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Ethics of Neurocognitive Disorders

Jenna C. Schneider

Western Michigan University

Abstract

Many individuals have misperceived ideas of what neurocognitive disorders are and how to effectively treat and care for individuals that have these disorders. Individuals working in healthcare need education on what neurocognitive disorders are to be able to provide ethical interventions, and have general knowledge on how to provide care to these people.

Neurocognitive disorders, especially among older individuals, is a prevalent health complication that needs attention in order to prevent misunderstanding, and increase the possibly of knowing when intervention is needed. Additional training directed towards ethical practices is essential for both the understanding of caregivers and for the safety of the individual with a neurocognitive disorder. The study aimed to assess experiences working with individuals with neurocognitive disorders and their opinions about the effectiveness of additional training. An anonymous survey was created in order to determine this. The participants were male and female undergraduate students between the ages of 18- 50 at Western Michigan University (WMU) that were either a healthcare provider or are studying to become one. The results of this study indicated that a majority of students would want additional training on neurocognitive disorders and there were correlations between the confidence a student had and the amount of training they have received. These findings suggest that it would be beneficial to have additional trainings for healthcare workers pertaining to ethically working with these individuals through both place of employment and through additional material in health training programs at the university.

Keywords: neurocognitive disorders, training, healthcare students

Introduction

A neurocognitive disorder is an acquired cognitive decline that interferes with daily living and independence (Ganguli et al., 2011). This includes decreased cognitive abilities, ability to perform activities of daily living, and a decrease in memory and social capabilities. Neurocognitive disorders may be the result of a degenerative brain disorder or other secondary conditions (Sousa et al., 2020). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) has three categories for cognitive disorders: delirium, mild neurocognitive disorders, and major neurocognitive disorders (McDonald, 2017). Some examples of neurocognitive disorders are Alzheimer's disease, Frontotemporal dementia, or Vascular dementia (McDonald, 2017). Individuals with neurocognitive disorders often are forced to rely on caregivers to offer support with activities of daily living. Caregivers can be family members, friends, or staff from an assisted healthcare program. Improper training can lead to unethical practices such as caregiver burnout, increased burden due to not knowing how to properly care for the individual, and a decrease in safety for both the caregiver and individual with the neurocognitive disorder (Novais et al., 2018).

Healthcare ethics has been an ongoing concern for years; however, it has started to become more emphasized in healthcare curriculums. When healthcare workers observe their colleagues or the healthcare organization participate in unethical practices, this can lead to stress, burnout, and demoralization (Gabel, 2011). It has been found that students who have observed an incident of unethical behavior among other students were more likely to engage in unethical practices in fear of not fitting in or receiving a poor evaluation from their peers (Papadakis et al., 2005). As ethics are often considered as a perception of what is considered morally acceptable, healthcare workers would benefit from regularly scheduled trainings or seminars, consultations

about ethical practices, and discussion groups (Gabel, 2011). If ethics are not properly taught or trained in healthcare, individuals often rely on peer observations to indicate how they should behave (Papadakis et al., 2005).

Understanding how to ethically treat and care for patients with neurocognitive disorders is essential as the number of individuals increases dramatically each year. Approximately 40% of individuals over the age of 85 are diagnosed with Alzheimer's disease and the worldwide estimate of individuals diagnosed with dementia doubles every 20 years (McDonald, 2017). In 2010, there were 35.5 million individuals worldwide that were diagnosed with dementia and it is estimated by the year 2030 that the number will increase to 65.7 million individuals and 115.4 million by the year 2050 (McDonald, 2017). In the United States alone, about 5.2 million people are diagnosed with Alzheimer's disease (Gaugler et al., 2018). Alzheimer's disease is the most common type of neurocognitive disorder and this disease can last between 3 to 20 years (Gaugler et al., 2018). As the number of individuals diagnosed continues to rise, specific training should be provided for every healthcare provider in order to provide ethical care, treatment, and practices.

As many individuals with neurocognitive disorders reside in nursing homes or assisted living facilities, it is essential that all the staff have adequate training. Almost two-thirds of all United States nursing homes having residents with some type of a cognitive impairment (Gaugler et al., 2018). Requirements for training fail to adequately address many mental health problems as many training programs focus on medical care and lack in behavioral healthcare. Having required mental health training can result in safer and more ethical practices, and caregiver and staff satisfaction (American Geriatrics Association, 2003).

Without proper training of how to ethically work with individuals with neurocognitive disorders, unethical practices may take place. Potential ethical training topics should include what neurocognitive disorders are, correct and incorrect ways to care for patients, coping strategies when feeling frustrated, and behavioral intervention techniques. Many individuals working in healthcare have had little or no training related to working with individuals with neurocognitive disorders, resulting in a lack of knowledge of how to ethically deal with complex situations (Kallivayalil, 2012). Although it can be difficult to work with individuals with neurocognitive disorders, it is still expected that ethical practices take place. Proper training can also allow for more effective communication, which can help decrease frustration for both the caregiver and the individual (Kallivayalil, 2012).

The purpose of this study was to assess students' understanding of neurocognitive disorders and to identify if additional training would be beneficial. As many students know someone or work with individuals with neurocognitive disorders, it is essential to have an understanding of what they are and how to ethically care for them. It was predicted that many students may think they know what neurocognitive disorders are, but lack ethical considerations when providing assistance to these individuals when needed. The purpose is to observe how students answer the questions in the survey, and make correlations between healthcare experience and the amount of training the students have or have not received.

Literature Review

There is not much research that assessed undergraduate students' understanding of neurocognitive disorders and whether they would want additional training. Most of the studies are centered around the caregiver's personal belief of whether there are unethical practices,

aggression in the facility, or if they believe that high quality care is being administered. Although this does have a similar message that ethical care needs to be improved, most of the studies found do not survey if additional training would be wanted or evaluated their confidence level in working with someone with a neurocognitive disorder.

A study surveying 464 medical students asked questions relating to healthcare ethics and professionalism in their education and observations (Yadav et al., 2019). Of the students surveyed, 40.8% indicated that they have seen unethical behavior among other students and 28.3% indicated that they have not received adequate training in healthcare ethics (Yadav et al., 2019). The study also demonstrated that a larger percent of medical students indicated that they have had some form of healthcare ethics training as the number of years they have been in medical school increased (Yadav et al., 2019). In year 1, only 55.3% said they have had some form of training and by year 5, 87% indicated that they have (Yadav et al., 2019). This may have been due to the fact that the medical students perceived healthcare ethics training as personal experiences or observations (Yadav et al., 2019). Although the survey questions are closely aligned with what is being studied, these questions do not address ethics surrounding neurocognitive disorders.

A study observing the impact of training on ethics on nursing students demonstrated that students who had gone through ethics training were more likely to be able to correctly identify when there were ethical violations and be able to identify correct examples (Baykara et al., 2014). In this study, 25 nursing students went through ethics training and consultancy services, while 25 students did not (Baykara et al., 2014). After the training, all students were given questions to answer involving ethical sensitivity, situations, as well as clinical observations (Baykara et al., 2014). The study concluded that after training, the ethical sensitivity of students

increased in comparison to the students who had not received the ethics training (Baykara et al., 2014).

Another study was conducted in a nursing facility surveying 497 caregivers in 7 different nursing facilities in order to evaluate the quality of care and safety that their residents were being offered (Buljac-Samardžić & van Woerkom, 2018). The results of this survey indicated that only 13.3% of the participants considered that the care they provided to be high quality and 22.2% of the participants experienced aggression incidents frequently (Buljac-Samardžić & van Woerkom, 2018). Although the survey did not discuss whether additional training would be desired, these results indicate that a very few percent of the caregivers feel strongly about their ability to offer safe and high quality care. Care that is safe, ethical, and high quality derives from additional training.

There was a study that evaluated the confidence that primary care providers (PCPs) had on effectively treating and diagnosing individuals with neurocognitive disorders. A survey conducted to evaluate PCP's performance demonstrated that only 20% of these individuals reported being highly confident in interpreting the results from cognitive tests and 14% reported being highly confident to recognize a patient had a neurocognitive disorder (Bernstein et al., 2019). With the growing number of individuals who are diagnosed with neurocognitive disorders each year, it is essential that adequate training of all healthcare providers is given to ensure ethical treatment and practices.

Methodology

Participants

Participant Description:

The participants for this study were any undergraduate students at Western Michigan University who were between the ages of 18-50 years old. In order to complete the survey, they must have worked in healthcare or have the intention to. There were 65 participants total in this study. Of the 65 participants, 43 individuals indicated that they had worked in healthcare and 21 individuals indicated that they had not yet worked in healthcare yet.

Subject Recruitment:

The student investigator worked closely with the Psychology 1000 class at WMU, which is where the majority of the survey responses derived from. The survey was approved by Western Michigan University Human Subjects Institutional Review Board (HSIRB) on April 5, 2021 (IRB # 20-03-29). The students were recruited by emailing an approved script (Appendix A) along with the link to the questionnaire. The students were offered two points of extra credit by screenshotting the last page of the survey (Appendix B) and then emailing this to the student investigator. Another form of distribution was through the principal investigator sending the link to students WMU's School of Interdisciplinary Health Services Programs. Participation in this survey was voluntary and the responses were anonymous.

Measures

The study was conducted fully online through a survey. The survey questionnaire was designed to assess students' understanding of neurocognitive disorders and whether these individuals would want additional training. Students filled out the questionnaire based on their personal assessment of how strongly they agreed or disagreed with the option.

Survey Format:

All data were collected through an anonymous online survey created by the student investigator using Qualtrics software(Appendix C). The survey asked questions relating to knowledge of what neurocognitive disorders are, amount of training they have received, if they have learned about this topic in class, confidence working with these individuals, and if they would want additional training. The participants answered the survey questions by selecting two multiple choices questions, two short responses, and using a Likert scale to answer questions based upon individual assessment.

Likert Scale:

The participants used the Likert scale to answer most of the survey questions. The Likert scale uses a scale that consisted of: strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree, and strongly agree. The participants chose one of the options based on the assessment of their personal thoughts or abilities.

Results

The survey evaluated the responses of 65 students at Western Michigan University who either work in healthcare or plan to. The results indicated that 43 students currently work in healthcare and 21 students are planning to. Of the students who completed the survey, 89.2% indicated that they either somewhat agree or strongly agree that if additional training on neurocognitive disorders was provided at work, they would want to attend this. The results also indicated that 84.6% of the individuals either somewhat agreed or strongly agreed that they wished to be educated more on this topic before working or continuing to work in healthcare. The overall results (Appendix D) indicated that there were several correlations between the confidence that a student has working with someone with a neurocognitive disorder with the amount of training they've received, as well as the education they have received on the topic.

There was a strong statistically significant relationship between the number of hours of training for neurocognitive disorders that an individual had and confidence to work with someone with neurocognitive disorders. This data had a P-Value of 0.00943 and a Cohen's f value of 0.672. Data for 'not applicable' was not included in this analysis as this indicated that they have not received any training yet. Of the 55 students who indicated that they have had training, 58.2% of these individuals have received less than 1 hour of training. The highest confidence was indicated in those students who have received 1-2 hours of training, which may be the result of the fact that the average training class is about that time length. For the purpose of describing the results in the table, the following format has been used: 1= strongly disagree, 2= somewhat disagree, 3= neither agree nor disagree, 4= somewhat agree, and 5= strongly disagree.

Relationship Between Number of Hours of Training and Confidence Level

Number of Hours of Training on Neurocognitive Disorders	Number of Students	Average Confidence Level (scale 1-5)
0-1 hours	32	2.69
1-2 hours	3	4.33
2-3 hours	6	4.00
3 or more hours	14	4.07
Total	55	-
Average	-	3.27

**Figure 1 indicates the relationship between hours of training and confidence to work with an individual with a neurocognitive disorder.*

There was also a positive correlation between “I am confident to work with someone with a neurocognitive disorder” and “I have learned in class what neurocognitive disorders are and/or how to work with these individuals.” With a sample size of 65 students, the P-value was <0.00001 and the Pearson’s r was 0.553. Figure 2 represents that there is a strong correlation between how much they disagree or agree that they’ve learned in class about neurocognitive disorders and their confidence to work with those individuals. Of the 9 students who indicated that they strongly agree that they have learned in class what neurocognitive disorders are or how to work with these individuals, 8 of these students indicated that they strongly agree that they are confident to work with someone with a neurocognitive disorder. The results also indicated that 100% of the 9 out of the 65 students who selected that they strongly agree that they have learned about this topic in class also selected that they either somewhat agreed or strongly agreed to being confident to work with someone with a neurocognitive disorder.

Relationship Between Learning in Class about Neurocognitive Disorders and Confidence

<i>“I am confident to work with someone with a neurocognitive disorder.”</i>	<i>“I have learned in class what neurocognitive disorders are and/or how to work with these individuals.”</i>				
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Strongly disagree	50% (4)	28.6% (4)	0% (0)	4% (1)	0% (0)
Somewhat disagree	12.5% (1)	7.1% (1)	11.1% (1)	16% (4)	0% (0)

Neither agree nor disagree	0% (0)	28.6% (4)	66.7% (6)	16% (4)	0% (0)
Somewhat agree	37.5% (3)	35.7% (5)	11.1% (1)	60% (15)	11.1% (1)
Strongly agree	0% (0)	0% (0)	11.1% (1)	4% (1)	88.9% (8)

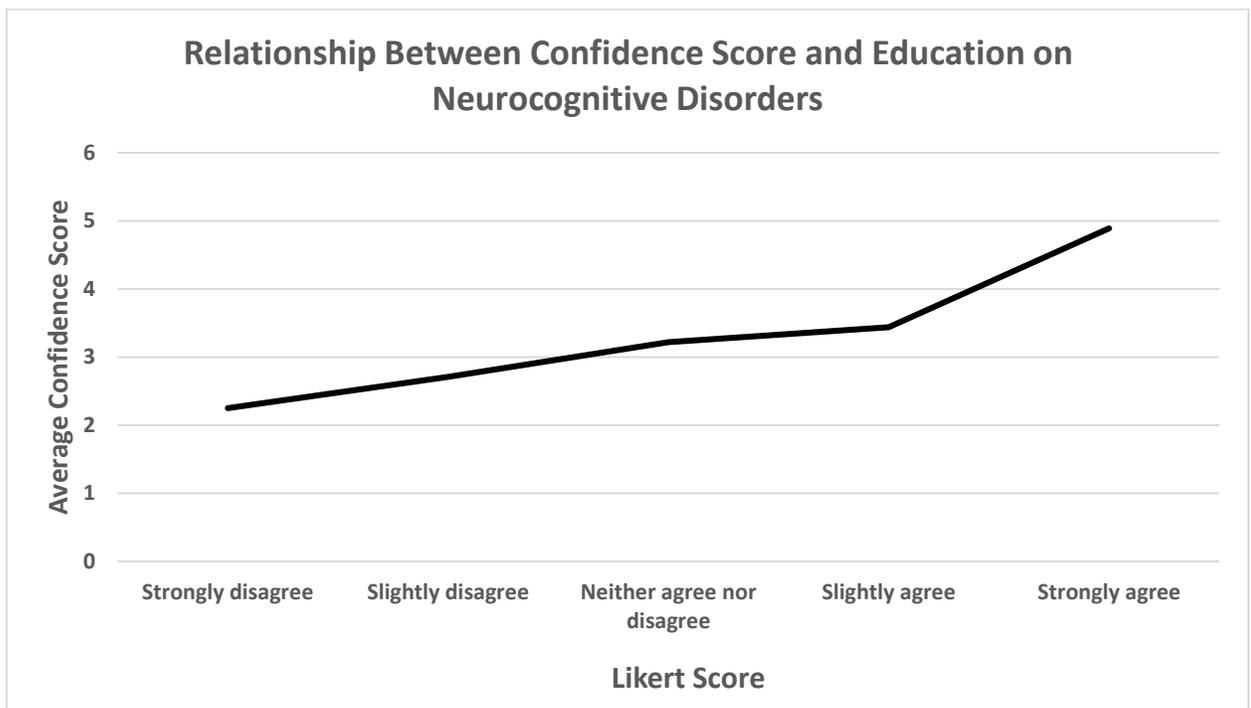
**Figure 2 represents the percent relationship between learning in class about neurocognitive disorders and the student's confidence in working with these individuals. The percentages are representing the number of individuals who chose each response in the column. The number in parenthesis represent the total number of students who selected each response.*

Figure 3 represents that on average, the more that an individual has learned in class, the more confidence they have to work with these individuals. The highest average confidence score was 4.89 out of a possible score of 5 for the individuals who strongly agreed that they have learned in class about what neurocognitive disorders are or how to work with these individuals. The lowest average confidence score was 2.25 for the individuals who strongly disagreed that they have not learned this topic in class. The more the student agreed that they have learned this topic in class, the average confidence of the student also increased. The same scale was used for figure 3 as was used for figure 1, with a score of 1 indicating that the student strongly disagreed to 5 indicating that the student strongly agreed.

Relationship Between Confidence Score and Education on Neurocognitive Disorders

<i>“I have learned in class what neurocognitive disorders are and/or how to work with these individuals.”</i>	Number of Students	Average Confidence Score (1-5)	Median Confidence Score (1-5)
Strongly disagree	8	2.25	1.5
Somewhat disagree	14	2.71	3.00
Neither agree nor disagree	9	3.22	3.00
Somewhat agree	25	3.44	4.00
Strongly agree	9	4.89	5.00

**Figure 3 represents the relationship between confidence score and how strongly the individual indicated that they have learned in class about neurocognitive disorders. The tables uses a scale from 1 (strongly disagree) to 5 (strongly agree).*



**Figure 4 represents the graphed relationship between the confidence score and Likert*

score of how strongly the individual indicated that they've learned about neurocognitive disorders in class.

Discussion

Findings:

This research was designed to assess students' understanding of neurocognitive disorders, as well as find correlations between the amount of training or education they have received on neurocognitive disorders in relationship to the student's confidence to work with these individuals. The survey indicated that 84.6% of the students who took the survey either strongly agreed or somewhat agreed that they wished to be educated more on neurocognitive disorders. These findings help to demonstrate that students are aware of the importance of neurocognitive disorder training as it is a prevalent health condition that has many ethical considerations that needs to be taken account for in healthcare.

Although this particular study has not been done before, it is consistent with previous research that has been done. Quality of healthcare is an important factor that many healthcare providers struggle to maintain or deliver due to inadequate ethical training and lack of knowledge. The confidence that a student indicated to work with someone with a neurocognitive disorder was directly correlated with their indication if they've learned what a neurocognitive disorder was in class. The ability to explain a neurocognitive disorder to someone was also correlated with the confidence to work with someone with a neurocognitive disorder. These findings indicated that the less confident students are to work with these individuals, the more training they wish to receive.

Implications:

As there has not been much research on undergraduate students' understandings of neurocognitive disorders, this study helps to indicate the importance of training for caregivers,

healthcare staff, and those pursuing a career in healthcare. These findings can assist nursing homes, assisted living facilities, psychiatric facilities, and hospitals on understanding the importance of adequate training and how it directly correlates with the confidence that an individual has to work with these individuals. Confidence leads to safer practices, more ethical decisions, and an overall better understanding of how to assist the individual with a neurocognitive disorder.

These findings can help demonstrate why investing in better training programs on neurocognitive disorders for all healthcare staff is essential to increase their confidence and knowledge, which can result in more ethical care and practices among these individuals. These findings also demonstrate the importance of implementing more education on neurocognitive disorders as there is a correlation between the confidence that a student has working with individuals and the amount they have learned in class. Educating students on the ethics of neurocognitive disorders can set a strong foundation of the care they will provide as a healthcare worker.

Limitations:

There were a few limitations to this study. Many individuals who had not had any training on neurocognitive disorders because they haven't worked in healthcare yet were more likely to select that they strongly disagree to wanting to be educated more on neurocognitive disorders. The students most likely had a hard time understanding the value and significance of having ethical training. Another limitation was the fact that many students may not have truly understood the complexity of what a neurocognitive disorder entails and the benefits that training has on the ethics and safety of healthcare facilities. The results indicated that some students who had selected that they strongly disagree to have worked with someone with a neurocognitive

disorder also selected that they strongly disagree that they would want to attend additional training (Appendix E). Without working in healthcare, being able to make assessments and ethical judgement may appear to be simple; however, these come with experience and training. Also, the survey was only open for eight days, which may have reduced the number of students who decided to take it. The survey also failed to ask students what major they were pursuing. This resulted in there not being any data to make correlations between confidence and undergraduate major.

Conclusion

As the number of individuals with neurocognitive disorders increases every year, ethical training will assist healthcare workers in understanding how to properly care for these individuals. Training on ethical practices and care is essential for the safety and quality of care for individuals with neurocognitive disorders, as well as the healthcare workers who care for them. The survey indicated that a majority of the students would want to attend additional training on neurocognitive disorders, as well as wish to be better educated on the topic. As there is a strong correlation between the amount of training or education that an individual has with the confidence level to treat these individuals, ethical training needs to be better established in healthcare. Additional training on the ethics of neurocognitive disorders can lead to a higher confidence in treating individuals with neurocognitive disorders, which will allow for more ethical practices.

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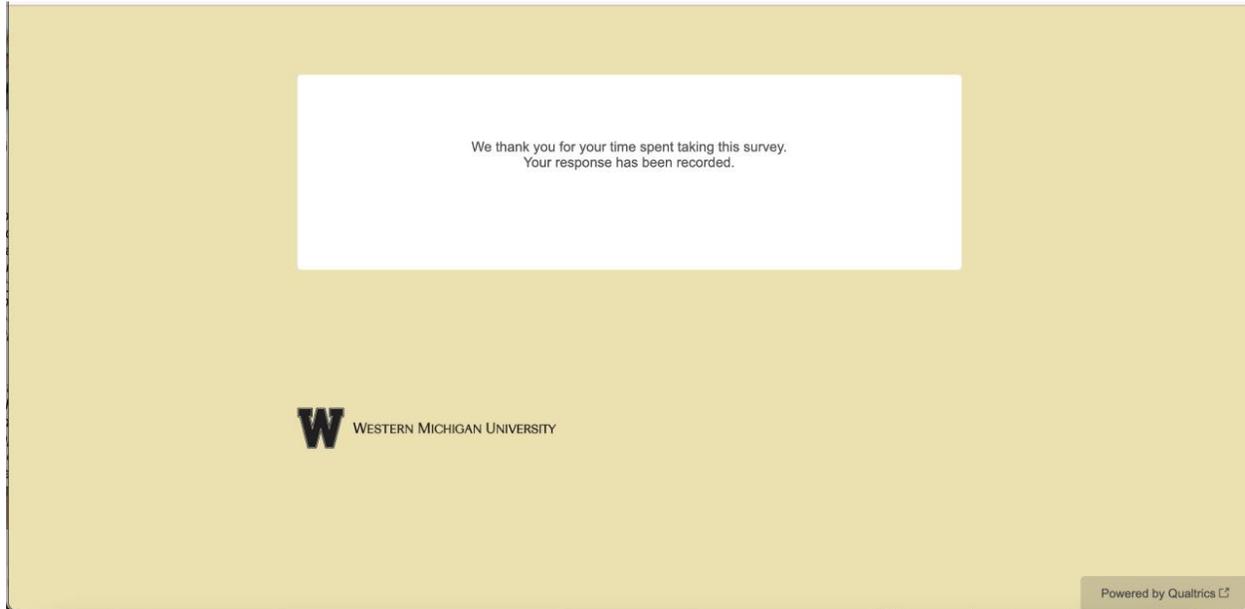
Appendix A

Script to be sent to Psychology 1000 students:

Hello! Are you working in healthcare or plan to work in healthcare one day? Take this brief, 5-minute survey to demonstrate your knowledge with neurocognitive disorders. This anonymous survey will ask questions related to your knowledge of neurocognitive disorders or any training you've had. For taking this survey, you will receive extra credit! Send a screen shot of the last screen that indicates that you have completed the survey, as well as your class section number to jenna.c.schneider@wmich.edu. By screenshotting the 'thank you for completing this survey' page, it will ensure your answers remain anonymous. Please reach out for any questions you have.

Appendix B:

End of Survey Screen



Appendix C:

Online Survey

Western Michigan University
Department of Health and Human Services

Principal Investigator: Dr. Janet Hahn
Student Investigator: Jenna Schneider
Title of Study: Ethics of Neurocognitive Disorders

You are invited to participate in this research project titled "Ethics of Neurocognitive Disorders"

STUDY SUMMARY: This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. Participation in this study is completely voluntary. You may choose to not answer any question. The purpose of the research is to assess students' understanding of neurocognitive disorders and how they would handle individuals with these disorders. It will serve as Jenna Schneider's thesis for the requirements for a honors degree in Interdisciplinary Health Services. If you take part in the research, you will be asked to answer survey questions on Qualtrics. Your replies will be completely anonymous, so do not put your name anywhere on the survey. Your time in the study will take about 10 minutes to complete the survey. Possible risk and costs to you for taking part in the study may be discomfort from answering the questions. A potential benefit of taking part in this survey may be assisting in expanding knowledge on the ethics of neurocognitive disorders. Your alternative to taking part in the research study is not to take part in it.

The anonymous information collected for this research may be used by or distributed to investigators for other research without obtaining informed consent from you.

Should you have any questions prior to or during the study, you can contact the principal investigator, Dr. Janet Hahn at janet.hahn@wmich.edu or the student investigator, Jenna Schneider at jenna.c.schneider@wmich.edu. You may also contact the Chair, Institutional Review Board at 269-387-8293 or the Vice President for Research at 269-387-8298.

This consent has been approved by the Western Michigan University Institutional Review Board (WMU IRB) on April 7, 2021.

Participating in this survey online indicates your consent for use of the answers you supply.

- I consent
 I do not consent

Please select which option you most agree with.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I can explain a neurocognitive disorder to someone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have worked with someone with a neurocognitive disorder.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident to work with someone with neurocognitive disorders.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have learned in class what neurocognitive disorders are and/or how to work with these individuals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If additional training on neurocognitive disorders was provided at work, I would want to attend this.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wish to be educated more on neurocognitive disorders before working/continuing to work in healthcare?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Who did you work with who had a neurocognitive disorder? (If not applicable, indicate so).

How many hours of training for neurocognitive disorders have you had?

0-1 hours

1-2 hours

2-3 hours

3 or more hours

Not applicable

How long have you worked in healthcare? If you haven't worked in healthcare yet, but plan to, please indicate so.

0-1 years

1-2 years

2-3 years

3 or more years

I have not worked in healthcare yet.

Please indicate any other information you wish to share.

Appendix D

Overall Results from Online Survey with 5-point Likert Scale

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
<i>“I can explain a neurocognitive disorder to someone.”</i>	10.8% (7)	12.3% (8)	13.8% (9)	43.1% (28)	20% (13)
<i>“I have worked with someone with a neurocognitive disorder.”</i>	26.6% (17)	7.8% (5)	10.9% (7)	18.8% (12)	35.9% (23)
<i>“I am confident to work with someone with neurocognitive disorders.”</i>	13.8% (9)	10.8% (7)	21.5% (14)	38.5% (25)	15.4% (10)
<i>“I have learned in class what neurocognitive disorders are and/or how to work with these individuals.”</i>	12.3% (8)	21.5% (14)	13.8% (9)	38.5% (25)	13.8% (9)
<i>“If additional training on neurocognitive disorders was provided at work, I would want to attend this.”</i>	4.6% (3)	1.5% (1)	4.6% (3)	33.8% (22)	55.4% (36)
<i>“I wish to be educated more on neurocognitive disorders before working/continuing to work in healthcare.”</i>	3.1% (2)	4.6% (3)	7.7% (5)	35.4% (23)	49.2% (32)

Appendix E

Relationship between individuals who have worked with an individual and would want additional training

	<i>“If additional training on neurocognitive disorders was provided at work, I would want to attend this.”</i>				
<i>“I have worked with someone with a neurocognitive disorder.”</i>	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Strongly disagree	66.7% (2)	0% (0)	33.3% (1)	23.8% (5)	25% (9)
Somewhat disagree	0% (0)	0% (0)	0% (0)	4.8% (1)	11.1% (4)
Neither agree nor disagree	33.3% (1)	0% (0)	0% (0)	19% (4)	5.6% (2)
Somewhat agree	0% (0)	100% (1)	33.3% (1)	14.3% (3)	19.4% (7)
Strongly agree	0% (0)	0% (0)	33.3% (1)	38.1% (8)	38.9% (14)