures are in place to protect the safety of research participants) may look at the research documents. These documents may have information that identifies me on them. This is a part of their monitoring procedure. I also understand that my personal information will not be shared with anyone.
13. I have been told about any possible risks that can happen with my taking part in this research project.
14. I also understand that I will not be given money for any patents or discoveries that may result from my taking part in this research.
15. If I have any questions concerning my participation in this project, I will contact the student researcher: Kayla Pair at 214-998-1286 or email kayla.rae.pair@tcu.edu
16. If I have any questions concerning my rights as a research subject or with questions about research-related injuries, I will contact Dr. Tim Barth, Co-Chair, TCU Institutional Review Board, Phone: 817-257-6427

CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY

I have read and understood what has been explained to me. I give my permission to take part in this study as it is explained to me. I give the study researcher permission to register me in this study. I have received a signed copy of this consent form.

Signature of Participant

Date

Witness to Signature

18. I have discussed this project with the participant, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks. I believe the participant understood this explanation.

Researcher/Principal Investigator

Date

Appendix C

Focus Group Interview Schedule

1. Tell me about your thoughts and feelings about PWD.
2. Tell me what you know about PWD.
3. Tell me about your thoughts and feelings about the VDT.
4. What was the most significant thing about the VDT for you?
5. Has the experience changed you in any way? Tell me about that.
6. Did the VDT influence your dementia simulation experience?
7. How could the VDT better influence your dementia simulation experience?
8. Could anything about the VDT be changed to better improve the way you care for PWD?

Appendix D

Focus Group Themes and Exemplar Quotes

Theme	Exemplar
Dementia Knowledge Demonstrated	“No matter if they are on the same level of the [dementia] spectrum, they’re going to behave differently because they have different experiences”
Desire for More Dementia Specific Education	“I feel like nurses should be caring for people, so teach us how to care for [people with dementia]”
Clinical Relevancy	“It’s just not particularly a population that I’m totally head over heels about, but it’s still something that is inevitable for any nurse in just about any situation”
Poor Care for People with Dementia Observed.	“It’s sad because she couldn’t even say anything for herself”
Perceived Low Preparedness by Students	“For someone with dementia, making sure the family knows how to care for them and how to communicate with them and what to do is super important. And that’s something that we have next to no knowledge on”