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Austin Matus, BSN, RN
Editor-in-Chief

Austin Matus, BSN, RN is a Ph.D. Candidate and RN at the University of Pennsylvania School of Nursing in the Biobehavioral Health Sciences Department. Mr. Matus holds a Bachelor of Science in Nursing from Boston College and a Certificate in Translational Science from the Perelman School of Medicine Institute of Translational Medicine and Therapeutics. Overall, his research aims to better understand the relationships between self-care and psychosocial factors in the management of chronic diseases such as heart failure and diabetes mellitus. His current work focuses primarily on the dynamic relationships between attitudes, self-care, and impaired awareness of hypoglycemia in adults with type-1 diabetes mellitus. Mr. Matus is a member of Sigma Theta Tau International Nursing Honor Society, the American Heart Association, and American Diabetes Association.

Helena Addison, MSN, RN
Editor-Elect

Helena Addison, MSN, RN, is a registered nurse and a PhD student at the University of Pennsylvania School of Nursing, in Philadelphia, PA. Ms. Addison earned her bachelor's degree in Psychology at University of Maryland, Baltimore County, graduating Magna Cum Laude. She completed her nursing degree through the master's Entry in Nursing Program at the Johns Hopkins University School of Nursing. Ms. Addison is passionate about advancing health equity by improving mental health symptoms and health-related quality of life (HRQoL) in trauma-exposed and marginalized populations. Her current research is focused on how incarceration history influences mental health symptom severity, health-related qualify of life, health-seeking behaviors, and engagement in health care in formerly incarcerated Black men. Ms. Addison is a Penn Presidential PhD fellow, a fellow in the ANA/SAMHSA Minority Fellowship Program, and a Jonas 2021-23 Scholar.

Mission

The Journal of Nursing Doctoral Students Scholarship (JNDSS) is a scholarly publication dedicated to the development of nursing doctoral student scholarship and the advancement of nursing science. This journal is peer reviewed by doctoral students, edited by doctoral students and targeted towards health practitioners, educators, scientists and students. This journal has both a professional and an educational mission. First, to serve the profession, each issue features articles that represent diverse ideas, spark intellectual curiosity, and challenge existing paradigms. Doctoral students will have an opportunity to explore and analyze issues and ideas that shape healthcare, the nursing profession and research around the world. Second, to fulfill its educational mission, doctoral students will be trained in the editorial and administrative tasks associated with the journal's publication and assisted in preparing original manuscripts for professional publication. This journal will be evidence of the scholarly development of nurse scientists.

Journal of Nursing Doctoral Students Scholarship Editorial

Austin Matus, BSN, RN (Editor) and Helena Addison, MSN, RN (Editor-Elect)

In the past 2 years, the educational, professional and social climates of the doctoral student experience have fundamentally changed in light of the COVID-19 pandemic. In Spring of 2020, many if not all students enrolled in Nursing Doctoral programs found themselves transitioning off-campus to a virtual learning environment and research setting in-home. Within this new setting, these scholars found ways to maintain productivity, continue their education, and progress nursing science. Further, despite the unknown dangers of the emerging pandemic, many of these clinician-scientists turned their sights directly toward the clinical scene to see how they could help make a difference in the lives of patients and communities. Socially, physical isolation limited the potential for supportive interactions typical of peers, family and loved ones. Yet, many doctoral students have managed to pivot toward alternative routes of communication; even cohorts who entered their doctoral program in the height of the pandemic have developed bonds with their peers. Thus, it is with great pride that we reflect on the resiliency demonstrated by our peers during these trying times. Further, it is our privilege to share some of the remarkable work they have managed to accomplish despite the many obstacles.

With this in mind, we proudly present the 8th edition of the *Journal of Nursing Doctoral Students Scholarship*, a publication by nursing doctoral students designed to both highlight the work of those enrolled in doctoral programs as well as provide an avenue for further training in publication practices such as manuscript submission, revision, and review. By virtue of receiving many high quality and diverse submissions, despite the circumstances, our theme for this issue is not defined by manuscript content but by those who produced it: resilience. In this issue, you will find articles ranging from concept analysis and theoretical critique to literature reviews and reflections on scholarly collaboration and support during the challenges of the COVID-19 pandemic. With the assistance of high-quality peer review, the manuscripts selected have been identified as significant in content and excellent in presentation. We believe that the works presented offer food for thought and inspiration for future inquiry.

That being said, we would like to take this opportunity to thank the many doctoral students who volunteered to serve as reviewers, as well as those who submitted manuscripts. Furthermore, we would like to extend our thanks to those who submitted original and thought-provoking artwork for this installment's issue. Finally, we would like to thank the Penn School of Nursing and their staff for the tremendous assistance they provided to put this edition together. The success of publishing this issue, despite the setbacks of the pandemic, is an accomplishment for us all.

Concept Analysis: Perceived Self-Efficacy Among Vulnerable Adolescents in Foster Care

Christina Ross, PhD, RN

As of September 2018, there were 437, 283 children in foster care in the US (Adoption & Foster Care Statistics, 2019). Children under the age of 18 enter foster care due to various adverse childhood experiences (ACEs) or trauma such as maltreatment, neglect, various forms of abuse, and abandonment (Greeson et al., 2011). Foster care serves as a temporary solution for children removed from their homes due to adverse living conditions (Foster Care, 2016). Foster caregivers are responsible for providing a safe, stable, and nurturing environment that will promote the child's positive development (Foster Care, 2016).

ACEs or childhood trauma can have negative effects on an individual. Adolescents who were victims of child-hood trauma often display behavioral problems, lack trust in others, and avoid interactions by being guarded (Crosby et al., 2014; Thiessen Love et al., 2005). Histories of complex childhood trauma were associated with psychiatric diagnoses such as posttraumatic stress disorder, anxiety, and affective disorder, subsequent psychiatric treatment, and even hospitalizations (Greeson et al., 2011; Thompson & Hasin, 2012). In addition, youth with a history of trauma are also at an elevated risk for self-harm such as suicidal ideation and attempts and are at great risk for substance abuse, unintended pregnancy at an early age, and contracting HIV from unprotected sex (Harpin et al., 2013; Pilowsky & Wu, 2007; Thompson & Auslander, 2011). Yampolskaya et al. (2011) in their study of 13,212 adolescents, found that youths in foster care with a traumatic history of chronic maltreatment such as threatened harm (47.6%), physical abuse (28.3%), neglect and sexual abuse (38.5%) were more likely to be placed in a juvenile delinquency facility or a detention center compared to youth without a history of childhood trauma.

Interestingly, despite facing various ACEs and ongoing challenges, many adolescents go on to be very pro-ductive adults and not engage in negative or risky health behaviors (Bruner et al., 2014). It is beneficial that youth-serving workers understand what attributes vulnerable adolescents possess that enables them to overcome their adversities and thrive. A concept frequently discussed in the research literature and under the framework of Positive Youth Development (Development, 2018) is *Perceived Self-Efficacy*. This paper will explore the concept of *Perceived Self-Efficacy* mainly among youth and then discuss its linkage to nursing and vulnerable adolescents such as those in foster care.

Purpose of Concept Analysis
The purpose of this concept analysis is to understand perceived self-efficacy by looking at its origins, theoret-ical underpinnings, its current empirical use, and how it can be used to support vulnerable youth by focusing on their assets and ability to make positive choices. At the end of this concept analysis, there is a clear indica-tion of how vulnerable youth, such as those in foster care who have experienced ACEs, may thrive and make positive health choices despite facing challenges.

Perceived Self-Efficacy Defined

The historical roots of perceived self-efficacy can be traced back to Bandura's (1977) social learning theory, which was renamed social cognitive theory in 1986. According to Bandura (1977), higher sense of self-efficacy is related to positive outcomes such as better health outcomes, better academic performance, and lower chances of being involved in high-risk behaviors. Bandura (1977) also posits that individuals will avoid certain tasks if they believe they do not have sufficient coping skills to make them successful at accomplishing that task.

As a result, perceived self-efficacy may have direct influences on the task an individual chooses to undertake. Perceived self-efficacy is not just a mere thought that an individual can do something. The concept involves various factors that form perceived self-efficacy and can lead to an individual having positive outcomes (Bandura, 1977). Factors involved include performance accomplishments, vicarious experiences, verbal persuasions, and emotional arousal (Bandura, 1977). It is important to note that definitions exist for generalized self-efficacy versus perceived self-efficacy, which is the focus of this concept analysis. Perceived self-efficacy is applied to certain tasks and specific health outcomes such as adolescents' risk-taking behaviors and symptom management for cancer patients (Conner & Norman, 1995; Crosby et al., 2001; White et al., 2017).

Generalized self-efficacy involve the following: personal action control or agency, where if a person believes that they can produce a desired effect, they can lead a more active and self-determined life (Scholz et al., 2002). In other words, if a person believes they can do something, they exude a sense of control over their environment and will be able to control challenging aspects of the environment by adaptation (Scholz et al., 2002). Self-efficacy can also be described as an optimistic and self-confident view or a person's ability to deal with various life stressors (Scholz et al., 2002). In summary, self-efficacy determines how individuals feel, think and motivate themselves and behave in various life situations (Tsang et al., 2012). The concept of self-efficacy has been used in research as "task self-efficacy," which depicts a person's ability to perform a particular behavior, and "coping self-efficacy," which depicts an individual's ability to prevent, control or cope with potential challenges that she/he might face when engaged in a certain performance (Tsang et al., 2012).

Conceptual Map

The concept of self-efficacy has been used to guide the understanding of human behavior (Tsang et al., 2012). The theory includes a triadic reciprocity theme, which states that an individual's behavior is frequently under the reciprocal influence of the environment and personal cognitions (Tsang et al., 2012). For example, when looking at adolescent development, the theory indicates that an adolescent's action (behavior) is influenced by how her/his beliefs (cognitions) are affected by support from significant individuals such as parents, teachers, caregivers, and peers (environment) (Tsang et al., 2012). Bandura strongly believed that self-efficacy is the most critical factor affecting an individual's cognition (Tsang et al., 2012).

As illustrated in Appendix A, the chosen concept map was taken from Bandura's social cognitive theory, which is based on the notion that learning occurs in a social context with multifaceted interactions between the person, environment, and behavior. Bandura (1986) calls this interaction *reciprocal determinism*. Reciprocal determinism falls under the belief that 1) personal factors such as cognitive, affective, and biological events, 2) behavior, and 3) environmental influences create relationships or interactions that can lead to triadic reciprocality (Pajares, 2002).

The concept map can be applied to vulnerable adolescents, such as those in foster care. Youth enter foster care due to various adverse experiences, and child welfare workers are responsible for helping them achieve an

optimal output (Childwelfare.gov, n.d). As a result, for this concept analysis, the map was not altered/changed. Adolescents in foster care are constantly under the influence of their environment, personal factors, and environmental factors as they strive to have better health outcomes.

Empirical Application

Health researchers have extensively examined the linkage between perceived self-efficacy and health outcomes. Researchers are either developing a scale to measure certain self-efficacy attributes or customizing the General Self –Efficacy (GSE) Scale. Matthias Jerusalem and Ralf Schwarzer originally developed the Generalized Self-Efficacy Scale, which is frequently used to assess self-efficacy, as a German version in 1979 (Schwarzer & Jerusalem, 1995). After revision by other authors, the scale is now available in 26 languages (Schwarzer & Jerusalem, 1995).

According to Schwarzer and Jerusalem (1995), the GSE Scale was developed to assess a general sense of perceived self-efficacy and the ability to determine an individual's ability to cope with daily hassles and their ability to adapt after facing various stressful life events. The scale can be used by the general adult and adolescent populations, but not for individuals under the age of 12. The scale is self-administered and involves ten items to be answered. Responses are made on a 4-point scale, and scores range from 10 to 40 points. In terms of reliability, Cronbach's alphas ranged from .76 to .90, with the majority in the high .80s, in samples from 23 countries (Schwarzer & Jerusalem, 1995). Strengths of the scale are that it has been used internationally with success for over two decades and is suitable for a broad range of applications (Schwarzer & Jerusalem, 1995). It can be taken to predict adaptation after life changes, but it is also suitable as an indicator of quality of life at any point in time (Schwarzer & Jerusalem, 1995). One weakness of the scale is that as a general measure, it does not tap specific behavioral changes. In most applications, items have to be added to cover the particular content of the survey or intervention, such as smoking cessation self-efficacy or physical exercise self-efficacy (Schwarzer & Jerusalem, 1995). An example of the GSE scale can be found in Appendix B.

Perceived Self-Efficacy and Sexual Risk

Perceived self-efficacy does not always equate to successful task accomplishment (Crosby et al., 2001). In a study of 522 female African American adolescents, examining the relationship between perceived self-efficacy and demonstrated ability to apply a condom, higher perceived self-efficacy for applying a condom did not equate to higher demonstrated ability (Crosby et al., 2001). This finding did not support Bandura's (1997) perceived self-efficacy theory that if an individual has perceived self-efficacy, they can successfully complete an attempted task. In contrast, there are times when perceived self-efficacy does equate to success in accomplishing a task, as evident in sexual risk behavior studies (Conner & Norman, 1995). Research indicated that if adolescents perceived self-efficacy in their ability to exercise control over their sexual activities and condom use, they were more likely to engage in effective contraceptive use (Conner & Norman, 1995).

Wilson's Method of Concept Analysis

Wilson's method of concept analysis was used to evaluate and understand the concept of perceived self-efficacy. Wilson's method of concept analysis involves 11 steps and was used by Avant and Abbott in 2000 to show its relevance to nursing (Avant & Abbott, 2000). Wilson believed that questions of concept, not fact or value, require analysis, with the definition and meaning of a concept dependent on circumstance (Lynch & Lobo, 2012; Meleis, 2017). Using Wilson's method, the questions of what is perceived self-efficacy and how it can benefit vulnerable adolescents was asked, then answers were generated, and various cases (model, exemplar, contrary, invented) were used for clarity. The concept's application to a social context and looking at its current and practical uses, and tension related to the concept, were also explored.

Step 1: Questions.

The questions that this concept analysis sought to answer were *what is perceived self-efficacy, and how can it benefit vulnerable youth who were victims of ACEs?* Ultimately, the goal is to understand how some youth who experienced ACEs go on to have positive lives and healthy outcomes, while others might not.

Step 2: Generate Answers.

As mentioned before, perceived self-efficacy can be defined as an individual's beliefs about their ability to produce various designated levels of performance that can have influence over events that affect their lives (Bandura, 1994). Building on this definition, we can now move forward and continue to understand the concept of perceived self-efficacy by generating cases.

Step 3: Model Cases

Model cases represent typical and not so typical features of the concept (Wilson, 1963). Model cases are exemplars that really illustrate what the concept is. If a model case does not illustrate what the concept is, then nothing else will (Lynch & Lobo, 2012; Meleis, 2017). In the context of adolescent health and adolescents in foster care, the goal can be for those adolescents to avoid contracting an sexually transmitted infection (STI) or having an unintended pregnancy, and having a healthy health trajectory. The following is a model case:

> Mary, an adolescent, lives in a nurturing environment with her married parents and brother. Mary talks to her parents about sensitive topics such as sexual intercourse and contraceptive use because her parents believe in having open conversations that will enable Mary to talk to them about anything. Mary also has supportive mentors from her church and after-school program. Due to Mary's supportive environment, she advocates for condom use with her partner, speaks up for herself, and has high-perceived self-efficacy, leading her to have healthy social relationships and avoid high-risk behaviors. Mary can be considered an exemplar model case due to her self-efficacy, supportive environment, and positive decision-making skills. Having supportive mentors and being in a supportive environment can foster positive development (Zimmerman et al., 2013; Development, 2018).

A study looking at family communication, self-efficacy, and risk behavior among 25 white adolescents found that adolescents who grew up in homes with healthy family communication culture were able to have more control at home and within their peer group environment (Koesten et al., 2002). These adolescents also had no problems sharing their opinions, establishing boundaries, and making decisions that placed them in control (Koesten et al., 2002). Their self-efficacy was linked to decreased incidence of risk behaviors.

Step 4: Contrary Cases

Contrary cases are those cases that are direct opposite to model cases (Wilson, 1963). The following is a contrary case:

> Sarah is 16 and has been in foster care since five. Adults who were close to her, sexually and physically abused her as a child. Sarah has never been able to have positive communication experiences with others since. Due to abuse, Sarah had difficulty trusting others, forming relationship bonds, and advocating for herself. Sarah often has difficulty focusing in school, gets poor grades, and gets in trouble with her teachers due to her lack of involvement in class. Sarah believes no one understands or cares about her. Sarah is in a relationship with John, who is also an adolescent, gives her money frequently, always calls her, and tells her that he is the only one who loves her. Sarah believes him because of the attention she is getting. John hates to use condoms and gets upset when Sarah mentions using contraceptives. As a result, Sarah ends up pregnant at 16, and John is no longer in the picture.

Sarah's case is contrary, due to lack of supportive mentors or environment, lack of effective health care to promote healing from her ACEs, and ultimately low perceived self-efficacy to advocate for herself and make positive decisions. Unfortunately, Sarah has entered a negative health trajectory that is opposite to what we would hope to see when it comes to perceived self-efficacy and positive health outcomes.

Step 5: Related Cases

Related cases refer to cases that are based on similar concepts (Wilson, 1963). Perceived self-efficacy builds on the notion that if an individual believes in their capability to accomplish a task, they ultimately will. However, self-esteem and self-confidence are often related terms used to define an individual's ability to perform a task. Perceived self-efficacy moves far beyond merely a person's self-esteem or self-confidence in their ability to accomplish a task. The individual will require learned skills, good judgment on their actual potential, and personal characteristics to have effective perceived self-efficacy to accomplish their tasks (Zulkosky, 2009). The following is a related case:

> Mike is being assessed on his ability to apply a condom correctly. Mike reports that he can do it. During the assessment, the condom was applied incorrectly. This is a case where Mike is confident; however, without adequate skills, mentorship/guidance, and past successful performances, Mike cannot perform the task successfully.

This case illustrates the differences between merely being confident versus perceived self-efficacy, which involves actual skill sets, prior experiences, and capability to perform the task successfully.

Step 6: Borderline Cases

Borderline cases are those exemplars that can help to further develop the concept (Wilson, 1963). Ambiguities exist as to whether the exemplars belong to the concept or not. Under borderline cases, one can argue that self-esteem and self-confidence to accomplish a task falls in the same realm as perceived self-efficacy (Tsang et al., 2012). Another example is perceived self-efficacy versus generalized self-efficacy. One might argue that the concepts are the same, but they fall on the border due to various qualities that make them distinct from each other. Generalized self-efficacy has a broader, open definition. While perceived self-efficacy has a more distinct application when it comes to specific tasks such as sexual risk involvement (Tsang et al., 2012).

The following is a borderline case:
> Sue believes she can correctly apply a condom. Sue has never been taught how to apply a condom or saw the task done. Sue is a very optimistic person and often thinks positively. Sue completes the task successfully. The question here is, did Sue complete the task based merely on her self-belief, confidence, or self-worth?

This case is a borderline case because individuals with high-perceived self-efficacy can perform positively on tasks given various factors. With self-esteem, a person can accomplish a task based on their optimism and self-belief.

Step 7: Invented Cases

Invented cases are exemplars that were developed to illustrate the typical features or properties of the concept (Wilson, 1963). Invented cases can be found in stories, poems, or fables.

An example of the case can be the story of *The Ugly Duckling* by Hans Christian Andersen (1971), where a duckling that has been alienated and suffered abuse longs for acceptance and inclusion. The ugly duckling grows up to be the most beautiful swan. This story can be used to illustrate the struggles many adolescents with a

history of ACEs face when trying to feel accepted. However, an individual's situation can change positively at any given moment due to adoption into a positive and nurturing family or being involved in a supportive environment with foster parents, mentors, and health care providers.

Step 8: Social Context

Social context involves analyzing the concept to determine if others can use it, why they would use it, and how it may be used (Wilson, 1963). Concepts can occur both in the past and future. Meanings and interpretations of the concept in a social context can differ for various discipline, time span, locations, and cultures (Lynch & Lobo, 2012; Meleis, 2017).

When looking at the concept of perceived self-efficacy and evaluating adolescents or individuals who possess it, it is important to pay attention to the individual's background, cultural upbringing, and their current environment (Lynch & Lobo, 2012; Meleis, 2017). An individual from an affluent environment might have all the elements required to have positive health outcomes in addition to their perceived self-efficacy. Alternatively, an individual from a poverty-stricken environment, who might also represent an ethnic minority group, are often faced with various intersectionalities (Purdie-Vaughns & Eibach, 2008). Intersectionality can be a challenge for adolescents who are trying to use their perceived self-efficacy to obtain a positive outcome. The challenges of being a female, minority, low income, and from a high crime community are intersectionalities that many youth face (Purdie-Vaughns & Eibach, 2008). As a result, we have to be aware of the social context an individual is in and how it affects their outcomes despite having perceived self-efficacy.

Step 9: Underlying Anxiety

Underlying anxiety involves evaluating any feelings that can be related to the concept and determining if there are any stigmas, controversies, or debates related to the concept (Wilson, 1963). The current state/effect of the concept can generate feelings that are influenced by history, meanings, and unresolved issues (Lynch & Lobo, 2012; Meleis, 2017). The concept of perceived self-efficacy can create debate and controversy because many adolescents do not have the same support systems as other adolescents. Historically and currently, African American adolescents are markedly affected by elevated rates of STIs and unintended teenage pregnancy in comparison to White adolescents (CDC, 2016; 2018). These disparities are ongoing, and when we encourage adolescents to develop perceived self-efficacy, we need to be mindful of the language we use and be sensitive to the historical trauma associated with various populations, ethnicities, and cultures.

Step 10: Practical Results

Practical results illustrate the potential use of the concept, show the various elements, and its relationship to current practice (Wilson, 1963). Practical results should be able to show how the definitions of the concepts can be applied to real life and current situations or contexts (Lynch & Lobo, 2012; Meleis, 2017).

Practically, we can apply the concept of perceived self-efficacy to adolescents who are vulnerable, recognizing that there are numerous compounding factors that affect an individual and places them on various life and health trajectories. For example, youth in foster care have often experienced ACEs (Greeson et al., 2011) that can make it challenging for some of them to achieve various goals (Crosby et al., 2014; Thiessen Love et al., 2005). When working with vulnerable youth, we have to be mindful of their background and the resources available to them. It is also important to make interventions trauma informed, practical, and effective.

Step 11: Results in Language

The language and words used to reflect the concept should be carefully selected, because words can have

various meanings and ambiguous interpretations (Lynch & Lobo, 2012; Meleis, 2017). It is imperative that when the term perceived self-efficacy is being used, there are clear definitions of what the concept means and illustrations of how perceived self-efficacy differs from generalized self-efficacy. In addition, it is important to understand how it differs from self-esteem, self-worth, and self-confidence.

Discussion

Relevance to Nursing
The concept of perceived self-efficacy and understanding how individuals use it to face and overcome various challenges is very important to health care and nursing specifically. As nurses, we encounter patients such as youth in foster care who are vulnerable due to their history of ACEs and its potential to direct them toward a negative health path (Harpin et al., 2013; Pilowsky & Wu, 2007; Thompson & Auslander, 2011). Also, some individuals with past negative experiences may have low perceived self-efficacy due to lack of a nurturing environment, lack of influential mentors, and psychological and physical disturbances (Crosby et al., 2014; Thiessen Love et al., 2005). However, due to the positive potential of a high level of perceived self-efficacy, we can empower vulnerable youth to identify their potential and perceived self-efficacy in order to deal with their various life challenges. It has been shown that a strong sense of perceived self-efficacy can lead to better health, higher achievement, and better social integration (Scholz et al., 2002). Individuals with higher perceived self-efficacy invest more effort and thrive longer than others with low perceived self-efficacy, and in times of adversities, high self-efficacious people recover more quickly and continue to be committed to their goals (Scholz et al., 2002).

As nurses, we can serve as role models, advocates, and nurturers to vulnerable youth, which in turn has the potential to equip youth with support to engage in vicarious (model person) and symbolic experiences (persuasion by others) to develop their perceived self-efficacy skills (Bandura, 1977). By understanding the concept of perceived self-efficacy and the factors that influence its development, nurses can design and implement interventions that can promote and refine an individual's self-efficacy potential and lead to positive youth development.

The concept of perceived self-efficacy can also be applied to nursing education. It has been shown that through the use of clinical simulation exercises and role playing, nursing students attain knowledge and ultimately have increased perceived self-efficacy, that positively impact their nursing practice (Robb, 2012). Additionally, nursing students with low perceived self-efficacy can benefit from academic support and motivation to improve their perceived self-efficacy (Robb, 2012).

As nurses, working with the adolescent population or patients in general, we have the potential to build or improve an individual's perceived self-efficacy. Overall, a strong sense of perceived self-efficacy can lead to better health outcomes, higher achievement, and better social integration (Conner & Norman, 1995; Bandura, 1997).

Conclusion

Future Nursing Implications
Often, individuals focus on the negative aspects of vulnerable youth and view adolescents as problematic (Pittman et al., 2003). Youth serving providers need to move from a self-deficit approach or lens to an assets approach, and focus on adolescents' strengths to promote positive youth development (Bruner et al., 2014). Nurses and health care providers should be adequately trained and equipped to understand the various contexts

of adolescents, their history of ACEs, and how to effectively serve adolescents (SAMHSA, 2014). Analyzing the concept of perceived self-efficacy indicates that vulnerable adolescents have the potential to have successful and positive lives despite their history of ACEs. However, the success rate of being able to have positive health outcomes can be greatly improved if they have good role models and mentors, are able to communicate effectively with others, and are in an environment that will foster their positive development (Benson et al., 2006).

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Treatment as Prevention: Theory Analysis and Evaluation

Elise Corasmin, MSN, RN, CNL
Rutgers, The State University of New Jersey

Health promotion and disease prevention are integral to building healthier communities and society. Treatment as Prevention (TasP) is a key phenomenon that is not well known to the public but has implications for establishing different approaches to HIV prevention that may impact entire groups and communities. The situated Information Motivation Behavioral Skills Model of Care Initiation and Maintenance (sIMB-CIM) is a model that can be used to integrate with TasP to contribute to management of chronic conditions with improved outcomes for vulnerable populations. The sIMB-CIM model proposes that information and motivation have direct effects on behavioral skills needed for either care initiation or maintenance in a situated context (Amico, 2011 - see Figure 1). This paper will discuss application of the sIMB-CIM model to various health conditions. This theory analysis is important to highlight and raise awareness of the sIMB-CIM model and its potential for developing approaches to facilitate adoption of TasP in high-risk groups. TasP represents an underutilized opportunity for nursing to advance health promotion and disease prevention. Therefore, this theory analysis will address a gap in knowledge of the sIMB-CIM model as a way to improve nursing and public knowledge of TasP as an evidence-based approach to disease prevention.

The framework developed by Fawcett and DeSanto-Madeya (2013) was used for this theory analysis. This framework was selected as it provides for detailed examination of the theory's determinants and propositions. This process of analysis reveals the features and the utility of the theory and facilitates understanding of the original meanings as intended by the author. According to Fawcett and DeSanto-Madeya (2013), this framework allows for a systematic examination of the theory scope, theory context, and theory content to understand the author's interpretations rather than other interpretations of the theory. These three areas will be discussed in this analysis, including significance, internal consistency, parsimony, testability, empirical adequacy, and pragmatic adequacy.

Introduction to Treatment as Prevention

Treatment as Prevention (TasP) is a promising biomedical strategy for HIV prevention. TasP involves taking antiretroviral therapy (ART) to reduce HIV level in the blood to a point where HIV transmission is not likely to occur (Young et al, 2015). Despite the efficacy of TasP, HIV transmission remains prevalent in some areas and among certain groups, particularly members of ethnic minority groups and gay and bisexual men (HIV.gov., 2021). Some people who have transmitted HIV are not aware of their HIV status and, therefore, are also not aware that they are placing others at risk. Furthermore, HIV positive individuals may also transmit resistant strains of HIV, which makes treatment more challenging.

TasP has two main goals: (1) treatment for HIV positive individuals, and (2) prevention of HIV transmission to uninfected individuals. This dual role makes TasP one of the preferred methods for reducing new HIV infections. An advantage of this dual role is that both HIV-infected and non-infected individuals may benefit from the

treatment. TasP presents healthcare professionals with a new way of viewing chronic disease management and provides an opportunity for nursing research to study relationships between treatment and prevention. In addition, TasP provides a chance to develop and test theoretical frameworks that provides guidance on how both roles can be effective and complementary approaches in management of chronic diseases. TasP is not well known and understood by the public. There is a lack of knowledge and misconceptions that exist on newer forms of HIV prevention methods that are available. Nursing research addresses knowledge gaps and explores effective interventions that may improve public acceptance and adherence with these interventions.

Introduction to sIMB for Care Initiation and Maintenance

The sIMB-CIM builds on the Information, Motivation, and Behavioral skills (IMB) model originally developed by Fisher and Fisher (1992). The IMB model was first introduced in 1992, during the height of the AIDS epidemic, to provide a conceptual map for AIDS-risk-reduction in high-risk groups (Fisher & Fisher, 1992). The IMB model suggest that the combination of providing an individual with information, motivation to change, and necessary skills is the most effective way to enact behavioral change. Similar to the IMB model, the sIMB-CIM model shares the proposition that information and motivation have direct effects on behavioral skills needed for either care initiation or maintenance (Amico, 2011). The "situating" component allows for consideration of various factors, such as culture, sexual orientation, and unique characteristics when applying the core determinants to various groups (Amico, 2011). In the IMB model, the situated context is described as the moderator. The major aim for development of sIMB-CIM was to provide a model that addressed chronic disease management at the individual level. Amico (2011) believed that few existing models provided guidance on interventions for persons with chronic medical conditions. As a result, the sIMB-CIM model offers a framework that can be transformed into feasible and actionable intervention strategies (Amico, 2011). Fisher and Fisher (2003) described this aspect of the IMB model as specifying a set of generalizable operations for constructing, implementing, and evaluating health promotion interventions. The process proposed include *elicitation, intervention, and evaluation*.

The sIMB-CIM model is important for nursing research as it provides a theoretical framework to examine core determinants that may influence management and outcomes of various chronic medical conditions and aids in the development of targeted strategies. The sIMB-CIM model explains TasP as TasP information and TasP motivation related to HIV/AIDS leads to TasP behavioral skills initially or throughout care. The sIMB-CIM model can be applied to TasP as a framework for guiding intervention strategies. When HIV positive individuals are well-informed, motivated and possess the behavioral skills needed to act effectively, they will be more likely to adhere to treatment (Fisher & Fisher, 1992). This presents an opportunity to impact outcomes of persons both infected and uninfected with HIV.

Data Sources

There were three theoretical sources used for this analysis. Two of the sources discussed development of the original IMB model and were written by the theorists. The third source discussed an updated application of the IMB model, (i.e., sIMB-CIM) and included an example of how the updated model applies to a chronic medical condition. Primary research studies examining the utility of the sIMB-CIM model were identified through a literature search in PubMed, Google Scholar, and Ovid MEDLINE using the terms information, motivation, behavioral skills, and situated IMB-CIM. The initial search was limited to clinical trials published within the past five years with two exceptions. The first study completed in 2012 was included for consideration because it was the only study that applied the updated sIMB-CIM model. The second study's year of publication was 2015, however, application of the IMB model to a behavior different than examined in the other studies was considered relevant to this review. After reading the abstracts, studies were excluded if they did not explicitly examine

the IMB model. Some of these studies used the IMB model in a different context than presented in this analysis, other studies did not examine all determinants of the model, and there were studies that examined behaviors that were not associated with a medical condition. As this analysis was focused on application of the model in addressing behaviors with chronic health conditions, health condition was used as another inclusion/exclusion criteria. Six studies were selected for evaluation of the model.

Theory Analysis

Scope of sIMB-CIM

As described by Fawcett (2005), the sIMB-CIM model can be described as a middle-range predictive theory because it is "narrower and more concrete" than a grand theory (p. 35) and because it "moves beyond description to prediction" (p.36). The core determinants of this model, Information, Motivation, Behavioral Skills, and Care Initiation or Maintenance are specific and measurable. The sIMB-CIM model can also be viewed by some as explanatory since the core determinants help to explain why people either engage or fail to engage in targeted health behaviors. The sIMB-CIM model goes beyond explanatory to predictive since the desired outcome is to influence people's health behaviors through the core determinants and focused intervention strategies.
Context of sIMB-CIM

Although the sIMB-CIM model is not specifically described as a nursing theory, it addresses the four general propositions outlined by Fawcett and DeSanto-Madeya's criteria for theory analysis (2013). The model proposes core determinants that influence health behaviors of human beings. The environmental context of the model is reported as the cognitive-affective social-environmental, in which individuals process, adjust, and settle their care (Amico, 2011). The antecedent knowledge that was used in the development of the IMB model originated from review of AIDS-risk-reduction literature, which according to Fisher and Fisher (1992) are conceptually based, group specific, and focused on providing information, motivation, and behavioral skills as the most impactful bases for intervention.

Content of sIMB-CIM

The concepts of the sIMB-CIM model include information, motivation, behavioral skills, and care initiation or maintenance. Fisher and Fisher (1992) recommended that the model's determinants include specific content that are relevant to a particular population's health practices. Individuals may be more likely to adhere to instructions and education when the information is relatable. The information is generally delivered through patient education. There are various factors that influence the motivation determinant of the model, including attitudes, social norms, and health beliefs. Amico (2011) divided motivation into two categories: intrapersonal and interpersonal. Intrapersonal is described as personal motivation related to a person's feelings about self-care and treatment. Examples include family, employment, or other chronic conditions that persons may be managing. The interpersonal category is related to social motivation in which a focus is social support or potential negative social experiences that may play a role. Stigma is an example of the interpersonal motivation. The effects of information and motivation are seen primarily as a result of the application of behavioral skills (Fisher & Fisher, 2003). The outcome of interest is observed either when an individual first accesses care or during continued maintenance of care.

Theory Evaluation

Significance, Internal Consistency, and Parsimony
Significance. Fisher and Fisher (2003) described the IMB model as a social psychological view for understand-

ing and influencing health behaviors as derived from a review of previous research on AIDS risk-reduction. The IMB conceptual model originated from a three-factor conceptual model of AIDS-preventive behavior, which served as the fundamental determinants of risk reduction at that time (Fisher & Fisher, 1992). The social significance of the IMB model is evident in its capacity for improving peoples' health outcomes, extending the length and quality of life. Although a secondary consideration, the fact that, healthier lives can reduce financial cost to the individual, healthcare system, and society suggests additional advantages.

The IMB model has theoretical significance since it contributes to general knowledge about people's health behaviors, determinants, and interventions. The model provides a framework to examine how specific determinants interact with each other leading to change in health behaviors. The model also provides information on initiation and management of chronic conditions as it applies to a variety of health behaviors and diseases. This knowledge contributes to developing effective interventions for groups and communities. Studying health behaviors and practices are vital to understanding peoples' views and perceptions of health. This knowledge is useful in providing more insight to human beings, their responses to health, and management of their chronic conditions.

Internal Consistency. The description of the IMB model, concepts, and propositions are consistent throughout the studies in this review with some differences noted. First, the concepts are well defined with the same terminology used as descriptors. For example, the theoretical articles discuss information, motivation, and behavioral skills as being the fundamental determinants of health behavior. One of the areas where a difference is noted is with the description of the motivation determinant of the model discussed in the original theoretical source. Fisher and Fisher (1992) discusses the model using Fishbein and Ajzen's theory of reasoned action to provide a social psychological approach that can be applied to understanding and changing motivation with diverse groups. According to Fisher and Fisher (1992), there was not a conceptual framework that is sensitive to the effects of various elements that may impact motivation and the theory of reasoned action is proposed as a solution. One aspect that may be viewed as inconsistent is with the terms used for describing the outcome behavior. Health promotion behaviors, behaviors, behavior performance, health behaviors or preventive behaviors have all been used to describe the outcome behaviors.

The IMB model proposes that information and motivation may have direct effects on behavior when complicated behavioral skills are not required to perform the behavior (Fisher & Fisher, 2003). This is an important proposition because it can lead to differences in descriptions of the moderators and situational variables that may be assessed when the model is applied. The moderators described by Fisher and Fisher (2003) are certain situational and personal characteristics that may influence the relationship between the IMB determinants. Some examples of moderators discussed in the applied research papers include psychological health, living situation, access to medical services and substance abuse or addiction (Fisher & Fisher, 2006).

Parsimony. The IMB model is clear and concise. The model is clear even with application to complex health conditions such as HIV. For example, one of the propositions from the model is that an individual should be well informed, motivated and possess the behavioral skills to engage in the targeted behavior. This proposition was clearly stated in a study by Wang et al., (2019) which demonstrated the complex aspect of the IMB model by testing the model with consistent condom use. The study developed a structural equation model which examined variables such as sexual transmission information, non-sexual transmission information, perceived risks, attitude, social support, negotiation skills, and refusal skills (Wang et al., 2019). The simplicity of the model's proposition was clear although there were multiple variables and relationships studied. Similarly, Dunn Navarra et al., (2020) agreed with their findings that the constructs of the IMB model are applicable to

persons living with HIV, however, they concluded that the model did not fully explain the meaning of adherence behavior to antiretroviral therapy. Seif et al. (2019) stated that the IMB model has received much attention because it provides a simple explanation for complex health behaviors and identifies constructs that are needed for behavior change. Even with the updated model sIMB-CIM; the additional concepts of situation, care initiation, and maintenance are simple and direct concepts that can be used to describe complex aspects of human behavior.

Testability

This evaluation of the literature demonstrates the testability of the IMB model. One criterion for evaluating the theory's testability is the extent to which the empirical indicators appropriately measure the theory concepts (Fawcett & DeSanto-Madeya, 2013). Across all the studies included in the present review, the measurement tools used incorporated the information, motivation, and behavioral skills determinants of the IMB model. Similarly, each study tested the determinants of care initiation and maintenance represented in the context of various health behaviors.

A second criterion for evaluating the theory's testability is the methods employed to test/reflect the theory assertions (Fawcett & DeSanto-Madeya, 2013). The tools used included questionnaires, interviews, and educational modules. Five of the six primary studies used questionnaires or interview guides with items that addressed a specific determinant of the model (Bian et al., 2015; Dunn Navarra et al., 2020; Seif et al., 2019; Smith et al., 2012; Wang et al., 2019). One study employed a qualitative design using both a questionnaire and the semi-structured interviews to explore the determinants in relation to participants' retention in HIV care (Smith et al., 2012). The fifth study employed an intervention design to determine if information, motivation, and behavior skills educational modules facilitated smoking cessation (Cooperman et al., 2017). The instruments and specific items used to measure the concepts were appropriate empirical indicators as they addressed information, motivation and behavioral skills of the specific behavior being studied.

The studies used various methods to evaluate construct validity. Seif et al. (2019) assessed content validity through peer review and internal consistency in a pilot study with fifty caretakers. Another study described a "treatment fidelity measure," which involved clinicians providing feedback of interventions implemented during weekly supervision (Cooperman et al. 2017). Smith et al., (2012) used a variety of coding strategies including content coding to assess the sIMB-CIM determinants. The interview guide used in the study by Dunn Navarra et. al., (2020) was reviewed by two experts for "consensus validation" and to gather data on the IMB determinants. Cheng et al. (2015) used examination of participants' understanding of questionnaire items as a method of continuous improvement. Wang et al. (2019) reported Cronbach alphas calculated for the three instruments used to measure each determinant. Information was measured using the Brief HIV Knowledge Questionnaire (Cronbach's alpha=0.687), three constructs were used to measure motivation (Cronbach's alpha=0.890) and behavioral skills were measured using four items from the Condom Influence Strategy Questionnaire (Cronbach's alpha=0.764). Bian et al., (2015) used one questionnaire that consisted of specific items to measure each determinant. Information was measured using twenty items (Cronbach's alpha=.782), motivation was assessed using 22 items (Cronbach's alpha=.717), and behavioral skills was assessed using two items (Cronbach's alpha=.923; Bian et al., 2015).

A third criterion for evaluating the theory's testability is the extent to which the data analysis techniques permit measurement of theory propositions (Fawcett & DeSanto-Madeya, 2013). Across the studies, data analyses involved examining relationships between the model determinants and the desired behaviors. Data analysis techniques included correlational analysis, bivariate analysis, regression analysis, structural equation modeling,

and content coding in, which model concepts and propositions were tested. The techniques permitted measurement, testing, and comparisons of the IMB model concepts and propositions. However, there were differences between the studies in which propositions were tested.

Empirical Adequacy

Across the studies in this review, there is empirical support for the concepts and propositions of the IMB model. Findings from the various studies are consistent with the proposition that information, motivation, and behavioral skills work together as core determinants to influence health behavior. This proposition was well tested across the studies, with significant results; however, studies varied in terms of the level of influence each determinant had on the outcome behavior in question. There were also differences noted in contextual factors or moderators. The IMB model asserts that particular constructs will appear as more or less influential determinants of health behavior for given populations and behaviors (Fisher & Fisher, 1992). Motivation and behavioral skills had a significant impact on behavior in
the studies by Seif et al. (2019) and Wang et al. (2019). Across these two studies, the same relationship of the model being a good predictor of specific behaviors was tested and supported. The Seif et al. (2019) and Smith et al. (2019) studies both found that the information determinant alone did not lead to a significant contribution to the outcome behaviors. Similarly, according to Fisher and Fisher (1992), information is necessary, but not sufficient to change health behavior. The type of information provided is also important in influencing behavior change.

Pragmatic Adequacy

Although it originated from psychology, the IMB model is widely known and used in multiple disciplines, including nursing. Therefore, education and training are required on the model's content, context, and evaluation for its effective application. The Seif et al. (2019) study, which was conducted in affiliation with the department of nursing and public health, provided evidence of the IMB model's application to nursing practice. In addition, the various health behaviors that were examined across the studies included in this review (e.g., retention in HIV care, adherence to ART, consistent condom use, smoking cessation, rational drug use, and sexual /reproductive health communication) are areas that impact and are impacted by nursing care and practice. The feasibility of implementing practical activities based on the IMB model exists but also depends on the resources available. The practitioner has the legal ability to implement and measure IMB model related activities; however, training is needed to ensure that activities agree with the model's concepts and propositions. Model-based practical activities may be compatible with expectations for nursing practice, depending on the nursing role and setting. For example, the information determinant of the model is compatible with nursing expectations as patient education has been viewed as primarily a nursing function. As the nursing field evolves to include more advanced roles, the compatibility of the full IMB model with nursing practice may become more evident. The IMB model defines determinants and propositions that nurses can use in the context of various chronic conditions to promote health improvement.

Knowledge Gaps

One gap in knowledge that this review identified is the limited application of the updated version of the IMB model. The review included only one primary study of sIMB-CIM in which retention in HIV care was examined. The updated sIMB-CIM model contains care initiation and maintenance which has implications for nursing practice. The sIMB-CIM model may prove to be useful in that it presents a more comprehensive approach to management of various chronic diseases and is not limited to health behaviors. Another knowledge gap identified is with the proposition that information and motivation may have direct effects on behavior when complicated behavioral skills are not required to enact the behavior in question. Across the studies in this re-

view, there was no discussion of which behavioral skills are considered simple or complex. There are important implications for developing appropriate interventions when there is a clear distinction for simple or complex behavioral skills.

This paper's focus was on the phenomenon of TasP which is not merely a health behavior but a desired outcome. TasP requires that individuals are well informed of the benefits to all potentially affected individuals who may be at risk. It is this knowledge that has the potential to motivate individuals to act and adopt the appropriate behavioral skills (i.e., uptake of ART for HIV prevention). The sIMB-CIM model, as demonstrated by this review, provides a good theoretical framework for future research into the application of TasP for prevention of HIV and other chronic health conditions. Additional research is needed to study the model's effectiveness in encouraging TasP uptake with at-risk groups and various chronic conditions.

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Table 1.

sIMB Non-relational and Relational Propositions

| Non-relational Propositions	Relational Propositions
Information relevant to maintenance in care likely includes specific content concerning the long-term course of the chronic medical condition, management, and emerging treatment options for the condition at further stages of progression, purpose of monitoring, values monitored and their interpretation, and signs/symptoms of deterioration, resources available for funding on-going treatment when caps are met, limited funds deplete, or benefits change, and rights to privacy and advocacy when securing long-term benefits.	Information, motivation, and behavioral skills are fundamental determinants of performance of health behaviors.
Motivation includes perceptions of stigma and the multiple barriers and contexts in which one attempts to prioritize self-care.	Information and motivation influence behavioral skills, which then influence the outcome of interest.
Behavioral skills include sets of objective and perceived skills and one's sense of efficacy in implementing these skills.	Information and motivation work through behavioral skills to affect behavior.
A situated approach entails the exploration of the cultural, structural, and cognitive-affective context in which engagement in care is negotiated and in which information, motivation, and behavioral skills interact to promote initiation and subsequent maintenance in care.	Acute and even extreme conditions contextualizing care-use will operate through information, motivation, and skills to influence care-use in the predicted direction.
The proposed approach is at the individual level with use of situating to anchor the individual's knowledge, thoughts, feelings, and skills within the larger systems in which care is negotiated.	Information and motivation may have direct effects on behavior when complicated behavioral skills are not required to enact the behavior in question.
The model characterizes use of care when care is available, if care is not available, there is no individual level choice to characterize.	Information likely to be most influential of care initiation and subsequent maintenance include accurate information about available treatment, the process and sequence of treatment, the chronic medical condition itself (CMC), the process of adjustment to living with the CMC, and the systems of care.
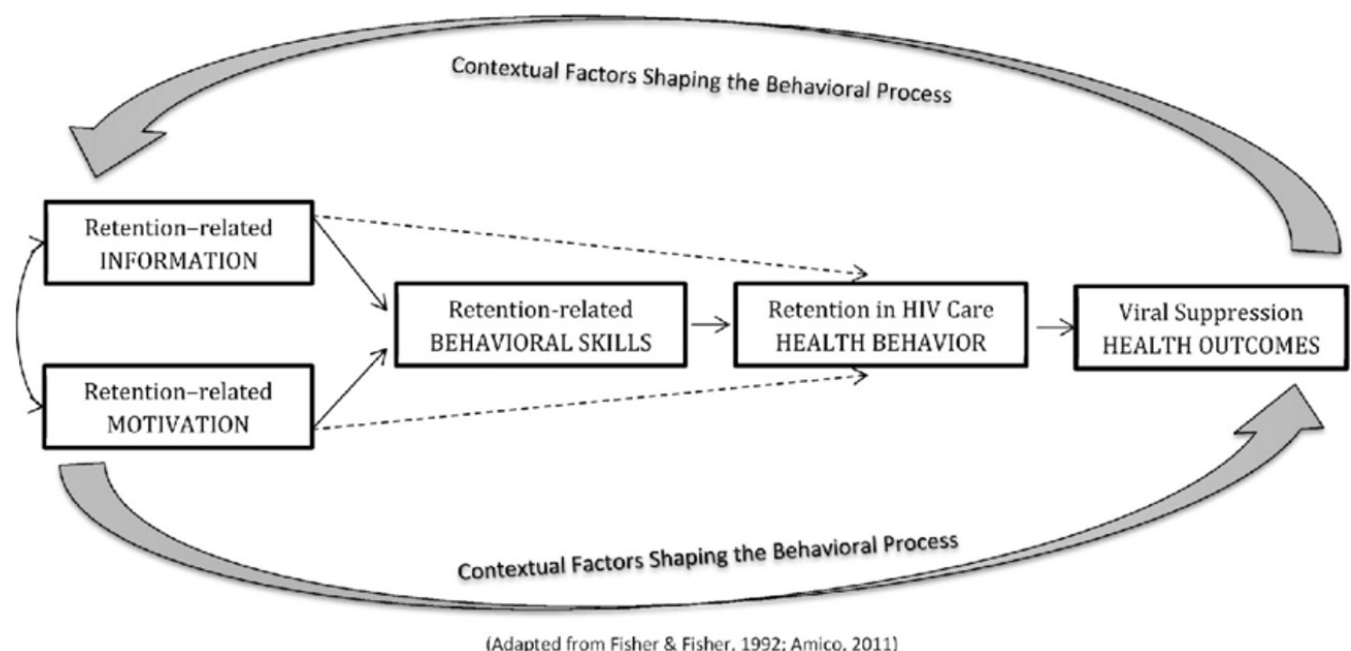
Figure 1. sIMB-CIM Model

The Role of Health Literacy amongst African American Family Caregivers of Persons living with Dementia: A Review of the Literature

Karah Alexander, MPH
PhD Program at Nell Hodson Woodruff School of Nursing at Emory University

Abstract

African Americans are twice as likely to be diagnosed with Alzheimer's disease and related dementia diseases compared to White individuals. African American family caregivers of those living with dementia report providing a higher rate of weekly care versus White and Asian American caregivers. Family caregivers are expected to identify and coordinate healthcare services and support and engage in conversations with healthcare providers on behalf of their care recipient, requiring them to have adequate health literacy skills. Limited research has examined the relationship between health literacy of family caregivers of persons living with dementia (PLWD), the demands of health systems, and caregivers' skills. African Americans have been found to have a disproportionately lower level of health literacy; thus, it is imperative that health literacy is assessed among African American family caregivers of PLWD. Due to limited research, this review was undertaken to highlight the scope and range of challenges related to health literacy that African American family caregivers of PLWD can face. A literature search was conducted using various databases such as PubMed, employing a combination of search terms. A total of 10 studies met the inclusion criteria. Four broad themes were identified: *health insurance literacy, print literacy/numeracy, communication with a healthcare provider, and health systems navigation*. Future research assessing health literacy of dementia family caregivers should focus on recruiting a larger amount of African American participants and work toward developing a health literacy tool unique to the dementia experience.

Keywords: Alzheimer's disease, dementia, African American, health literacy, family caregiver

Introduction

Family caregivers are family members, friends, or community members who provide assistance, typically unpaid, to someone who has limitations in their physical, mental, or cognitive functioning (Schulz, 2020). Caring for a person living with dementia (PLWD) can be overwhelming for family caregivers, leading to physical, emotional and financial pressures that can cause extensive family stress (Alzheimer's Association, 2020). Compared with care recipients without dementia, persons living with dementia are more likely to be older, take medications, and due to memory loss, disorientation, and other features of dementia, often have behavioral challenges and difficulties performing everyday activities (Kasper et al., 2015).

Dementia family caregiving can be especially overwhelming for African Americans, who are more likely to provide informal care versus institutionalizing care recipients or utilizing paid help compared to White caregivers

(Mullins et al., 2016). This is due to cultural values and a higher prevalence of African Americans having a lower income, thus not being financially able to utilize professional care (Mullins et al., 2016). One-fourth of African American caregivers of PLWD report providing a higher rate of care, spending an average of 21 hours or more per week caregiving, in contrast to 18 to 20 hours spent by White and Asian American caregivers (National Alliance for Caregiving & AARP, 2015).

A significant aspect of family caregiving responsibilities for PLWD requires health management tasks, which often include administration of medications, exchanging information with healthcare providers, accessing/understanding health information, and participating in health decision-making and problem-solving processes (Fields et al., 2018; Garcia et al., 2013). Such tasks also include identifying and coordinating healthcare services and supports such as preventative community-based groups and follow-up appointments (Fields et al., 2018). The responsibility of managing these health-related tasks is crucial for family caregivers, as care recipients, typically in the middle-late stage of the disease process, are not always cognitively able to navigate the healthcare system, engage in conversation with providers about their health and make health-related decisions (Clark et al., 2018; Garcia et al., 2013).

Health management tasks require family caregivers to have adequate health literacy skills. According to the Institute of Medicine, health literacy is an "individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Institute of Medicine, 2004). Low health literacy is a large problem in the United States, and it is estimated that approximately 80 million people have limited health literacy in the country (Garcia et al., 2013). Economists estimate that the adverse consequences of low health literacy add $106 billion to $238 billion annually to United States healthcare costs (Garcia et al., 2013). The consequences of inadequate health literacy include poorer health status, lack of knowledge about medical care and medical conditions, decreased comprehension of medical information, lack of understanding and use of preventive services, poorer self-reported health, poorer compliance rates, increased hospitalizations, and increased health care costs (Garcia et al., 2013). Unfortunately, little research has examined the relationship among caregiver health literacy, the demands of health systems, and caregivers' skills, specifically among family caregivers caring for someone living with dementia (Fields et al., 2018).

Low health literacy rates are disproportionately higher amongst African Americans, with 58% having basic or below basic health literacy compared with 28% of non-Hispanic Whites (Muvuka et al., 2019). Because low health literacy is an independent predictor of racial/ethnic disparities in health behaviors, access to healthcare resources, and health outcomes, it is imperative to address and understand gaps in health literacy skill levels amongst African American family caregivers of PLWD for the sake of their health as well as the health of their care recipient (Muvuka et al., 2019).

The purpose of this literature review is to highlight the scope and range of challenges that African American family caregivers of PLWD can face concerning health literacy. Identifying these specific challenges can aid in the development of culturally relevant interventions for African American family caregivers caring for a family member or friend living with dementia.

Methods

Search Strategy
A literature search was conducted to identify studies relevant to the purpose of the review using the bibliographic databases PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Health

Source: Nursing/Academic Edition. References from the retrieved studies were manually searched for any other relevant studies. The following search terms were used and the number of citations produced from each: 'African American' AND 'dementia caregivers' OR 'health literacy' AND 'dementia caregivers' OR 'family caregivers' AND 'dementia' AND 'health literacy' OR 'health literacy' AND 'chronic disease' AND 'caregivers' OR 'health literacy' AND 'informal caregivers' AND 'African American' OR 'Alzheimer's Disease' AND 'caregivers' AND 'health literacy' OR 'African American' AND 'caregivers' AND 'healthcare system' OR 'African American' AND 'informal 'caregivers' AND 'dementia'.

Inclusion Criteria

Studies were included if they were written in English, peer reviewed, or published within the last 10 years. Due to very limited published data on the research topic, studies did not need to examine health literacy of African American caregivers of PLWD to be included in the final review, but rather had to examine at least one of the following subject areas: family caregivers' health literacy challenges, family caregivers' difficulties with the health care system, and/or racial disparities in health literacy. The terms 'caregiver' and 'family caregiver' included only family members or friends who provided unpaid care to a loved one. Duplicate studies and those that did not examine family caregivers to older adults or dementia other chronic disease patients were excluded. There were no restrictions on study design; studies that used qualitative, quantitative or a mix of both quantitative and qualitative methods were included.
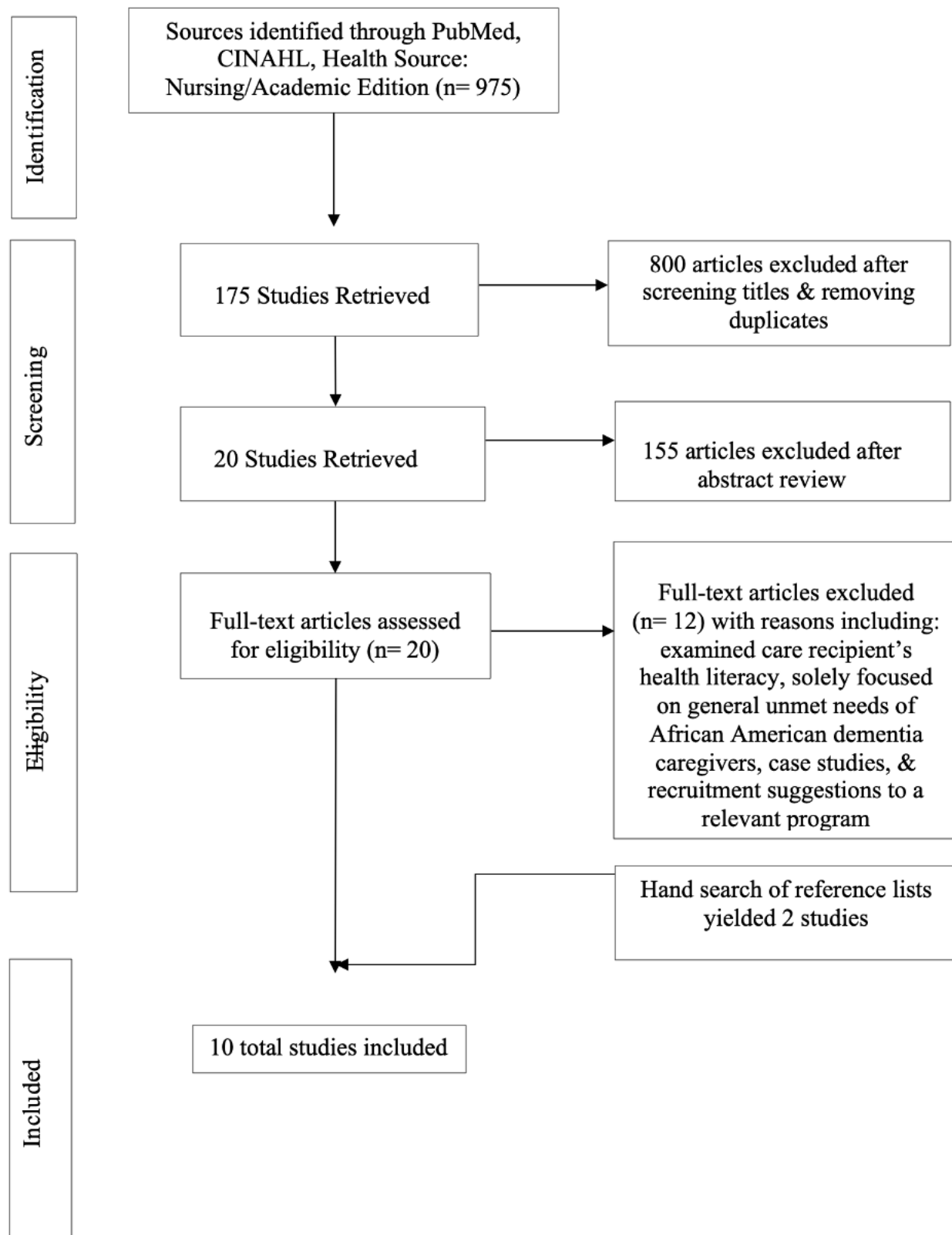
Results

Search Results

A total number of 975 citations were retrieved from searching the databases. After reviewing the titles and removing the duplicates, 800 citations were excluded. The abstracts of the remaining 175 citations were reviewed and 156 were further excluded. After examining the full text of the remaining 20 articles, 12 additional articles were excluded for the following reasons: focused on health literacy in care recipient (n = 8), solely focused on general unmet needs of African American dementia caregivers (n = 1), case study (n = 1), and recruitment suggestions to a relevant program (n = 2). Eight studies were confirmed to have fulfilled the inclusion criteria. After a manual search of the reference lists of the retrieved articles, 2 additional studies were deemed relevant and thus were included in the final review. Figure 1 represents a flow diagram of the literature review process.

Findings

Ten articles, diverse in study designs, met the inclusion criteria and were included in the final review. Three of the studies were conducted outside of the United States in Greece, New Zealand, and The United Kingdom. Four of the studies were qualitative, 1 mixed-method, and the remaining 5 studies were quantitative (surveys, cross-sectional design, and secondary analyses). Table 1 provides further characteristics of the qualitative and mixed-methods studies. Table 2 provides further characteristics of the quantitative studies.

One study included a sample of majority African American family caregivers of PLWD (Abramsohn et al., 2019). Two study samples were comprised of majority African American participants, however their role in the community was unknown (Villagra et al., 2019 & Ali et al., 2018). One study sample was comprised of oncology nurses who had interactions with caregivers (Wittenberg et al., 2018). Another study also included a sample of healthcare providers in addition to a sample of family caregivers of PLWD (Laparidou et al., 2019). Two secondary analyses assessed data from parent studies that included samples of family caregivers of older adults, specifically older adults with memory loss (Jiang, Sereika, & Lingler, 2018) and the second study noted that 24.2%

Figure 1. Flow diagram of the literature review process

Identification	Sources identified through PubMed, CINAHL, Health Source: Nursing/Academic Edition (n= 975)
Screening	175 Studies Retrieved → 800 articles excluded after screening titles & removing duplicates
	20 Studies Retrieved → 155 articles excluded after abstract review
Eligibility	Full-text articles assessed for eligibility (n= 20) → Full-text articles excluded (n= 12) with reasons including: examined care recipient's health literacy, solely focused on general unmet needs of African American dementia caregivers, case studies, & recruitment suggestions to a relevant program
	Hand search of reference lists yielded 2 studies
Included	10 total studies included

of the older adult care recipients had dementia or a dementia-related disease (Fields et al., 2018). The research protocol developed in Greece had a target sample of 200 primary caregivers and 200 secondary caregivers of PLWD (Efthymiou et al., 2017). The remaining studies were comprised of majority White family caregivers of PLWD (Hale et al., 2020 & Mullins et al., 2016).

The quantitative studies utilized a variety of data collection tools for health literacy, some of which were developed by authors for the purpose of the study and others were standard, valid tools, previously tested on a variety of populations. Jiang, Sereika, & Lingler (2018) utilized the Newest Vital Sign (NVS) to assess caregivers' health literacy. The NVS has been used to measure medication health literacy and has demonstrated high sensitivity across population; it has been recommended as a more sensitive measure of caregiver health literacy (Yuen et al., 2016). The NVS has established internal consistency with a Cronbach's alpha of 0.76 and moderate correlation of 0.54-0.59 with the established TOFHLA (Test of Functional Health Literacy in Adults) in populations that include older adults (Kirk et al., 2012 & Weiss et al., 2005). For Jiang, Sereika, & Lingler (2018) study, the internal consistency based on Cronbach's alpha was 0.73(n = 91). Fields et al. (2018) utilized a 3-item self-report questionnaire on confidence filling out forms, need for help with reading information, and comprehension with written information. The items were rated on a 5-point case from 1 (not at all difficult or never) to 5 (very difficult or always). This brief questionnaire has been shown to be highly predictive of more detailed performance-based measures of health literacy such as the S-TOFHLA (Short Test of Functional Health Literacy in Adults; Chew, Bradley, & Boyko, 2004).

Efthymiou et al. (2017) research protocol utilized the European Health Literacy Survey Questionnaire 16 (HLS-EU-Q16) to assess caregivers' of PLWD eHealth literacy. In preliminary studies, the HLS-EU-Q16 was validated in 107 older adults and the internal consistency of the scale using Cronbach's alpha coefficient was .77, which was somewhat lower than other validation studies (Efthymiou et al., 2017). Wittenberg et al. (2018) surveyed oncology nurses to assess their experiences with and demographics of patients with lower levels of health literacy. Researchers developed a 30-item survey to measure nurse communication and health literacy support. The survey was developed based on the researchers' prior published research on nurse communication and with the United States (U.S.) Department of Health and Human Service's National Action Plan to Improve Health Literacy as a Framework (Wittenberg et al., 2018). Additional items were included to learn more about communication in the context of patient low health literacy, which included a set of scale-based questions centered on 5 low health literacy patient populations developed by the authors. Lastly, Villagra et al. (2019) developed a 13-item survey that included questions about knowledge and use of health insurance terminology; no further details on the survey were provided by the authors.

Data analysis of five of the studies yielded moderating variables significantly associated with participants' health literacy (Villagra et al., 2019; Ali et al., 2018; Jiang et al., 2018; Wittenberg et al., 2018 & Mullins et al., 2020). Jiang, Sereika, & Lingler, (2018) found that health literacy has a large positive correlation with global cognitive function and a moderate negative correlation with increased age. The authors also noted that caregiver working memory is one of the key components that contribute to health literacy. In Wittenberg et al. (2018) nurses reported that the low health literacy populations they most frequently encountered were older adults (57%). Although these were oncology nurses referring to the caregivers of cancer patients, according to the National Alliance for Caregiving & AARP (2015), 62% of caregivers of PLWD are 60 years of age or older. Thus, it is crucial that health literacy interventions for this population of caregivers should account for age (National Alliance for Caregiving & AARP, 2015). Household income was assessed in one of the articles included in the review, however this variable was not found to be significantly associated with participants' health literacy (Villagra et al., 2019). Education was found to be a significant variable in 3 of the studies (Villagra et al., 2019; Fields et

al., 2018 & Mullins et al., 2016). According to health literacy research, education has been found to be the most influential variable on one's level of health literacy (Van der Heide et al., 2013). People with a lower education level have been found to demonstrate lower health literacy skills in comparison to people with a higher level of education (Van der Heide et al., 2013). Villagra et al. (2019) found participants with a bachelor's degree had a higher level of health insurance literacy compared to participants without.

RTI's (Response to Intervention) Health Literacy Skills Framework, which builds upon existing health literacy theoretical frameworks and depicts how health literacy functions at the individual level, was utilized to guide the identification of the common themes across the articles (Squiers et al., 2012). The Health Literacy Skills Framework highlights the core domains of health literacy including: Print Literacy (reading, writing, numeracy), Communication (listening, speaking, negotiating), and Health Systems Navigation (information Seeking & eHealth) (Squiers et al., 2012). Four major themes, which overlapped in some articles, were generated from the 10 studies. These themes included: *health insurance literacy, print literacy/numeracy, communication with a healthcare provider, and health systems navigation.* Although not a core aspect of the framework, health insurance literacy is often included as a domain of health literacy due to the relationship with established domains as described in the Health Literacy Skills Framework and was thus included as a theme in this review (Edward et al., 2019). These themes illustrated common challenges of health literacy amongst African Americans and/ or family caregivers.

Theme 1: Health Insurance Literacy (HIL)

This theme, highlighted in two of the studies, shines light on an individual's knowledge, ability, and confidence to find and evaluate information about health plans, select the best plan for their own (or their family's) financial and health circumstances, and use the plan once enrolled (Ali et al., 2018 & Villagra et al., 2019). The studies reflecting the theme of health insurance literacy had samples of either majority or a sizable number of African Americans, however there was no indication if they were family caregivers or not. Overall, it was found that African Americans had statistically significant lower health insurance literacy compared to White individuals (Villagra et al., 2019). African Americans reported numerous challenges choosing an insurance plan most appropriate for their circumstances and found it challenging to understand & use their coverage (Ali et al., 2018). Additionally, African American participants viewed the insurance selection process as complex and very political, some noting that these views prevented them from seeking needed treatment (Ali et al., 2018). When asked what would help make the process of selecting a plan smoother, most participants noted in-person assistance would be the most effective resource (Ali et al., 2018).

Theme 2: Print Literacy/ Numeracy

One study yielded the theme of numeracy/ print literacy (Jiang et al., 2018). Numeracy skills are defined as "the ability to apply arithmetic operations and the use of numerical information in printed materials"; it is sometimes referred to as quantitative literacy (Rothman et al., 2008 & Baker, 2006). Jiang et al. (2018) assessed the health literacy of caregivers of older adults living with memory loss, specifically caregivers' medication management skills which was not found to be an independent predictor of caregivers' health literacy in the hierarchical multiple linear regression (Jiang et al., 2018). Caregivers had an average health literacy score of 4.02, indicating overall adequate health literacy, and health literacy showed a small positive correlation with medication knowledge (p=.02; Jiang et al., 2018).

Theme 3: Communication with Healthcare Providers

Four studies yielded the theme of communication, specifically with healthcare providers (Laparidou et al., 2019; Fields et al., 2018; Whittenberg et al., 2018 & Mullins et al., 2016). Effective patient-provider communication

"requires that the information given by the provider be complete, accurate, timely, unambiguous, and understood by the patient" (Patak et al., 2009). Family caregivers faced challenges discussing the condition and needs of their care recipients with respective providers. In Mullins et al. (2016), family caregivers reported feeling that health providers have a theoretical knowledge of dementia, but don't understand how dementia affects patients & their caregivers or how best to help them. Researchers also found that communication challenges varied by the caregiver's relationship with the recipient. Child caregivers, specifically daughters, found that emotional barriers prevented them from asking needed questions due to frustrations with role reversal and discomfort with asking "hard questions", because they were not used to having to care for their parent (Mullins et al., 2016). Spousal caregivers, particularly husbands, lacked experience and confidence in providing for their wives which prevented them from having productive conversations with the provider (Mullins et al., 2016). Some husbands noted numerous frustrations with the doctor and felt they did not provide enough information about the progression of Alzheimer's disease or how certain symptoms can arise in the later stages of the disease (Mullins et al., 2016). When discussing concerns about his wife who was in late-stage Alzheimer's disease and experiencing incontinence, one participant stated, "...*it might be easier if doctors brought it [incontinence] up, instead of me having to bring it up with them.*" Extended family and friends faced the greatest difficulties, reporting rarely being invited to participate in clinic visits of their care recipient with the provider & had less access to answers to questions due to not being closely related to the care recipient (Mullins et al., 2016).

In Laparidou et al. (2019), HCPs discussed the challenge of diagnosing dementia and expressed the need for caregiver education about the ins and outs of the disease to improve dementia literacy. Additionally, providers recognized the lack of support caregivers to PLWD receive and the mismatch of communication and expectation from the providers themselves.

Theme 4: Health Systems Literacy (HSL) and eHealth

Health systems literacy is one's ability to understand the different levels of care (i.e., self-care, primary care, urgent care, emergency care, etc.) and the different ways to access needed services (Ali et al., 2018). Five studies highlighted the theme of HSL and navigation (Abramsohn et al., 2019; Villagra et al., 2019; Ali et al., 2018; Fields et al., 2018 & Efthymiou et al., 2017). Abramsohn et al., (2019) sought to gain perceptions of African American caregivers of PLWD about community resources needed to support caregiving as well as their own self-care and how they navigate and obtain such resources. Majority of participants lacked knowledge of how to achieve needed resources for their self-care or for the health and benefit of their care recipient (Abramsohn et al., 2019). When accessing resources, "word of mouth" exchange was repeatedly cited as the most important source of information about the resources necessary to take care of people with dementia (Abramsohn et al., 2019). Stigma associated with having memory problems and other mental health issues among African Americans, often resulted in caregivers' hesitancy to access dementia care and resources needed for their care recipients as well as their own self-care (Abramsohn et al., 2019). Fields et al. (2018) found that caregivers (to older adults & PLWD) helping care recipients with more activities of daily living had greater difficulty with healthcare communication and navigation of services and supports.

The aim of Efthymiou et al. (2017) research protocol was to investigate the level of eHealth literacy and health literacy of primary and secondary caregivers of PLWD, explore the association between health and eHealth literacy, as well as their association with the caregiving variables: self-efficacy, coping, and caring perception. Preliminary data of the HLS-EU-Q16 was the only data provided in the protocol.

Discussion

This review highlighted the various challenges related to health literacy that family caregivers can face. Not all studies were exclusive to family caregiver's of PLWD, some included a wider sample of family caregivers of

older adults and older adults with memory loss. Although some studies did not specifically examine family caregivers of PLWD, caregivers included in the review may experience similar if not identical challenges with health literacy and thus results were generalized to informal caregivers of PLWD. Majority of the family caregivers across the studies were women. Not only are women more likely to be affected by Alzheimer's Disease and related dementia diseases, but they are also more likely to become family caregivers. More than 60% of family caregivers of PLWD are women and over one-third are daughters (Alzheimer's Association, 2020).

Articles that focused on health insurance literacy included samples of African Americans who were not necessarily caregivers. These articles shed light on the ethnic/racial disparities in health literacy, specifically health insurance literacy. African American caregivers are in a good position to benefit from resources and services covered by various insurance plans such as Medicaid Assistance Programs, including Home and Community-Based Services (HCBS) -Waiver Programs such as adult day care, in-home, and respite care (Kingsberry & Mindler, 2011). African American PLWD are underserved, living without the financial assistance and support services that programs such as HCBS can provide (Kingsberry & Mindler, 2011). This is primarily due to poorer health insurance literacy among the African American community, including misconceptions of not meeting required financial criteria, the application process perceived as too difficult and time-consuming to complete, and the false notion of African American caregivers losing their assets and homes upon receiving assistance (Kingsberry & Mindler, 2011).

Only one studied included a majority sample of African American family caregivers of PLWD (Abramsohn et al., 2019). Although there is a large population of African American family caregivers of PLWD, they are poorly represented in this body of research. The lack of trust in research and medicine is often the root of African Americans' poor representation in research and may contribute to the poor health literacy of African American participants in the studies included in the review. Ali et al. (2018) found *mistrust of the healthcare system* to be a major theme in examining African Americans' HIL and HSL, with participants expressing a lack of trust in providers and their motives and citing past negative experiences with healthcare.

Perhaps one of the most dynamic factors relating to mistrust of the healthcare system by African Americans is the lack of cultural competence by healthcare providers (Kennedy, Mattis, & Woods, 2017). It is this lack of cultural sensitivity and cultural competence on the part of the physician and other healthcare workers that breeds mistrust of medicine and healthcare by this minority group (Kennedy, Mattis, & Woods, 2017). Many healthcare providers, unless they are of the same ethnic background, know very little about how to interact with the African American client population and are often influenced by cultural biases (Kennedy, Mattis, & Woods, 2017). Cultural biases combined with family caregivers' skepticism of provider competency in how best to aid caregivers of PLWD could result in poor, ineffective provider communication with African American family caregivers of dementia patients.

Two studies surveyed and incorporated views of healthcare providers on health literacy challenges in caregivers to PLWD (Wittenberg et al., 2018 & Mullins et al., 2016). The authors suggest that nurses and other health providers can serve as valued sources of accurate information and be able to interpret confusing clinical information for caregivers, however these conversations can be ineffective due to poor communication practices. Contributing factors that perpetuate ineffective patient-provider communication include the lack of a systematic method for nursing assessment, evaluation, and monitoring of patient-provider communication needs and interventions; and lack of standardized training of healthcare providers (Patak et al., 2009).

Established tools exist to assist nurses in assessing and communicating with patients who have limited health literacy, including the use of screening questions and plain language communication strategies (Wittenberg et

al., 2018). However, current research highlights a major gap in nurse's knowledge and assessment of patient's health literacy (Wittenberg et al., 2018). It is beneficial to include samples of HCPs who commonly interact with dementia patients and their informal caregivers. Their perspectives in combination with the caregivers' can pinpoint the disconnects and help bridge the gap of communication.

Villagra et al. (2019) found education level to be significantly associated with participant's health insurance literacy. However, the authors found it limiting that they did not account for quality of education. Educational experiences can be characterized with respect to duration, for example, using years of schooling completed or degrees attained, or with respect to quality of schooling (Sisco et al., 2014). The degree of cognitive abilities resulting from the respective education level may better correspond with measures of educational quality than solely one's level of education (Sisco et al., 2014). Though hard to capture, accounting for quality of education is important in health literacy research, particularly when examining African American older adults, because many adults now aged 50 years and older grew up during the influence of segregation laws (Sisco et al., 2014). Educational quality has varied widely across states and over time in the United States with distinct differences especially between northern and southern parts of the country; historically, many African Americans received their education in the south and most Southerners attended segregated schools, and schools for Black students offered significantly lower quality education than schools for whites (Barnes, 1983). Such educational quality has been found to have significant impact on late life cognition and may also have impact on African American older adults' health literacy (Sisco et al., 2014).

Strengths
The articles included in the review employed various study designs, which shed light on different aspects of health literacy and the greatest challenges faced when encountering them. The articles utilized a mixture of valid health literacy measurements and original tools developed for the purpose of the respective study. Including international studies allowed for broadened perspective and introduced new health literacy tools yet to be validated in the U.S. population.

Limitations
This review does not include many studies, but this may be attributed to the specificity of the topic. Furthermore, this highlights that this topic may not be well-researched. Many of the studies had small sample sizes and very few had samples comprised of the review's target population - African American family caregivers of PLWD. Although it is beneficial to examine international healthcare systems, healthcare systems vary differently between countries, so these study results may not be applicable to the U.S. population. In addition, one of the international studies was a research protocol which only had preliminary data surrounding the data collection tool. Other limitations included the lack of a quality assessment tool or formal data synthetization process utilized for this review; thus, the results may be skewed by biases from the methodology. Lastly, health literacy was operationalized differently across the quantitative studies; some studies utilized one to multiple standardized tools and others used measurements developed by researchers. Although certain tools measure different aspects of health literacy, this still raises questions about consistency- which tools and how many are needed to most accurately capture one's health literacy skill level.

Implications for research
Little research has examined health literacy and its role in the caregiving experience of family caregivers of PLWD, particularly African American caregivers. Future research should make a special effort to recruit African American family caregivers who face the greatest challenges with health literacy yet are underrepresented in research studies. Identifying gaps can lead to culturally tailored interventions created accordingly and bring

awareness to nurses and other healthcare providers who commonly interact with dementia patients and their family caregivers. It would be of benefit to utilize or develop a novel health literacy measurement tool with items unique to the dementia experience.

In the age of technology and eHealth, more family caregivers are turning to the internet for information and resources to aid in the caregiving experience (Efthymiou et al., 2017). Future research should consider examining eHealth literacy and determine whether older adults are struggling to utilize technology and whether family caregivers of PLWD are turning to the internet for information versus health care providers and specialists.

Implications for nursing research and practice
- Highlight the need to develop a health literacy measurement tool designed to assess health literacy in family caregivers of persons living with dementia based upon healthcare practices and common experiences among caregivers of PLWD.
- Establish and/or improve health literacy screening for geriatric providers who commonly interact with these family caregivers.
- Bring awareness to the challenges concerning health literacy that are impacting African American family caregivers of persons living with dementia.

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Table 1. Characteristics of Qualitative and Mixed-Method Studies

Author/ Year	Method of Data Collection	Focus Point(s) of Interviews/focus groups	Sample Dynamics	Themes
Abramsohn, M.E., Jerome, J., Paradise, K., Lostas, T., Spacht, A.W., & Lindau, T.S. (2019)	Semi-structured interviews	Gain perceptions of African American caregivers to PLWD about community resources needed to support caregiving as well as their own self-care and how they navigate to gain such resources	N = 13 Family caregivers of PLWD who self-identify as black or African American 77% female	Most common facilitator to accessing community resources: "word of mouth" exchange Barriers to accessing community resources: inability to leave the person with dementia unsupervised
Ali, M.N., Combs, M.R., Muvuka, B., & Ayangeakaa, D.S. (2018)	12 focus groups	Assess residents' health insurance and health systems needs and identify ways of assisting residents with navigating the healthcare system and utilizing their health insurance coverage	N = 87 African American adults from West Louisville, KY neighborhoods	Health Insurance & Health Systems Complication Mistrust of the healthcare system Prohibitive or Unknown Costs Disparities Between Public and Private Health Insurance Health Insurance Information Delivery Preferences
Hale, L., Mayland, E., Jenkins, M., Buttery, Y., Norris, P., Butler, M., Holland, M., McKenzie-Green, B., & Kayes, N. (2020)	Semi-structured interviews	Capture thoughts on what it means to be a caregiver, how they feel supported in this role, and on how they are able to help their family member or friend to help themselves.	N = 25 Family caregivers of a PLWD 84% female Majority white New Zealand	Overarching themes that described how carers perceived their roles and experiences focused on constructing normalcy for the person they were caring for: Keeping the peace Facilitating participation Facilitating independence Ensuring safety Facilitating happiness Barriers to constructing normalcy: additional health issues, legal issues, symptoms of dementia, lack of knowledge (i.e., additional resources)
Laparidou, D., Middlemass, J., Karran, T., & Siriwardena, N.A. (2019)	Focus Groups 1 Semi-structured interview	(Caregivers) type of information and support they'd received; satisfaction with this and what they would like to receive from HCPs (HCPs) the issues informal caregivers typically face from a provider's perspective	N = 34 (17) informal caregivers of PLWD (17) health care providers (HCPs) Majority white, female Lincolnshire, UK	Themes captured the main challenges faced by caregivers and the type of support they wanted from health care services: The challenge of diagnosing dementia & obtaining appropriate health care. Caregivers' need and expectation of in-depth knowledge and understanding of dementia from HCPs. Need for carer education. Lack of support and mismatch of communication and expectation Carer involvement in monitoring care and disease.
Mullins, J., Bliss, Z.D., Rolnick, S., Henre, A.C., & Jackson, J. (2016)	Secondary analysis of a Mixed-Methods Study Parent study: focus groups, interviews, and written surveys	Capture the barriers to communicating with healthcare professionals and health literacy about incontinence in PLWD	N = 48 Family caregivers of PLWD & assist with incontinence 77% White 12.5% Black 31.25% Hispanic 8.3% more than 1 race	Themes yielded per caregiver type: (daughters): emotional barriers- reversal in roles (spouse): Husbands' health literacy about incontinence as low due to lack of experience and confidence in providing care for their wives in general (extended family/friends): looked at as invalid carers; less access to questions due to not being closely related to care recipient

Table 2. Characteristics of Quantitative Studies

Author/ Year	Method of Data Collection	Measurement	Sample Dynamics	Outcomes
Efthymiou, A., Middleton, N., Charalambous, A., & Papastavrou, E. (2017)	Research Protocol	(1) European Health Literacy Survey Questionnaire 16 (HLS-EU-Q16) (2) Single Item Literacy Screener (SILS) (3) eHeals- self-report tool measuring eHealth literacy based on the Lily model adapted for carers (all standard)	Target Sample: N = 200 primary carers N = 200 second-ary carers recruited from 2 metropolitan cities in Greece	Pre-liminary data: HLS-EU-Q16 validated in 107 older adults Main study will investigate the relationship of eHealth literacy and health literacy with care-giving self- efficacy, coping strategies, and care management perceptions of carers of people with dementia.
Fields, B., Roadkow-ski, J., James, E.A., & Beach, S. (2018)	Secondary analyses of cross-sectional data from the Pittsburgh Regional Caregivers Survey in 2017 Parent study: telephone survey	Healthcare communication and navigation of services and supports (HCNS) 5- item scale. Health literacy measured with self-report questions on confidence filling out forms, need for help with reading information, and comprehen-sion with written information (developed by researchers)	N = 761 caregivers of older adults 24.2% caregivers to PLWD 79.9% white 65.3% female	Caregivers with low health literacy had 2.52 greater odds of difficulty communicating with a health care provider about themselves & the care recipient needs & locating & arranging services and supports for a care recipient vs. caregivers with high health literacy
Jiang, Y., Sereika, M.S., Lingler, H.J., (2018)	Secondary analysis of baseline data from a ran-domized control trial	Newest Vital Sign (NVS) (standard)	N = 91 caregivers to adults with mem-ory loss 85% White 70% female	Caregivers had an average health literacy score of 4.02, indicating overall adequate health literacy. Health literacy showed a small positive correla-tion with medication knowledge (p=.02) Findings suggest limited health literacy is a po-tential issue among informal caregivers of adults with memory loss
Villagra, G.V., Bhu-mika, B., Coman, E., Smith, O.D. & Fifield, J. (2019)	Telephonic Survey	13 questions about knowl-edge and use of health insur-ance terminology (developed by researchers)	N = 516 ACA enrollees in Connecticut 50% White 25% Black 61% female	Black respondents had lower health insurance literacy correct scores by 20.48 percentage points vs white respondents (53.29% vs 73.76% respectively). Low health insurance literacy disadvantages racial/ethnic minorities disproportionately
Wittenberg, E., Fer-rell, B., Kanter, E., & Buller, H. (2018)	Open-ended survey	(1) 30-item survey to measure nurse communication and HL support (2) 5 low health literacy pa-tient populations presented & scaled based questions asked accordingly (both developed by researchers)	N = 74 oncology nurses 62.2% clinical nurses hospital setting - 67.6% outpatient/ ambulatory care-18.9%	Majority nurses reported greatest commu-nication challenges with patients who spoke English as a second language (41%), patients with less than a high school education (10%), & ethnic minority (9%). Nurses reported that the low health literacy populations they encountered most frequently were older adults (57%)

Art Submission: "Palliative Cake"
Brianna Morgan, MSN, CRNP, ACHPN®

"Trauma Club": Reflections on Scholarly Collaboration and Psychosocial Support from an Adverse Childhood Experiences Student Research and Advocacy Group in the Time of Covid-19

Emily R. Hoppe, MSN, PMHNP-BC, Meredith Klepper, MS, RN, CPN, and Kathryn J. Spearman, MSN, RN
Johns Hopkins School of Nursing, Baltimore, Maryland, USA

In the context of online learning due to the Covid-19 pandemic, Ph.D. students and a post-doctoral fellow formed a research and advocacy group focused on their shared scholarly interest in adverse childhood experiences (ACEs). The purpose of this article is to provide background on the need for such a group, highlight the benefits of this learning model for new researchers, describe the group's activities so far, and reflect on future opportunities for growth.

Background

ACEs are experiences of child maltreatment and household or community dysfunction that are experienced before the age of eighteen. ACEs were initially described in a landmark study by Felitti and colleagues (1998) as experiences of child maltreatment or household dysfunction. In that study, the authors collected survey data from patients (n= 9,508) of a large healthcare management organization and found a dose-response relation-

ship between the number of reported ACEs and poor physical and mental health outcomes in adulthood, including depression, suicidality, smoking, alcohol abuse, heart disease, cancer, stroke, and diabetes. Researchers have proposed a number of potential mechanisms for this relationship between childhood experiences and later adult health and psychosocial outcomes, including stress-induced inflammatory pathways, immune dysregulation, and disrupted neurodevelopment (Felitti et al., 1998; Franklin & Kerchner, 2012).

ACEs are the focus of a briskly expanding body of research. In the period between 1998, when the first ACEs article was published, until 2018, a total of 789 studies about ACEs were published in twelve different research fields, with the annual number of articles more than doubling between the years 2014-2016 (Struck et al., 2021). Scientists' conceptualization and understanding of ACEs has changed in the 20 years since the Felitti et al. (1998) study was published, with research establishing the importance of including community-based ACEs, such as experiencing discrimination, bullying, or witnessing community violence (Cronholm, et al., 2015; Woods-Jaeger, et al., 2019). Furthermore, the number of ACEs an individual experiences is a poor predictor of that individual's health outcomes, such that ACEs are best understood at this point as indicators of community- or population-level risk (Baldwin, et al., 2021). Other scientists are investigating the mediators, moderators, confounders, and neural correlates of ACEs, as well as protective factors such as positive childhood experiences (PCEs), to better understand the variation in individual outcomes (Weems, et al., 2021; Bethell et al., 2019).

ACEs represent a pervasive public health problem and urgent social justice issue. In the United States, 61.5% of the population is estimated to have experienced at least one ACE, and 24.6% have experienced three or more ACEs (Merrick, et.al., 2018). ACEs disproportionately impact disadvantaged and oppressed communities, and have been linked with health disparities (Heberle, et al., 2020; Brockie et al., 2013). Therefore, in addition to reducing the population-level burden of ACEs, it is an urgent matter of social justice that ACEs be prevented and mitigated in communities already overburdened by their impact.

Journal clubs have been referenced in the literature since the late 19th century, and generally provide space for groups of clinicians or researchers to meet for discussion of leading-edge academic journal articles in a particular subject area (Deenadayalan et al., 2008; Meleger et al., 2020). The documented benefits of journal articles include increased student or practitioner knowledge related to subject or methodology, improved translation of research to practice, improved critical appraisal skills, and collegial support (Abboud et al., 2017; Deenadayalan et al., 2008). Journal clubs are typically positioned outside of the traditional curriculum and offer a learner-driven, dynamic approach to engaging with a particular subject. While pedagogical benefits of journal clubs have been documented in the literature, less attention has been given to the psychosocial benefits of such groups, or to the potential for advocacy arising from this collaborative learning experience.

The ACEs Research and Advocacy group was formed in October 2020 at the Johns Hopkins School of Nursing after several first-year Ph.D. students recognized their shared scholarly interest in ACEs and related social justice issues. In the context of an unexpected online year of learning due to the Covid-19 pandemic, there was a need to intentionally connect with peers around common interests, passion for research and advocacy, and the shared experience of being a Ph.D. student. An initial, informal meeting via Zoom led to the conceptualization of the group as both a journal club and a source of informal support. There were also second-year Ph.D. students and one post-doctoral fellow who were identified as potential members and subsequently joined. In the 2020-2021 academic year, students' research interests represented a broad range of ACEs-related science, including the neurobiology of ACEs, psychometric issues in ACEs research, LGBTQ+ children and families, adolescents' exposure to community violence, arts-based interventions promoting resilience, food insecurity, the intersection of intimate partner violence and child maltreatment, ACEs' influence on parenting, and PCEs.

The members then established leadership positions to be recognized as an official student group, sought faculty support from leading scholars in the field at the institution, and wrote the mission statement of the group:

> The mission of the ACEs Research and Advocacy group is to bridge scholars, organizations, initiatives, and community members focusing on the science of adverse childhood experiences (ACEs) and resilience. Through interprofessional learning and collaboration, the group aims to (1) provide a platform for ACEs resources and information exchange, (2) support engagement in research and practice related to ACEs, and (3) advocate for policy change to improve physical and mental health outcomes for those who have experienced childhood adversity.

Description of Activities

The primary activity of the group consisted of weekly meetings with an informal structure. The meeting agenda was agreed upon by consensus during the previous week to best meet the needs of students at a given time. Students sought help from one another in finding the most fitting paradigms, theoretical frameworks, and conceptual models for ACEs research and adapting them when indicated to the specific research focus. An electronically stored and shared file with dozens of relevant peer reviewed journal articles organized by subject, meeting notes, and other resources was created and shared with all members of the group. In addition, students emailed the group between meetings to share information about ACEs-related webinars, conferences, presentations, and newly published articles.

Students also supported one another's engagement in research related to ACEs, which took several forms. Students' diverse research interests within the broader field of ACEs led to rich discussion of the state of the science and methodological challenges in the field. Students came to meetings with questions regarding methodology or theory, or with new or interesting articles to discuss. For example, during one meeting, students investigating PCEs were trying to determine whether PCEs could be treated as a mediator or a moderator in a statistical model with ACEs and sought insights from the group to aid in their investigation. During another meeting, students discussed a newly published finding that ACEs were poor predictors of individual outcomes in statistical models (Baldwin, et al., 2021) and considered implications of this for students' developing research aims. As the year progressed, meetings increasingly focused on crafting and revising dissertation specific aims statements and developing and practicing presentations, with constructive critiques offered by other group members.

As ideas were discussed with trusted peers, new ideas formed for both individual and collaborative projects, with several manuscripts now in progress. A few pre-licensure Master of Science in Nursing students reached out and joined for several sessions to observe and learn more about ACEs research and the activities of Ph.D. students. A Ph.D. student from another institution also joined in for several weeks for discussions around measurement issues with ACEs.

The group maintains a commitment to advocacy for policy change informed by ACEs research as an essential aim of group activities. During the 2020-2021 school year, group members attended community-based advocacy events and shared information about these events with the group. One of our initial advocacy efforts was to sign on in support of a policy brief written by Campaign for Trauma-Informed Policy and Practice (CTIPP) and leading ACEs scholars for the Biden-Harris administration. This policy brief advocated for a comprehensive, coordinated action plan that the administration should take in its first 100 days in office to create a trauma-informed continuum of care to address ACEs, historical trauma, and nurture resilience. The group planned to invite authors to speak about articles that had been discussed but this was deferred due to time constraints, as well as the limitations of meeting online versus in person. In the 2021-2022 school year, the group is focusing

on community engagement with the goal of integrating community members' concerns into ACEs-related research and practice. As one step to achieve this, we are organizing a panel of young people from the Healing Youth Alliance, a youth-led organization in Baltimore City, who will present their ideas and perspectives on ACEs to the Johns Hopkins School of Nursing research and practice communities.

In addition to research-focused activities, there was also a focus on navigating Ph.D. studies. Discussion topics include relationships with advisors, mentors, and collaborators, grant writing, course electives, research residencies, and managing the many competing demands experienced by Ph.D. students. The group developed a warm rapport that facilitated both professional collaboration and psychosocial support for the unique stressors experienced by Ph.D. students during a global pandemic. This has led to an environment of robust psychosocial support within the group. Students were able to lean on the group for psychosocial support during times of doubt and struggle and celebrate accomplishments together as well. The group frequently engages in problem solving sessions together, empathic reflection, and identification of resources to meet the psychosocial needs of Ph.D. students beginning their academic careers during a pandemic.

Benefits

One of the student members of the ACEs Advocacy and Research group lightheartedly referred to the weekly meetings as "trauma club." While meant in jest, the phrase sheds light on the ways that this group benefited the student members. First, while ACEs are a growing area of research, they can be difficult to discuss due to stigma, as well as the sadness or discomfort that may arise while thinking about them. Having a community or "club" of like-minded students who are passionate about solving challenging problems related to trauma and violence allowed for a free flow of discussion that did not always exist in the classroom setting or in our broader community. Secondly, members were extremely supportive and responsive to each other, providing a safe space for the emotions that can accompany spending so much time contemplating ACEs. Therefore, we believe that this group provided some mitigation of the impact of the secondary trauma associated with being immersed in ACEs research. Conversations also included discussions around compassion fatigue and best practice approaches to trauma-informed research and scholarly work. Establishing rapport and building trust among group members can help offset issues of secondary trauma that may arise while researching and discussing childhood adversity (Paavilainen, Lepisto, & Flinck, 2013; Hardesty, Haselschwerdt, & Crossman, 2019).

Meeting as a group helped members to refine and implement their research ideas, and generated collaborative relationships that have led to several articles in development. Members have generously shared their personal and professional networks, making introductions to other scholars and community advocates in the field to help answer challenging questions. One student described their experience this way:

> Being a Ph.D. student can be incredibly isolating and that feeling is compounded during a pandemic when we haven't even been in the same room as most of the people in our cohort. The ACEs Research and Advocacy Group gave me grounding and a network of like-minded colleagues to lean on and learn from during a time of unprecedented stress and collective trauma. The experience has made me a better scholar and helped to develop my self-reflexivity around trauma topics. It has been invaluable, particularly as a first-year Ph.D. student during the COVID pandemic.

Another student described their experience as providing connection, immersion, and support:

> Being a part of this group provided a sense of community during a time when community felt hard to access while doing online learning for the Ph.D. I learn so much from my peers, and the weekly meetings give me a sense of immersion in ACEs research and advocacy that would otherwise be missing from my Ph.D. experience. Their support has helped me through the many challenges of this year.

Areas for Growth and Future Plans

While members derived benefit from the group, there were limitations to the group this year, and areas for growth. The group will be strengthened by future involvement of students and faculty who represent the inter-disciplinary nature of ACEs research. This can be accomplished through the implementation of a speaker series offering guest speakers from non-profit, governmental, and community-based organizations as well as leading scholars working to address ACEs. Future plans also include opportunities for collaboration on secondary data analyses and other manuscripts, providing structured peer support to new nursing students, and expanding outreach to other graduate and post-doctoral students at other schools at our institution, including the Medical School, School of Public Health, and the School of Education. Unfortunately, Covid-19 continues to impact our educational experience and student presence on campus. For now, using the Zoom platform for weekly meetings offers the best accessibility for group members and will likely continue as the primary meeting space for this group. Our hope is to plan in-person events with invited speakers when university Covid-19-related restrictions are eased.

Conclusion

The ACEs Research and Advocacy Group was formed at the Johns Hopkins School of Nursing to bolster support, initiate scholarly endeavors around ACEs, and advocate for trauma-informed policies for children. Comprised of a mix of Ph.D. students and a post-doctoral fellow at the school, the group has examined many facets of ACEs in the past year. This collaborative group has plans to further explore the current ACEs literature and to support each other in expanding the boundaries of science and policy in this field. The model of the ACEs Research and Advocacy Club could be an asset for new scholars in other fields, especially those related to violence, trauma, substance use, sexually transmitted infections, and other fields that face a high degree of stigma. Scholars in these areas can experience secondary trauma and this model offers support in coping with these stressors, as well as the demands of the early stages of developing a program of research. Moving forward, the vision for the ACEs Research & Advocacy Group is to advance the science of understanding ACEs and contribute to the growing body of knowledge around ACEs and PCEs while providing holistic support for emerging scholars.

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A Brief Theory Critique:
The Theory of Moral Reckoning

Kathleen E. Fitzpatrick Rosenbaum, BSN, RN, RNC-NIC, CCRN

Abstract

Nurses continually face moral dilemmas and endure moral distress. As a result, nurses experience emotional, physical, and professional consequences. When nurses experience moral distress the nursing workforce is hurt, and patient outcomes suffer. The theory of Moral Reckoning is a framework to understand how nurses process the experience of moral distress. Theory critique is a tool to test the functionality of a theory. This brief theory critique of Moral Reckoning examines the theory's application value.

Introduction

Although the term moral distress was originally coined in 1984 by ethical philosopher Andrew Jameton, it has been discussed since the 1970's and continues to be applicable to nursing. Nurses experience moral dilemmas when a moral decision between two options must be made, but they are unsure which decision is best. Moral distress occurs when nurses know which moral decision to make but find it difficult to act accordingly or feel forced to act contrary to their moral beliefs (Hamric, 2000; A. Jameton, 2017; Andrew Jameton, 2013). Physical and mental expressions of moral distress include stress, feeling ill, anger or depression, and negativity- personally and regarding their work environment (Huffman & Rittenmeyer, 2012; Lamiani et al., 2017; Morley, Ives, Bradbury-Jones, et al., 2019).

Poor nurse staffing, high workloads, lack of resources, strained work environments, and poor nurse job outcomes (e.g., burnout, job dissatisfaction, and intent to leave) are associated antecedents and consequences of moral distress among nurses (Burston & Tuckett, 2013; Huffman & Rittenmeyer, 2012; Lamiani et al., 2017; Morley, Ives, Bradbury-jones, et al., 2019), and have been long-standing chronic conditions (Aiken et al., 2002). These antecedents and consequences have been associated with poor patient outcomes (Duffield et al., 2010; Kutney-Lee et al., 2013; Lasater et al., 2021; Nathaniel, 2006).

Recently, during the COVID-19 pandemic nurses experienced a surge in understaffing, insufficient time to care for individual patient needs, and end-of-life care (Lake et al., 2021), all of which have been associated with nurses' moral distress (Huffman & Rittenmeyer, 2012; Andrew Jameton, 2013). The pandemic likely increased the frequency and intensity of moral distress among nurses. This highlights the increasing importance of moral distress within nursing and the need for effective theories to understand and improve nurses' experience with moral distress.

Theory critique is a tool to closely examine and test the functionality of a theory. It is comprised of two parts, analysis and then critique. During analysis the theory's components are objectively examined for understanding. Critique involves testing and judging the theory's concepts and propositions to assess the claims' accuracies.

Nathaniel's theory of Moral Reckoning examines the personal process of nurses as they experience moral distress. Moral Reckoning is a framework to understand this process. It is comprised of four stages: ease, situational binds, resolution, and reflection. The theory begins examining a nurse at ease, without distress, until a situational bind occurs, a moment of moral distress. During resolution the nurse must decide to act as a result of the moral distress. While in reflection, the nurse reviews and thinks about the experience as a whole.

The purpose of this paper is to critique Alvita Nathaniel's theory of Moral Reckoning using Walker and Avant's method of theory analysis and Jacqueline Fawcett's theory critique methods, evaluation. This paper examines the main and overarching concepts, definitions, and relationships within the four stages of Moral Reckoning. This brief theory critique of Moral Reckoning examines the theory's application value.

Walker and Avant's Theory Analysis Method

Walker and Avant's theory analysis method was selected for its prescriptive nature which enhances objectivity when examining the theory of Moral Reckoning's assets, vulnerabilities, and areas requiring additional work (Walker & Avant, 2019).Walker and Avant's method is comprised of seven steps, five of which were used-1. **origins**, 2. **meaning**, 3. **logical adequacy**, 4. **usefulness**, and 5. **generalizability** (Walker & Avant, 2019). The last two steps, parsimony and testability will be addressed within the theory critique (evaluation) section.

1. Origins is the first step in Walker and Avant's theory analysis which describes the theory of Moral Reckoning's original development and provides insights to understand the theory (Walker & Avant, 2019). The theory of Moral Reckoning stems from the concept moral distress by philosopher and ethicist Andrew Jameton. It is defined as being in a position where you think you know the morally correct action to take but feel hindered to do so (Andrew Jameton, 2013; Smith & Liehr, 2018). Jameton characterized moral distress by three aspects: 1) psychological distress from, 2) being constrained to act within such situation, 3) in a way you know to be correct (Andrew Jameton, 2013). Jameton's work was integrated into nursing by nurse Wilkinson (Nathaniel, 2006); both were foundational for the theory of Moral Reckoning's development.

Alvita K. Nathaniel theory of Moral Reckoning emerged as her dissertation work at the University of West Virginia *A Grounded Theory of Moral Reckoning in Nursing*, in 2003 and published in 2006, almost 20 years after Jameton's concept of moral distress was coined (A. Jameton, 2017; Nathaniel, 2006). Nathaniel's initial query was also informed by literature describing the diminishing nurse workforce due to experiences of moral distress and its consequences such as poor patient-nurse relationships (Nathaniel, 2006).

Nathaniel's work was developed through a grounded theory approach. Studying 21 volunteer registered nurses, Nathaniel aimed to answer "what transpires in morally laden situations in which nurses experience distress" (Nathaniel, 2006, p. 421). The history of moral distress and the use of grounded theory place the assumptions of this theory's development at an interesting crossroad. Grounded theory methods require one to discard prior knowledge and assumptions and let the data tell the story; however, Nathaniel's work was to expound upon the concept of moral distress by Jameston (Nathaniel, 2006; Smith & Liehr, 2018) "[t]o further elucidate the experiences and consequences of professional nurses' moral distress and to formulate a logical, systematic, and explanatory theory of moral distress and its consequences" (Nathaniel, 2006, p. 421).

2. Meaning examines major ideas within the theory through the lens of semantics. It is the process of extracting meaning and includes identifying concepts, examining definitions and their uses, identifying statements, and examining relationships (Walker & Avant, 2019). The theory of Moral Reckoning has four *identified concepts*- **ease**, **situational binds**, **resolution**, and **reflection**.

First, **ease** is *primitive* as its identity stems from expressing a nurse's experience (Walker & Avant, 2019) within their state of practice. In this *descriptive* definition, nurses in this stage are comfortable, lack restriction or emotional angst, are skilled, and feel confident within their place of work (Nathaniel, 2006; Smith & Liehr, 2018). The main statement of ease is *relational, and time ordered*. It focuses on the sequential stages of a nurse's practice development. First the initial novice phase, the nervousness and excitement of being a new nurse. Then a state of ease follows, which has an ordered composition of first becoming, second professionalizing, third institutionalizing, and fourth working (Nathaniel, 2006; Smith & Liehr, 2018).

Becoming occurs through the development of values and an identity as a nurse. It is shaped through experiences and observing modeling (Nathaniel, 2006; Smith & Liehr, 2018). *Professionalizing* takes place as the nurse gains an understanding of what nursing is and what makes a good nurse. When the nurse is integrated within an institution and subscribes to workplace cultures and norms, *institutionalizing* happens. *Working* comprises the experience of being an independent nurse, working to skillfully care for and support patients (Nathaniel, 2006; Smith & Liehr, 2018).

Second, **situational binds** interrupt the state of ease, thus being *linear* in relation to the concept of ease. The concept is also *primitive* as it is situated within the context of common experiences of nurses. It is *theoretical* in definition as it cannot be measured but is described abstractly and subjectively (Walker & Avant, 2019). Situational binds are characterized as severe and convoluted moral conflict where questioning of self- purpose, morals, and loyalty- begin (Nathaniel, 2006; Smith & Liehr, 2018). Therefore, the defining statement also has a *causal* relationship; it begins the process of Moral Reckoning.

Third, **resolution** is the process to end the situational bind by solving turmoil and alleviating conflict (Nathaniel, 2006; Smith & Liehr, 2018): a *concrete* concept with an *operational* definition. Its main relational statement is *explicit* in content and *time ordered* as it must directly follow situational binds (Walker & Avant, 2019; Smith & Liehr, 2018). Resolution is a critical point in Moral Reckoning; a nurse makes a stand and/or gives up. A nurse may originally make a stand and then give up, or vis versa. A nurse makes a stand when they decide to act according to their moral conscience while experiencing a situational bind; it always presents a personal threat (Nathaniel, 2006; Smith & Liehr, 2018). Giving up involves the nurse acknowledging the ineffectiveness of making a stand, and they commence mournfully against their conscience (Nathaniel, 2006; Smith & Liehr, 2018).

Fourth, **reflection** is reconciliation of past experiences, actions, and judgments. It is the reflection upon personal questions. This process is often continuous and does not always conclude (Nathaniel, 2006; Smith & Liehr, 2018). It is an *abstract* concept with a *descriptive* definition. Reflection involves *remembering*, *telling the story*, *examining conflicts*, and *living with the consequences* (Nathaniel, 2006; Smith & Liehr, 2018). During *remembering*, the nurse recollects the feelings, images, and or smells from the event. *Telling the story* involves sharing their experience and, in the process, provides opportunity for healing and personal growth (Nathaniel, 2006; Smith & Liehr, 2018). Questions regarding what happened- the why, how, and who of the story- takes place as the nurse *examines* the *conflict*; it is a process of pondering. The nurse then *lives with the consequences* of the experience, in which they often switch their place of employment or career trajectory (Nathaniel, 2006; Smith & Liehr, 2018).

3. Logical adequacy addresses the logical composition of the theory's concepts and statements (Walker & Avant, 2019). The theory of Moral Reckoning follows a logical sequence of events. A nurse is comfortably situated within their work environment (**ease**), then experiences something that interrupts their comfort (**situational binds**), which causes the need to resolve their discomfort (**resolution**), and then they ponder and revisit the

cascade of events encompassing their experience (**reflection**). Therefore, this content is plausible and provides a framework to make predictions demonstrating logical adequacy. However, room to question the theory as the best predictor of the phenomenon is required (Walker & Avant, 2019).

4. Usefulness refers to the theory's ability to add value and be implemented within the nursing discipline (Walker & Avant, 2019). The theory of Moral Reckoning was built upon the well-established and accepted concept of moral distress (Smith & Liehr, 2018). Jameton himself denotes the ubiquity of moral distress within nursing (Jameton, 2017). Moral Reckoning has been used to teach student and new-to-practice nurses how to act in situations of moral distress: and as a theoretical framework for unit-based moral distress improvement projects as a means of prediction (Smith & Liehr, 2018). Nathaniel's dissertation in 2003 has been cited 52 times and her theory publication in 2006 has been cited 229 times per PubMed, within and without the discipline of nursing (Smith & Liehr, 2018).

5. Generalizability describes the theory's scope of application within various context (Walker & Avant, 2019). Although the theory of Moral Reckoning was originally situated within nursing, its application has extended globally and into numerous disciplines such as medicine, ethics, education, pharmacology, and law enforcement (Smith & Liehr, 2018). Additionally, the theory of Moral Reckoning within research, dissertation work, and clinical practice among other areas (Smith & Liehr, 2018) shows the vastness of its generalizability within nursing and other fields.

Jacqueline Fawcett's Theory Critique Method: Evaluation

Jacqueline Fawcett's criteria for evaluation of theory contains six steps, 1. **significance**, 2. **internal consistency**, 3. **parsimony**, 4. **testability**, 5. **empirical adequacy**, 6. **pragmatic adequacy**, and does not distinguish different criteria for qualitative or quantitative methods (Fawcett, 2005) . As the theory of Moral Reckoning utilizes a qualitative method, Fawcett's criteria provide a framework that addresses the theory's characteristics appropriately, hence was selected.

1. Significance reflects the magnitude of the theory situated within a nursing context and requires clear delineation of conceptual foundations, antecedents, and propositions with adequate literature support (Fawcett, 2005). Informed by ground theory and the concept of moral distress, Alvita Nathaniel conducted a qualitative study examining 21 nurses' personal experiences. Hearing the nurses' share their stories informed the theory of Moral Reckoning's development (Nathaniel, 2006; Smith & Liehr, 2018). The theory stipulates precise descriptions of *antecedents* which occur during the theory's first stage, ease an include **becoming**, **professionalizing**, **institutionalizing**, and **working** (Nathaniel, 2006; Smith & Liehr, 2018). *Propositions* are identified within the text and visually through one-way arrows, identifying that after a **situational bind** interrupts the stage of **ease**, the bind leads to **resolution**, which then starts the stage of **reflection**. Significant literature, internal and external to nursing, is cited throughout the theory's history (Smith & Liehr, 2018, p. 330). This theory is often used to educate nurses in preparation to face moral distress.

2. Internal consistency requires uniform consistent language, definitions, and connections between concepts (Fawcett, 2005). Nathaniel's terms, concepts, and structure presented are uniformly used, both in her and other's application of the theory. The theory of Moral Reckoning has retained integrity. Nathaniel's terms and process have been succinctly crafted, explicitly stated, and precisely maintained to achieve internal consistency.

3. Parsimony offers a means to examine a theory's succinctness. It is especially evident when a visual model or graphic, used to depict the theory, matches the provided explanatory text (Fawcett, 2005; Walker & Avant,

2019). Nathaniel's model crisply illustrates the concepts and relationships between them, as described in her writings. Descriptions are judiciously drafted to provide context and bounds with proficiency.

4. Testability examines the theory's sound development, ensuring that correct methods and measurements were utilized, and that they are appropriate to the theory (Fawcett, 2005). Moral Reckoning was developed through grounded theory methods, an inductive process. Nathaniel provides details on her methods used to allow for proper tracing of steps and decision-making points. Because the theory of Moral Reckoning has precise definitions, antecedents, propositions, and consequences, the theory can be tested.

Corley et al. (2001) created and validated the Moral Distress Scale (MDS). The MDS statistically measures moral distress among nurses. It was revised by Hamric et al. in 2012 and named Moral Distress Scale- Revised (MDS-R), Hamric et al.'s survey instrument is the currently used within the literature to measure moral distress. Both measure situational binds and resolution. Moral Reckoning's stages supplied Bermudez (2020) a route to develop the Moral Comfort Questionnaire (MCQ), a validated tool. The MCQ quantitatively measures positive outcomes (resolutions) after nurses experience moral distress. This instrument is unique. Most discussions and measurements, related to moral distress, focus on negative outcomes. All three scales are validated instruments used to quantitatively capture moral distress within studies informed by Moral Reckoning. However, Moral Reckoning lacks an encompassing instrument to directly measure all four stages together.

5. Empirical adequacy requires the effective use of empirical facts such as established literature to validate the theory's concepts and propositions (Fawcett, 2005). Each concept and proposition of the theory has supporting literature (Smith & Liehr, 2018). It has been used to identify and understand the experience and process of moral distress which has led to solutions. Its documentation in various disciplines and contexts decreases the possibility of circular reasoning (Fawcett, 2005).

6. Pragmatic adequacy emphasizes the effectiveness and use of the theory's application for nursing practice (Fawcett, 2005). There is an established need for the application of the theory of Moral Reckoning (Jameton, 2017; Nathaniel, 2006; Smith & Liehr, 2018). Although pragmatic adequacy is similar to Walker and Avant's usefulness step, a key difference Fawcett addresses, is the questioning of whether or not nurses have the understanding and capacity to apply the theory to practice (Fawcett, 2005). This distinguishment is important to Moral Reckoning. As noted earlier in usefulness, this theory has been widely implemented and proven advantageous to nursing and other disciplines. It is frequently utilized as a tool to facilitate *teaching* nurses about moral distress and the process of Moral Reckoning (Smith & Liehr, 2018).

From the theory of Moral Reckoning, Allen and Butler (2016) successfully developed and implemented an intervention to improve their nurses' moral distress. After identifying and understanding situational binds within their own institution, they created educational modules and cultural changes. These modifications enhanced coping skills and improved the frequency and intensity of moral distress experienced among their nurses (Allen & Buttler, 2016). Pratt et al. (2013) analyzed six published studies to apply Moral Reckoning as the theoretical framework to understanding moral dilemmas and moral distress among nurse educators faced with the choice to pass or fail a student. Although the concept is applicable and widely applied, it is not completely pragmatically adequate.

Summary & Conclusion

Overall, this is a well-developed theory that appropriately articulates each point of theory analysis and evaluation. Literature shows its utilization in various areas of research across the world, not just in nursing (Smith & Liehr, 2018). The theory of Moral Reckoning has also been used as a blueprint for implementing unit-based projects to change culture and improve the experiences of nurses and patients (Allen & Buttler, 2016; Smith & Liehr, 2018). A possible barrier to Moral Reckoning's uptake and application within the practice setting and in healthcare systems, is the requirement for buy-in from administrative stakeholders. This buy-in is necessary to facilitate a sponsored position to teach and captain the theory's implementation.

Without having support from administration, management, and or nurse educators, this theory is not easily implemented. It takes a unit and a healthcare system to shift and support the application of Moral Reckoning. I believe its utilization offers a great return on investment for all parties involved but buy-in is difficult and essential. An alternative to offset this aspect is its use in schools of nursing to teach student nurses. The alternative avenue is not equitable to a cultural shift but may act as a tool to better prepare new nurses for turmoil in the workplace. Moral Reckoning is a well-founded theory with great potential for improved application. I theorize adjustments to the theory that create a change in uptake would result in better teamwork, a healthier nurse workforce, and improved patient care experiences.

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Nursing Education in the Era of Social Media

Samuel Byiringiro, MS, RN, Katie Nelson, MSN, RN, Alvine Akumbom, MS, RN, Patricia M. Davidson, PHD, MED, RN, FAAN, Mengchi Li, BSN, RN, Chandler Moser BSN, RN, Jennifer Lee, BSN, RN, Sydnee Logan, Oluwabunmi Ogungbe, MPH, RN, Mona Shattell, PHD, RN, FAAN

Authors' Affiliations: PhD Candidates (Mr Byiringiro, Ms Nelson, Ms Akumbom, Ms Li, Ms Lee, Mr Moser, Ms Ogungbe), Johns Hopkins University School of Nursing, Baltimore, Maryland; Social Media and Digital Content Coordinator (Ms Logan), Johns Hopkins University School of Nursing, Baltimore, Maryland; Vice-Chancellor & President (Dr Davidson), University of Wollongong, Wollongong, Australia; Professor (Dr Shattell), University of Central Florida, Orlando, Florida

Corresponding author: Mr Byiringiro, PhD Candidate, Johns Hopkins University School of Nursing, 525 N. Wolfe Street, Baltimore, Maryland 21205 (sam6as@yahoo.com)

Abstract
Background: Nursing education has made advances over the last few centuries in high-, low- and middle-income countries. However, less interactive methodologies of education are still predominately used. Social media platforms—ubiquitous in multiple facets of societal life—are potential tools for engaging a collaborative methodology of education in and beyond the classroom.

Problem: Nurse educators do not holistically understand the potential value of integrating social media training in nursing curricula.

Approach: This paper discusses social media integration into nursing education, presents an exemplar of integrating Twitter into the training of nurses at the doctoral level within a large School of Nursing in the mid-Atlantic region of the United States, and presents special barriers encountered by low- and middle-income countries, and proposes a way forward.

Conclusions: Failure to train nurses to engage with the community on social media platforms is a missed opportunity.

Keywords: Nursing education, social media, education, LMIC

Introduction

Nursing education has made great strides over the last few centuries, pivoting from solely clinical practice apprenticeships to become a more praxis-oriented profession, weaving in complex theoretical knowledge (Jones-Schenk, 2019; Pfeil, 2003). Pioneers of contemporary nursing education established nursing schools in the United Kingdom in the 1860s and other institutions followed suit, expanding nursing education globally (Young et al., 2011). The nursing profession has become increasingly versatile, offering various avenues for educational advancement that enables nurses to become leaders in research, policy, and clinical practice.

Education was characterized by students expecting to acquire an entire set of knowledge and/or skills from their assigned course instructor, or in the case of early nursing education, through hospital-based apprenticeships. Such methods of education, well described in the *Pedagogy of the Oppressed* by Paul Freire (2000), urged students to memorize content without ever completing any critical reflection. This has since been connoted as mental colonization and identified as a significant barrier to innovation and development. Unfortunately, evidence still shows similar instances of outdated educational methodologies being used across nursing schools today (Kermansaravi et al., 2015; Lateef & Mhlongo, 2019; Xu, 2016). There is, however, increased recognition that pedagogical methodologies emphasizing interaction and collaborative exchange of ideas between students and instructors may alleviate remnant oppression in nursing education and beyond (Kaplan & Lewis, 2013).

The implementation of interactive educational methodologies has never been more within reach than it is now. Advances in technology have brought ~3.96 billion people with varied expertise and from different settings and cultures around the globe – together on the same platforms, currently referred to as social media (Kemp, 2020). In the nursing educational arena, social media platforms grant nursing students access to experts and colleagues such as the very authors of the texts or articles they are studying, fellow professors and students, experienced practitioners and researchers, policymakers, patients, and community members whose health they strive to improve. Yet, formal consideration of such novel interactions in nursing education are often overlooked.

The current paper discusses nursing education in the era of social media and the possible benefits and challenges of formal integration of social media into nursing education. The discussion is explored from various standpoints: in high- and low-income higher education settings, and during unprecedented times such as the COVID-19 pandemic and its response. We share the case study of how a large School of Nursing in the mid-Atlantic region of the United States (US) formally engaged doctoral level nursing students and the public in an orchestrated research event via Twitter. We conclude by making recommendations that nursing educational institutions around the globe could explore moving forward.

What is social media?

Social media comprises websites, applications, and platforms that enable users to create and share content (Oxford, 2016). The use of social media has increased exponentially since its inception in the late 1990s, such that one million people join a form of social media each day (Rogers, 2019). In the US, social media outlets were initially adopted by young adults (who continue to use them at high levels); however, the usage among older adults has significantly increased (Rogers, 2019). The use of social media increases with economic status and education, and tends to be more common among females than males (Rogers, 2019).

Social media is not one-size-fits-all. Various outlets offer different platforms for engagement. Growing evidence shows that YouTube and Facebook are used among older adults more frequently than any other age category

(Pew Research Centre, 2018). These outlets enable socialization and relationship-building from the comfort of home, which can also help mitigate isolation among older adults (Berg-Weger & Morley, 2020). In the context of COVID-19, the use of technologies such as Skype and Zoom has increased, which enable users to stay visually connected while maintaining public health distancing guidelines. Overall, people tend to rely on multiple platforms to meet both professional and personal engagement needs.

Social media has attracted users within nearly every facet of society. For instance, business owners have taken advantage of social media's ability to promote their products and services to wider audiences, hence boosting their sales (Alalwan et al., 2017; Guesalaga, 2016). This shift in the communication landscape has had complex implications for the healthcare sector. Some researchers have found social media to be beneficial for health promotion efforts such as smoking cessation and dietary campaigns (Jiang & Beaudoin, 2016; Namkoong et al., 2017; Swindle et al., 2018). Despite the far-reaching use of social media in society, the educational services industry has not wholly embraced social media, as evidenced by a lack of coordinated support for faculty and students on the appropriate, beneficial, and responsible use of social media (Sinclair et al., 2015).

Use of social media in nursing education

Use of social media in nursing educational institutions is mostly limited to marketing educational programs, yet the ubiquity of social media entreats institutions to move a step further into integrating social media as tools for instruction (Jacquemin et al., 2014). Nearly 80% of students entering higher education routinely use one or more social media platforms (Sinclair et al., 2015); and nursing students have reported positive experience when engaging with professors on social media (Waldrop & Wink, 2016). However, formal use of social media in nursing educational curricula could be expanded at the institutional levels.

There are both positive and negative aspects of incorporating social media into nursing course structure. Studies have shown that social media helps increase the relevance of in-class learning to the real world and helps instill confidence in some students who are usually quiet in the classroom (Jacquemin et al., 2014; Javaeed et al., 2020). Harnessing platforms such as Twitter that are known for frequent user engagement enables informal dialogues between students, faculty, and community/clinical stakeholders around relevant issues in real-time (Byiringiro et al., 2021; Sinclair et al., 2015). This has primarily been explored among health professions programs such as nursing, medicine, pharmacy, etc. (Benetoli, Chen & Aslani, 2015; Wanner, Phillips & Papanagnou, 2019; Daigle, 2020; Ranginwala & Towbin, 2018). As the digitization of healthcare increases, nurses and other healthcare professionals must be equipped with the skills necessary to not only engage with patients and the public in real life but also virtually. This should include the understanding of a moral responsibility to share scientifically proven health knowledge with the community on social media.

Slow integration of social media in nursing education has been met with notable challenges. Some students have cited lack of privacy, time it takes to learn, and poor quality of information as barriers to embracing social media in their education and clinical practice (Sinclair et al., 2015). It is crucial to be mindful that this pedagogical and technological shift requires faculty to lean into a confidence they may not have – but their students do (Tuominen et al., 2014). Tuominen et al. (2014) found 95% of nursing students used some form of social media in their free time, and 69% reported they would benefit from using those tools in classroom settings. This presents an opportunity for collaborative learning experiences; by leveraging the innate savviness found among many younger students, faculty may actually find students are more active participants in the classroom and self-directed in their learning (Tuominen et al., 2014). Collaboration between students and instructors can engrain the educational methodology that boosts students' self-confidence, and thus bolster their problem-solving skills.

Nursing educational methodologies: the role of social media

Nursing education augmented with social media is structured in the educational model described by Freire (2000). The traditional banking model of learning presupposes students are empty receptacles for instructors to deposit information (that is, a unidirectional relationship). This modality may stifle development of critical thinking compared to the more advantageous problem-posing educational model, such as creation (Freire, 2000). Several studies have shown higher dispositions toward critical thinking among nursing students when *problem-posing* learning models are integrated into their education (Ip et al., 2000; Ozturk et al., 2008; Tiwari et al., 2006).

Problem-posing learning is achieved through solving authentic, well-structured, real-world problems (Hung, 2011). The process of solving real-world problems motivates students as they realize the relevance of the content knowledge to their future professional or personal contexts (Barrows, 1986). The problem-posing learning model effectively enhances problem-solving and critical thinking skills by motivating students' thinking processes, which are critical for all nursing roles. As the student becomes a novice nurse, the ability to retrieve knowledge and apply it in clinical settings helps the novice nurse develop into an expert healthcare professional (Benner et al., 2009).

Social media opens students to society and helps them learn how to interact with scientific and general communities before entering the workforce. Byiringiro et al. (2021) report how PhD students converted the usual class seminar to an online Twitter chat. In addition to the usual course instructor, students engaged with experts outside the university on the topic of discussion. Such avenue of accessing experts and the community can only be provided by social media. Students not only learn how to interact with the broader community but engage in problem-posing model of learning.

The problem-posing model provides a framework for developing inquisitive nurses who are both competent professionals and well-equipped to participate in society. Conceptually, this involves breaking down the student-instructor barrier so that all participants in education take on both roles (Freire, 2000). For instance, social media can be used to pose problems and generate discussion, which helps students see their role in healthcare as active participants rather than as mere observers. The goal is for the problem-posing model to lead participants to a shared understanding. This can deepen their critical awareness and further enhance their disposition towards critical thinking and clinical inquiry.

Exemplar of student and public engagement via social media: Research Day on Twitter

Led by Doctor of Philosophy (PhD) and Doctor of Nursing Practice (DNP) students, the Dean of the School of Nursing, and the Social Media department prepared their annual Research Day event through Twitter. Twitter, a well-known social media platform, allows individuals or institutions to create and share messages also called "tweets" with the general public. The tweets appear on the screen of logged-in Twitter users, mostly those interested in (i.e., "followers" of) the individual/institution who posted the tweet. In the current exemplar, Twitter offered students the opportunity to: 1) network and engage with potential mentors, 2) share their research with a wide audience, and 3) simultaneously engage with collaborators, funders, community stakeholders, and policymakers. This event also served as an introduction to the platform where doctoral nursing students could learn how to use Twitter for research, networking, and professional development.

In preparing the event, the Twitter hashtag "#JHResearchDay" was created and promoted to audiences inside and outside the School of Nursing. Students and faculty submitted information beginning two weeks prior to the event. Faculty submitted information regarding: 1) their top three research topics, 2) links to their research,

(e.g., publications, articles, and websites), 3) highlights of any students involved in their research, and 4) made sure their faculty page was up to date. Students submitted information acknowledging: 1) if they were recipients of a National Research Service Award, 2) receipt of any foundation funding, and 3) their involvement in any research activities.

An open structure was used, whereby participants posted their updates and interacted in real-time. The host account shared graphics highlighting faculty participants and their research areas. Questions posed throughout the chat included: 1) asking faculty about their PhD research project(s), 2) asking them to share their publication(s), and 3) asking them to give advice to incoming doctoral nursing students. New and continuing students at the entire university and beyond got to share their research, perspectives, ask questions, and provide insights on their education.

The chat was a successful introduction to Twitter for professional development for doctoral nursing students. Students and faculty shared their research and modeled Twitter interactions to connect with colleagues online, and incoming students gained advice from faculty and students, alike. The event hashtag reached 44,130 accounts, had 244,126 impressions, and had approximately 30 active contributors. That same hashtag was the #1 trending topic in the entire city during the chat. The success documented in the current exemplar was, however, a sample of the type of interactions that would – soon after – become critical due to the COVID-19 pandemic.

Social media in nursing education during the COVID-19 pandemic
COVID-19 has disrupted the globe and caused uncertainty and, in many sectors, including educational institutions. Where resources permitted, nursing education institutions have necessitated recalibration and engagement of tools that were not existent before COVID-19 to continue operating. However, learning activities that require physical contact, such as simulation and clinical training, have been affected on a larger scale—especially in low- and middle-income countries (LMICs). The ability and commitment to engage in a digital world, refine cognitive agility to respond to new circumstances, build social connectivity, and the ability to adapt and foster resilience have never been more important. Despite controversy surrounding the value of social media, it has been a valuable tool for providing pandemic-related information, although ascertaining credibility of information remains critical. More than ever before, nursing educational institutions have adopted social media-like platforms for online learning to meet the educational needs of nursing students.

Social media can facilitate e-learning opportunities through dissemination of blogs and other resources, or by building communities of practice, which comprise groups of individuals with a shared knowledge goal (Ferguson et al., 2017; Wright et al., 2020). In the context of COVID-19, social media has been a source of advocacy and peer support (Daly et al., 2020; Maben & Bridges, 2020); however, when information is fluid and dynamic, access to contemporaneous information is crucial and absence of peer review can be problematic (Chan et al., 2020). Therefore, accessing information from bodies such as the World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC) is important.

Access to verifiable and actionable information is facilitated through a range of media including online interactive courses. For example, COVID-19: "Effective Nursing in Times of Crisis" on the Future Learn platform is a two-week course that requires approximately two hours of study per week (*Crisis Nursing - Online Course - FutureLearn, n.d.*). To date, nearly 10,000 students from 157 countries have joined the course and the Global Network of WHO Collaborating Centers for Nursing and Midwifery endorsed it. This and similar courses enable individuals worldwide to obtain access to information and resources free of charge and interact in peer learning even though resource-constrained communities and countries may face other unique challenges.

Social media engagement among nursing educational institutions in LMICs

Within the past decade, there has been significant technological gains, internet access, and social media utilization in countries referred to by the World Bank as emerging economies or LMICs (Poushter, 2016). Close to a third of the population in LMICs own a cell phone, and a median of 67% use the internet (Poushter, 2016). As internet access increases in parts of the Middle East, Latin America, Africa, and Asia, social media engagement and networking is more comparable to that of the US and Europe (Poushter, 2016). For health-related purposes, the use of social media in LMICs includes the following: health education and influences, interactions during infectious diseases and outbreak situations, in the contexts of natural disasters, terrorism, crises and emergency responses, and the producers (primarily healthcare governmental, and non-governmental organizations) and consumers of social media (Hagg et al., 2018).

Studies on nursing and healthcare educational use of social media in developed countries have shown important benefits (Ahern & Wink, 2010; Greenhow & Lewin, 2016; Schmitt et al., 2014); however, few similar studies have focused on LMICs (Chipps et al., 2015). Studies among students and health professionals in Nepal (Pimmer et al., 2012, 2013) and in South Africa (Pimmer et al., 2014) exploring the experience of utilizing social media to engage in educational content reported the increased participation in virtual professional communities and improved educational engagement beyond local communities. This included use of social media among midwives for reflective practice and the establishment of emotional support and inclusion (Pimmer et al., 2012, 2013, 2014). The convergence of social media and mobile devices connects learners and ultimately changes the learning environment (Pimmer et al., 2012, 2013, 2014).

The adoption of social media in nursing educational institutions across LMICs proffers unique challenges in addition to those experienced in high-income countries. Challenges include lack of culturally tailored tools to meet the needs of nursing educational institutions in LMICs, the fast-paced nature of social media, and a dearth of resources for instructors on the effective convergence of social media tools with pedagogical methodologies (Chipps et al., 2015; Nyangeni et al., 2015). Nursing educational institutions in LMICs are not economically capable of providing adequate support necessary for instructors to tackle the digital divide. LMICs share concerns with developed countries regarding the following issues: privacy and confidentiality of shared content, blurring of professional and personal boundaries, what has been described as a lack of accountability, and potential for misrepresentation of the nursing profession and respective nursing educational institutions (Nyangeni et al., 2015).

Implications and moving forward

According to the American Nurses Association, nurses' roles span from providing direct patient care to developing nursing practice standards, quality assurance procedures, and nursing-oriented healthcare systems (ANA, 2015). Nurses are obligated to be advocates for patients, families, and communities, and to conduct health improvement activities, which include but are not limited to, research, dissemination of findings, and community-based education. These activities require nurses to be engrained in their communities, yet methods for approaching clients have changed dramatically since the introduction of social media platforms. Social media has presented opportunities to reach a wider audience, rendering the work of nurses even more impactful. However, this necessitates more formal integration of social media within nursing education to ensure future nurses are well prepared to respond to ever-changing community needs and dynamics.

The dynamics of communities' needs and the impact of social media have been prominent during the COVID-19 pandemic. Misinformation about COVID-19 vaccines and lack of trust in science have been perpetuated through social media and remains a challenge in the pandemic response. Nurses and other healthcare

professionals have a moral obligation to step up and provide evidence-based information. Nurses ought to use social media, too, to share accurate information about the science behind vaccines and their effectiveness. A study conducted on social media reported that when people are nudged to question the accuracy of the content, they are likely to reflect on what they share on their social media platforms (Pennycook et al., 2020). Nurses could be one of the people who share strategies for discerning correct and incorrect information read on social media. A nurse trained on the moral ethics of nursing will understand that misinformation is as dangerous as any lethal virus and will take action to share correct information with the communities they serve. If nurses and other healthcare professionals shed their silence and shared trusted information on their social networks – the tide would turn in the response to COVID-19. This all begins with nurses understanding social media as a new way of interacting with the community and their moral responsibility to share their knowledge with them.

To prepare nurses, nursing educational institutions need to take active steps towards training students on appropriate ways to use social media and how to maximize its benefits. Training must incorporate moral ethics and responsible techniques for engagement. The nursing code of ethics clearly outlines nurses' scope in clinical practice, but must extend to translating and communicating knowledge via social media platforms. Nursing curricula should highlight social media as not only a means to communicate with community stakeholders but also to acquire and share knowledge through informal interactions with experts. Course faculty should prioritize teaching students to broaden their networks and expand interactions beyond their social capital to better prepare them to be contemporary health professionals.

Despite increasing demand and advocacy for social media incorporation in nursing curricula and its utilization as a tool for teaching, multiple aspects require clarification for successful implementation as interactions on social media warrant special considerations, such as the protection of peoples' privacy and confidentiality. Further, course instructors are less prepared than students to make changes in this realm amid a generational digital divide. Yet, where resources allow, nursing educational institutions may consider hiring social media experts – or even their students – to train instructors on impactful ways to incorporate social media in their respective courses. Additionally, fostering an open, collaborative environment in nursing educational institutions, by allowing students to impart their technological savviness in the classroom, will result in shared learning opportunities.

Though the exemplar provided is from a developed country, we expect that special considerations are necessary for LMICs to integrate social media as part of their nursing education. In many LMICs, nursing education is at its fledgling stage, which poses challenges and opportunities for incorporating novel educational methodologies capable of training students to solve contemporary challenges. Throughout the COVID-19 pandemic, many nursing educational institutions in developed countries converted to online learning and virtual simulations; meanwhile, their counterparts in LMICs were forced to close completely. Post-COVID-19, society will adapt based on lessons learned during these unprecedented times. Educational institutions will have to accommodate hybrid modes of education, combining both in-person and virtual activities, as will professional and community-based organizations. Hence, it is mandatory that educational institutions, especially nursing institutions in both high- and LMICs, intentionally incorporate training for students on the appropriate ways of behaving and engaging with audiences on virtual platforms, including social media.

Conclusion
The roles of nurses have adapted and nursing educational institutions should follow suit to ensure nurses can continue responding to contemporary healthcare problems across their respective communities. Social media is a ubiquitous mode of interaction that has transformed communication models, though nurses lack formal

training on the ethics of its use and how to maintain their roles within such platforms. It is time for nursing educational institutions around the world to reimagine modes of instruction for preparing nursing students to enter the profession. Social media holds great potential for helping nurses at all levels (that is, students, novices, and experts) reach wider audiences. Integration of these platforms in nursing education may significantly enhance health outcomes, especially those related to community health literacy. Apart from sporadic case studies on various social media events or platform trials in nursing education, we advocate for rigorous interventional studies exploring their effectiveness in nursing education and overall community impact of nurses trained on the professional use of social media to advance health outcomes for communities around the globe.

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Theoretical Exploration of Autism Spectrum Disorder: Prevalence and Health Disparities

Stacey L Bevan,
University of Pennsylvania

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by differences in social communication and restricted or repetitive interests (Williams et al., 2017). The CDC estimates that approximately 1 in 54 children have been diagnosed with ASD in the United States (Xu et al., 2018); however, worldwide prevalence is not well defined (Baxter et al., 2015). The treatment and educational costs in caring for a child with ASD are significant. This is in part because ASD is associated with an increased risk of other medical conditions, such as gastroenterological diagnoses (Sigmon et al., 2019). The estimated societal costs for caring for American children with ASD exceeds 11 billion yearly (Lavelle et al., 2014). While the symptom presentation of the disorder stabilizes prior to two years of age, the average age of diagnosis is between 3 and 4 years globally, and includes significant variation by geography (van 't Hof et al., 2021). Current estimates indicate that autism is over 4 times more prevalent in boys than girls (Maenner et al., 2020). The prevalence of ASD has increased over the last 20 years, prompting explanatory hypotheses from disparate disciplines (Graf et al., 2017). Moreover, there are significant disparities based on racial status in diagnosis and service provision for the disorder (Bishop-Fitzpatrick & Kind, 2017).

Trends in autism have been approached differently in research depending on theoretical orientation and methodology. For example, the feminist perspective discusses differences in symptom presentation based on gender identification (Bumiller, 2008). Broadly, the most employed paradigmatic approaches are positivism and postmodernism, which encompass many theories. Behavioral epigenetics, derived from the positivist perspective, and social construction nested in postmodernism are highly relevant to understanding autism phenomena. The purpose of this paper is to analyze trends in ASD prevalence and health disparities using two theoretical approaches.

Autism and Behavioral Epigenetics
Positivism

From a positivist perspective, there is a discoverable, biological mechanism to explain both the increase in prevalence over time and disparities by racial-ethnic groups. Briefly, positivism was founded by Auguste Comete in the early 1800s and is a philosophy of science that claims all observations can be scientifically or mathematically verified (*Auguste Comte: An Intellectual Biography*, 2009). Positivism is derived from an empiricism and aims to prove or disprove hypotheses based on observable experiments (Ryan, 2018). Similarly, positivism takes a reductionist organization to phenomenon, in that knowledge may be condensed to tangible and analytically related units (Michele, 2019). The process of differentiating between values and facts presumes that science is the only reliable source of truth (Nekrasas, 2016). There are several key assumptions that underpin

research in this paradigm, namely that reality is objective, tangible, and discrete. The goal of positivist inquiry is to explain a clinical phenomenon with the assumption that knowledge generated is consistent across time and context. Therefore, any true results are reproducible, and measurement tools used in science are accurate portrayals of reality. For example, abnormal behavior is considered diagnostic according to universally applicable clinical threshold. Positivist research questions are more likely to be centered on individual manifestation of behaviors, consistent with a medical approach. Positivism is compelling in the context of clinical problems because, theoretically, once the true diagnosis is established it will be reliably sensitive to treatment. The notion that meaningful etiologies of behavior exist is foundational to the biological science in ASD research. This is most apparent in the claims that there is a genetic basis of behavior and a subsequent search for specific genes associated with autism (Vorstman et al., 2017). A related subfield is behavioral genetics. Situated in the positivist paradigm, this theoretical orientation has been extensively applied in autism research.

Prevalence

Behavioral epigenetics is a field of study concerned with the role of the environment in changing how genes are expressed, in turn, shaping behavior. This perspective evolved from Darwinian assumptions, namely that over time environmental changes shape phenotypic expression (Lapidot & Conley, 2015). Implicit in this framework is the assumption that the diagnostic process for evaluating clinical phenomenon is unchanging and a true measurement. Therefore, differences in prevalence across time must have a biological basis. Behavioral epigenetics may situate the neurological system at the center of differences in social behavior (Moore, 2015). Steven Porges' Polyvagal Theory is representative of this approach. He posits that increased levels of neuroinflammation markers in children with ASD is evidence of biological differences related to social behavior (Porges et al., 2013). Inflammation is a well described mechanism to explain changes in gene expression (Alam et al., 2017). This line of thinking has also inspired thousands of studies investigating associations to child behavior, especially prenatal toxin exposures. The prenatal environment is especially sensitive to adverse events due to the neurodevelopment of the fetus (Beversdorf et al., 2005). Subsequently, environmental changes that have a biological imprint on the brain are clearly seen in parental exposures and having a child with ASD. These factors include parental age at conception, prescription of psychiatric and anti-epileptic medications during pregnancy and autoimmune disorders in pregnant women, such as diabetes and kidney disease (Sandin et al., 2016). From this perspective, increased prevalence over time is due to accumulation of these environmental factors.

Health Disparities

Furthermore, this perspective implicates differences between social groups as biological in nature. Importantly, behavioral epigenetics does not necessary align with racial essentialism, that there are inherently biological and/or genetic differences that predispose racialized groups to disease (Tsai et al., 2020). However, this problematic belief is embedded in some ASD research (Cuccaro et al., 2007). Racial ethnic disparities in Autism diagnosis, severity of symptom presentation and service provision are profound and persistent (Mandell et al., 2009). Behavioral epigenetics explains these health disparities through differential environmental exposures for socially constructed groups. To take one example, it is well established that premature birth is associated with development of autism in childhood (Kerin et al., 2018). In the United States, racialized Black women are more likely than White counterparts to have a premature delivery (Keiser et al., 2019). One mechanism for this difference is variable stress exposure during pregnancy (O'Donnell et al., 2009). Likewise, children living in cities are more likely to receive a diagnosis than children living in rural areas. The biological explanation to this pattern is increased exposure to environmental hazards like air pollution (Kerin et al., 2018). The philosophical and theoretical lineage of positivism in ASD has positioned biological processes at the center of disparities in diagnosis.

Limitations

The positivist approach to ASD disparities has significantly contributed to understanding longitudinal health implications of early biological risk factors, especially at critical points in neurodevelopment. However, research on the mechanisms by which this relationship takes place has produced limited clinically meaningful results (Zafeiriou et al., 2013). Scholars, especially in the sociological sciences, have dismissed an exclusively biological approach to autism as woefully incomplete (Leveto, 2018). Furthermore, the positivist paradigm assumes that the measurement tools for ASD diagnosis, which are predominantly based on clinician observation of behavior, are not dependent on historical or cultural context. This perspective therefore does not engage with the ongoing discussion of the appropriateness of diagnostic criterion or provider subjectivity in detecting autism (Como et al., 2020). Finally, there is significant heterogeneity in clinical presentation of autism. A positivist approach is less likely to accommodate variations in symptom profiles derived from the same biological exposure (Jeste & Geschwind, 2014). While a behavioral epigenetic approach advances autism research, it makes several assumptions that are criticized from a postmodern approach.

Autism and Social Construction

Social Construction

The social construction perspective fits within the postmodern paradigm, grounded in a series of assumptions that are in part a reaction to positivism. Social construction claims that meaning is socially determined, and knowledge is therefore created not discovered (Sveinsdóttir, 2015). These meanings are by necessity dependent on historical, political and economic conditions (Strongman, 2018). Unsurprisingly, social construction is also aligned with the naturalist perspective that embraces qualitative lines of inquiry (Hollin & Pilnick, 2015). Many philosophers have been associated with social construction, most notably Thomas Luckman and Peter Berger, who jointly published *The Social Construction of Reality* in 1966. This work argued that reality is deeply imbedded in social relationships and therefore socially determined, establishing a tradition in communication and sociology (Berger & Luckmann, 1966). Autism from a postmodern perspective rejects the idea that there is a meaningful threshold in which a child meets clinical criterion. Furthermore, the socially constructed model of autism is congruent with a the lack of biological basis for the disease, which has yet to emerge despite significant scientific investment (Laurelut et al., 2016). This is consistent with the neurodiversity movement, which claims that neurodevelopmental disorders are normal variations on a spectrum of human cognition (Kapp et al., 2013). Social construction in a medical setting makes the following assumptions: illnesses are contextualized in cultural meaning for patients, disease states are socially constructed based on experience, and knowledge about disease is created by those with power (Conrad & Barker, 2010). The first stated assumption is related to a historical paradigm, in which clinical phenomenon changes throughout time and geography. The latter is especially emphasized in the writings of Michael Foucault, whose focus on how power is operationalized in clinical settings culminated in a work entitled *The Birth of the Clinic* (Foucault, 1994). The patterning of autism diagnosis throughout time and between social groups will be explored through the social constructionist lens of history and power.

Prevalence

One of the limitations of the positivist perspective of Autism is an inability to accommodate changes to diagnostic criterion over time as explanatory of increases in prevalence. Studies conducted in the 1960s-1980s reported prevalence ranging from 2 to 5 in 10,000 children, typically evaluated more severe clinical presentations (Lotter, 1966). The current prevalence in the United States is 18.5 per 1,000 (Maenner et al., 2020). The historical shifts in autism diagnosis are increasingly difficult to ignore. Social construction argues changes in prevalence are socio-politically, historically contextualized as evidenced by controversies in diagnostic criterion, introduction of technology and evolving expectations for childhood.

Controversies in diagnostic criterion

The controversy over how the criterion for ASD have evolved throughout time is evidence of the socially defined definition that emerges through clinical language. While the DSM-5 has provided diagnostic guidance to providers over the past century, the 2014 revision was hesitantly received by the clinical community. Many clinical researchers, including leaders in the National Institute of Health, have outright rejected the recategorization of psychiatric phenomenon, claiming it is not evidence-based and therefore subject to bias (Decoteau & Sweet, 2016). Concerning ASD specifically, the DSM-5 collapsed several previously delineated diagnostic categories (Pervasive Developmental Disorder and Asperger Disorder) into one disorder, ASD (Craig et al., 2017). This new conceptualization created separate diagnoses for Rett Syndrome and Childhood Disintegrative Disorder. The primary criticisms of ASD as described by the DSM-5 include 1) heterogeneity of the disorder, which may be better understood as a collection of distinct clinical presentations (Lord, 2019), 2) proclivity towards male presentations of behavior (Cridland et al., 2014), 3) implicit conceptualization of ASD as a childhood disorder as opposed to a lifespan experience (Shea et al., 2019), and 4) lack of acknowledgment of the potentially adaptive behaviors of neurodiversity (Powledge, 2011). Typically, when characteristics currently considered immutable demonstrate dramatic changes over time, there is a strong argument for the social construction of the concept. The most researched example is race (Omi & Winant, 2016). In this context, the extent to which the autism diagnosis has been rearranged over time reflects the foundationally societal roots of the criterion (Davidovitch et al., 2020). Furthermore, disagreement within the clinical community provides further evidence of the instability of the diagnosis.

Technology

The social construction approach questions the way trends in science and technology influence the how we understand diagnostic phenomenon. As genetic and molecular understanding of ASD has not produced reliable clinical tools, the diagnosis of ASD is predominantly behavioral. As a result, alternative explanations have emerged for increasing ASD prevalence. Access to early intervention services in the 1980s incentivized providers to diagnose children at greater rates. At the same time, clinical criterion became more relaxed, allowing clinicians increased agency in their diagnostic practices (Grinker, 2007). Providers used to see patients in the community, where children could be evaluated in their daily social environments. Over time, the transition to clinical offices conferred increasing control to the medical establishment (Goffman, 1971). These spaces were foreign to the settings that children typically occupy, favoring the power distribution of clinical providers with less representation of the child's day to day behavior. This use of technology has enabled more complex observation of child behavior with increasing lax clinical guidelines. Additionally, recent trends have involved researching children at younger and younger ages, often before symptoms emerge. Investigations that closely monitor younger siblings of children who have been diagnosed with autism, some starting at birth, are considered among the most rigorous studies (Ozonoff et al., 2011). Moreover, more studies have integrated social communication in infants, like eye contact or advanced monitoring of neural networks, which is highly subject to interpretation (Thorup et al., 2016). In the past, diagnostic testing has relied heavily on language abilities, which emerge later in development. The turn towards infancy through technology has removed the ability of the child to contribute to the diagnostic process. Scholars argue this has created a somatization of autism, which depends on unconscious social responses defined by academic medicine instead of active engagement with the child. These two examples demonstrate how the emergence of technology may be responsible for the rise in ASD prevalence.

Child development

Finally, the social constructivist perspective argues that the notion of abnormal behavior serves the predominate political and economic perspective on children. The introduction of compulsory education fundamentally changed the societal value of children, who were until then viewed as an economic asset. The concept of childhood, which valued play and creativity, emerged with peer socialization in a structured school setting (Cunningham, 1998). Behavioral disorders were developed, predominantly in the western world, in concert with increased expectations of children to adhere to classroom norms and meet performance milestones (Haring et al., 2019). Therefore, this process relies on a sociocultural context. A historical understanding of child development is reinforced by the diverse ways that societies have understood children with developmental differences like autism. Throughout time, people with neurodivergent behaviors have been perceived as anywhere from ill to spiritually enlightened (Foucault et al., 2003). Otherwise stated, societal context defines what is considered abnormal behavior. The impact of culture on the interpretation of deviant child behavior is likewise evidenced by differences in parental understanding of child behavior depending on nativity (Bernier et al., 2010). Families that see the economic utility of childhood differently are less likely to engage with an illness narrative developed in a capitalist, western society. Especially in the United States, the 1980s brought a shift in the federal centralization of educational policy (Delandshere & Petrosky, 2004). In this time period, the prevalence of ASD began to exponentially increase.

Health Disparities

The social construction perspective contextualizes phenomenon in a historical and political period and is helpful in elucidating complex processes. Because it is not concerned with uncovering one discrete truth, this line of inquiry encourages the use of qualitative methods. Foucault's writing, considered foundational in social construction, is broadly concerned with how power is exercised over people who deviate from societal norms (Borch, 2005). In the context of autism, the ways in which this process unfolds differs between racial ethnic groups. Profound health disparities in the diagnosis and treatment of autism for people of color in the United States is well documented (Angell et al., 2018). Social construction provides a lens from which these differences manifest. Within this paradigm, the Foucauldian perspective clarifies how children, and their families navigate clinical institutions. For example, ASD diagnosis is administered in such a way that it shares power with some patients and not with others, often across racial lines. Moreover, patterns of treatment participation vary based on racial ethnic identity. Both phenomena are discussed in the context of Foucauldian ideas.

Diagnostic process

Foucault's concept of discourse is relevant to diagnostic interactions; it refers to the ways in which knowledge is constructed by the elite. Specifically, the way that the medical system communicates, or discourses, with families about autism helps explain different rates of ASD between racialized groups. Medical sociologists argue that the meaning for diagnosis is not grounded in an objective clinical observation, but rather a reflection of societal meaning the clinical label confers to the patient (Schnittker, 2017). Parents often report that they seek diagnosis because they have hope of "recovery" from autism for their child. Families engage with therapies because they believe that this treatment will cure their child of disease. This perspective is not uncommon among lay communities and has been reinforced by therapeutic approaches in the past. However, when parents experientially realize that ASD behaviors may be improved but not eradicated, disengagement and mistrust in the clinical system may result (Broderick, 2009). Moreover, norms administered through a clinical system are usually positioned in dichotomous 'normal' and 'not normal' discourses. In developmental-behavioral health, providers increasingly view symptoms on a spectrum, however; this is not the predominate practice in medicine. Racial minority families are more likely to understand autism in the traditional clinical framework (Decoteau, 2017). From a Foucauldian perspective, this 'discourse' of cure is adopted from the dominant power

structure. Over time, these different understandings of the utility of a clinical evaluation led White families to seek diagnosis and families of color to mistrust clinical institutions. This pattern may partially explain disparities in prevalence and age of diagnosis between racialized groups (Yuan et al., 2021).

An understanding of stigma contributes to another Foucauldian idea, that social control is achieved through discourse. In a study that investigated parental perceptions on shame, White caregivers reported that receiving a diagnosis was a powerful tool in overcoming social stigma related to their child's behavior (Farrugia, 2009). When facing challenges with child behavior, they engage with the medical system. In this theoretical perspective, these families have subscribed to an understanding of autism defined by specialists; they are subsequently controlled by this narrative. This is not the case families of color, however. Black mothers reported distrust of the medical system when their children displayed symptoms of ASD, preferring to advocate for community resources independent of a diagnosis (Burkett et al., 2015). This pattern is indicative of what Foucault calls resistance, where disenfranchised communities do not engage with powerful institutions and instead demonstrate independent, protective behaviors. In this way, these families are more likely use the curative discourse of ASD and resistance. They are consequently less likely to receive a diagnosis in the medical system. This disparity contextualizes differences in ASD prevalence and has consequences for receiving treatment.

Treatment

As discussed, socially constructed discourse about behavioral symptoms is often the motivator for seeking diagnosis. Another Foucauldian idea is relevant to treatment provision: discipline, or techniques for ensuring the order of human groups as efficiently as possible while increasing the docility of disciplined individuals. In the United States, receiving community and school-based services is dependent on a diagnosis of ASD conferred through the medical system (Zablotsky et al., 2015). A diagnosis allows the family to begin therapies; among the most popular is Applied Behavioral Analysis (ABA). ABA is a treatment in which professionals reinforce positive social behaviors. It is frequently administered at home or, depending on the age of the child, at school and is prescribed at up to 40 hours a week. In home treatment better emphasizes Foucauldian concepts and is therefore considered in this discussion. These therapies are forms of discipline because they are designed to align child behaviors with socially appropriate expectations. Consistent with Foucault's understanding of power, the intensity and intimacy in which these therapies are administered may be considered an attempt for the societally dominant perspective to surveille families of children with deviant behaviors.

Furthermore, racial minority children are less likely to receive treatment (Wiggins et al., 2020). In a study that described ABA utilization patterns by race, "57.7% of high users were White children compared to only 6.5% and 4.8% of Black and Hispanic children, respectively"(Yingling et al., 2019). Families with more alignment to societal norms are more likely to engage in discipline, in part because they report more stigma in the community (Grinker, 2020). Treatment helps lessen their child's deviance from societally acceptable behavior. This is especially relevant when children are school aged. ABA treatment emphasizes behaviors preferred by the education system (Zeng et al., 2021). Because the access to treatment helps children conform to the social norms of the educational system are less accessed, these children are more likely to display what are considered problematic behaviors in this setting (Foucault, 1994). While they have evaded discipline in the medical context, this concept is eventually administered by the educational system. As noted above, school expectations are increasingly standardized by societal norms. The social construction lens of stigma and power illuminates how differential participation in therapies has consequences for inclusion in the educational system.

Limitations

Evidence for a social constructionist perspective on ASD contextualizes how families engage with institutions over time and differentially by racial status. The Foucauldian perspective is particularly useful in this context. Social construction offers several approaches to explain trends that are not reliant on biological mechanisms. However, this perspective frequently dismisses the biological basis of disease entirely, claiming diagnosis is exclusively socially constructed (Leveto, 2018). While a concrete mechanism has not resulted from positivist inquiry, denying any natural causes of behavioral does not coincide with a robust evidence base for environmental risk factors or evidence for familial risk (Krishnan et al., 2016). Unsurprisingly, outcomes that are heavily determined by social context are less likely to produce interventionable results, at least on a biological level. While this perspective clarifies how disparities in diagnosis and treatment for ASD emerge, it does not offer concrete recommendations of how to ameliorate these differences.

Social Epidemiology

Finally, a line of inquiry that falls in the positivist paradigm is an epidemiological framework. Social epidemiology specifically is concerned with the effects of social-structural factors, such as class, on health outcomes at the population level (Honjo et al., 2004). This perspective has positivist assumptions but makes some concessions to postmodern ideas. Research in this paradigm has significantly contributed to an understanding of health disparities in autism. It has found that racial minority children in America are less likely to be diagnosed all together, are evaluated at older ages and receive a higher rate of misdiagnosis compared to White children (Angell et al.). For example, Black children in the US are much more likely to receive a diagnosis that emphasizes disruptive behavior rather than a neurobiological difference, such as conduct disorder or adjustment disorder, before receiving an ASD diagnosis (Mandell et al., 2007). Furthermore, disparities in rate of diagnosis have worsened over time, especially between Hispanic and White children (Williams et al., 2015). Understanding these patterns is only possible by sophisticated use of electronic medical records, nationally representative surveys and other epidemiological methods.

Research in this paradigm is almost exclusively quantitative and makes conclusions based on one discrete reality. However, predictors of these differences in prevalence and between groups from an epidemiological perspective include clinical and educational structures and state level interpretation of federal law for children with disabilities (Travers et al., 2014). These are socially contextualized institutions. Moreover, discussion of results in epidemiological research often uses ideas borrowed from social construction. One epidemiological study stated that the disintegration of clinical and educational practices poses a strong risk that "autism identification will be heavily influenced by advocacy, subjective diagnoses, and availability of resources" (Travers et al., 2013). Another study evaluated the rate of ASD diagnosis and access to ongoing treatment in different parts of the country, indicating that regional differences were significantly associated with racial disparities and unmet needs, which were greatest in the southern United States (Zablotsky et al., 2019). Contextualization of findings in this discipline utilizes postmodern concepts like institutional power and resistance. Therefore, this approach may facilitate meaningful interpretation of positivist findings while integrating the emerging literature from a social constructivist paradigm.

Conclusion

Both the positivist and social construction perspectives contribute evidence at different levels to the phenomenon increased diagnosis over time and disparities in ASD diagnosis. They also have limitations. The assumption that autism is a concrete, measurable and unchanging diagnosis from a positivist perspective is strongly criticized in the social constructionist framework. The latter presents compelling evidence that the differences in diagnostic rate are determined by socially constructed ideas from clinical medicine. Positivists conclude that increases in biological risks between racial groups explain disparities. This understanding is undermined by a social constructivist paradigm that argues social determinants place groups at greater risk for adverse health outcomes. Furthermore, the positivist perspective takes an apolitical approach to science, which does not consider historical changes in access, understanding of child development, centralization of medical power and the evolution of educational rights as influencing disparities. By contrast, social construction is perhaps overdependent on these factors, claiming that biological evidence is used as a tool to accumulate power and discipline those that demonstrate differences from normative behaviors.

Although the social constructionist perspective is helpful in framing the social factors that contextualize diagnosis, the lack of meaningful interventions from this critique limits its usefulness in clinical research. Moreover, these perspectives function on different levels, with the positivist approach operating in an individual, biological level and the social construction approach functioning on the level of society. Both perspectives are valuable, especially when they are pragmatically integrated. Social epidemiology is well positioned to employ positivist methodologies in the context of postmodern theories. This model underpins research in demography and sociology, allowing for the triangulation of data, theory-based methods and understanding the limitations of empirical lines of inquiry so they can be most appropriately leveraged to advance science. Importantly, this framework provides meaningful interpretation for clinical implications and health policy interventions. From this approach, the origin of health disparities and recommendations for systems level modification to advocate for more equitable distribution of resources may be advanced.

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