“THE BODY KEEPS SCORE”: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF THE HEALTH OF NONBINARY AND GENDER DIVERSE PEOPLE

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“THE BODY KEEPS SCORE”: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF THE HEALTH OF NONBINARY AND GENDER DIVERSE PEOPLE
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Nonbinary and gender diverse (NBGD) people are individuals whose gender identity is different than their sex assigned at birth and is between, outside, or beyond the gender binary. NBGD people are a disparate population that experiences stigmatization, discrimination, and poor mental and physical health at much higher rates than the general population and their binary transgender peers. Approximately 1.2 million lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ+) adults living in the United States (US) identify as nonbinary or gender diverse. Nursing science has failed to explore the health of, or disparities experienced by, NBGD people. Few studies have examined the experiences of NBGD people separate from binary transgender individuals. This constructivist interpretative phenomenological analysis study sought to address this gap by exploring how NBGD individuals understand and experience health. Seven NBGD adults assigned female at birth completed two semi-structured interviews and were asked to journal between interviews. The open-ended interview questions inquired about the participants’ definitions of health, factors that impact their health, and how they see their future health. *The Body Keeps the Score* emerged as the predominant way the participants experience health with *gender* and *trauma* as the two most significant factors. Highlighted in their gender experiences was the unique intersection of cisgenderism, transgenderism, sexism, and the invisibility of NBGD identities. The pervasiveness of traumas underscored the need to expand on Minority Stress Theory by considering non-gender related traumas and other intersectional experiences that impact NBGD individuals' health. Implications for nursing practice include acknowledgement and validation of diverse gender identities, more inclusive healthcare nomenclature and environments, and trauma-informed care that recognizes the varied and often hidden traumas that people carry.

Keywords: Nonbinary gender diverse, gender, trauma, intersectionality, interpretative phenomenological analysis.

DEDICATION

This dissertation is dedicated to the participants who bravely and openly shared their experiences with me and all nonbinary and gender diverse people who feel unseen, unheard, and invalidated.

And

To Mike…. Thank you.

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CHAPTER I

BACKGROUND AND SIGNIFICANCE

Nonbinary and gender diverse (NBGD) people are individuals whose gender identity is different than their sex assigned at birth and is between, outside, or beyond the gender binary (Darwin, 2017; Richards et al., 2017; Thorne et al., 2019b). NBGD people are a disparate population that experiences stigmatization, discrimination, and poor mental and physical health at much higher rates than cisgender people whose gender identity aligns with their sex assigned at birth (Goldberg et al., 2019; Harrison et al., 2012; Lefevor et al., 2019). Approximately 1.2 million lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ+) adults living in the United States (US) identify as nonbinary or gender diverse (NBGD) (Williams Institute, 2021), and this number is continuing to grow (Richards et al., 2016). In a 2018 position statement, the American Nurses Association (ANA Ethics Advisory Board) reinforced that nurses are required to not only provide culturally congruent care for LGBTQ+ people but also work to eliminate experienced health disparities and discrimination in healthcare. Despite this commitment, LGBTQ+ people continue to bear a higher burden of physical and mental health challenges, disparities, and discrimination in healthcare than heterosexual cisgender people (Medina-Martinez et al., 2021). Within the LGBTQ+ population, gender minorities face an even higher burden of disparities (Downing & Przedworski, 2018; Ferrucci et al., 2021; Goldberg et al., 2019; Gonzales & Henning-Smith, 2017; Harrison et al., 2012; Howell & Maguire, 2019; Jones et al., 2019; Kachen & Pharr, 2020; Klein et al., 2018; Lefevor et al., 2019). Compared to their cisgender counterparts, transgender, nonbinary, and gender diverse people experience higher rates of depression, anxiety, suicidal ideation, chronic conditions, poor quality of life, and unmet healthcare needs. These disparities are often related to fears associated with experienced or anticipated stigmatization, discrimination, and violence in social and healthcare settings, as well as cisnormativity (Downing & Przedworski, 2018; Ferrucci et al., 2021; Goldberg et al., 2019; Gonzales & Henning-Smith, 2017; Haire, et al., 2021; Harrison et al., 2012; Howell & Maguire, 2019; Jones et al., 2019; Kachen & Pharr, 2020; Klein et al., 2018; Lefevor et al., 2019). Cisnormativity is a stance that places cisgender perspectives in a privileged standing over any other gender identity (Hudson, 2019).

Evidence is beginning to emerge that NBGD people carry an increased burden of disparities than their binary transgender peers (Harrison et al., 2012). Binary transgender individuals are people who identify within the gender binary but opposite of their sex assigned at birth (Coleman et al., 2022). Compared to binary transgender people, NBGD people face challenges due to not fitting into the culturally accepted cisnormative gender binary (Cosgrove et al., 2021). They report increased invisibility, the need to hide their identity, and feeling alienated by the larger transgender community (Goldberg et al., 2019; Taylor et al., 2019). NBGD individuals experience more misgendering and more negative experiences with healthcare providers than binary transgender people (Goldberg et al., 2019). They have more unmet medical care needs, fewer wellness visits, and are more poorly insured (Gonzales & Henning-Smith, 2017; Reisner & Hughto, 2019).

Much of what we know about this population has been garnered through research that views binary and nonbinary transgender individuals as a homogenous group despite a variety of nuanced differences (Kattari et al., 2019). Differences include unique gender identities, gender expressions, lived experiences, and diverse gender-related healthcare needs (Todd et al., 2019). Burgwal et al. (2019) found that NBGD individuals have worse self-reported health, mental health, and general well-being than their binary transgender counterparts. Mental health challenges include more generalized and social anxiety, depression, psychological distress, and disordered eating (Goldberg et al., 2019; Lefevor et al., 2019). NBGD people are more likely to abuse alcohol (Reisner & Hughto, 2019), have attempted suicide (Harrison et al., 2012), and have personality disorders (Goldberg et al., 2019). They also are more likely to be HIV+ or not know their HIV status (Harrison et al., 2012). Fifty percent of NBGD people experience harassment, trauma, and sexual assault (Lefevor et al., 2019).

Despite the ANA's call to action, to date, nursing science and practice has failed to explore methods for improving the health and healthcare of NBGD people. The current study sought to address this gap by exploring how NBGD individuals understand and experience health.

Terminology

When discussing terminology related to gender, it is important to first differentiate between words used to describe sexuality and romantic attraction versus those that describe sex and gender. LGBTQ+ is an umbrella acronym that denotes a variety of sexual and gender minorities. While the acronym is useful, it risks oversimplifying the rainbow of identities it seeks to represent. As we attempt to use the acronym to be inclusive of an ever-expanding number of identities, we risk conflating the very identities we are attempting to serve, while simultaneously ignoring the intersectionality of those identities (Monro, 2020). In addition, the range of terms individuals use to describe themselves can vary from those used in scientific discourse. The following acknowledges these difficulties in representing diverse populations and attempts to be parsimonious in its terminology review.

Sexual attraction or sexual orientation is the feeling of sexual desire or wanting to have sexual contact with another person (Coleman et al., 2022; LGBT Center, n.d.). Romantic attraction is the desire to have romantic contact or interactions with another person. People can feel sexual and romantic attraction to the same or different types of people. Lesbian, gay, and bisexual (LGB) are terms that designate sexual attraction or orientation. Queer is a nonspecific term that can be used to describe a variety of identities, including sexual and gender identities (HRC Foundation, n.d.). The term queer has historical considerations related to both previous derogatory use and use as a re-claimed adjective to describe sexuality and, as such, should only be used if a person self-identifies as queer.

Sex assigned at birth (SAB) is the sex designation given to a person at birth, usually based on the appearance of external genitalia. The designations for SAB generally include male, female, or intersex. Some individuals use the acronyms AMAB, assigned male at birth, or AFAB, assigned female at birth to refer to their SAB (Coleman et al., 2022). Intersex indicates individuals whose internal or external sex characteristics do not match the male/female gender binary (Coleman et al., 2022).

Gender or gender identity is a person's intrinsic sense of self which can include male, female, a blend of both, or neither. Gender identity can be the same as or different from a person's sex assigned at birth (Coleman et al., 2022). Gender expression is the external representation of a person's gender identity and can be expressed through behavior, clothing, body characteristics, and/or voice (Coleman et al., 2022). Cisgender, or cis, is a term used to describe persons whose gender identity is the same as their sex assigned at birth (Coleman et al., 2022), for example a woman who is assigned female at birth and identifies as female. Transgender, or trans, is an umbrella term that represents persons whose gender identity and/or expression differs from their sex assigned at birth (Coleman et al., 2022). This includes persons whose gender is opposite of their sex assigned at birth and those whose gender is nonbinary. It should be noted that, for some, transgender specifically refers to those whose gender fits within the gender binary but is opposite of their sex assigned at birth.

Nonbinary, also written as non-binary, identifies several gender identities including those who are between that of male and female, those who experience being male or female at separate times, and those who renounce any gender identification (Matsuno & Budge, 2017). Gender diverse describes persons who have a broad range of gender identities and/or expressions that are outside of cisgender norms (Coleman et al., 2022). Some nonbinary and gender diverse people identify as transgender, and others do not.

In a systematic review of the literature, Thorne, et al. (2019b) found that the two most common terms used to represent the diversity of gender identities that exist outside the binary norm are nonbinary and genderqueer. As previously stated, the word queer has historical considerations related to both derogatory use and use as a re-claimed adjective to describe sexuality. As such, for this study, the adjective nonbinary gender diverse (NBGD) will be used to remain consistent with the literature and be respectful of the diverse identities that exist under the nonbinary umbrella. NBGD is defined as those whose gender is between, outside or beyond the gender binary (Darwin, 2017; Richards et al., 2017; Thorne, et al., 2019b). It should be noted that not all gender diverse persons use these terms to describe themselves and they were selected only as a means of simplifying discourse, not othering or labeling any individual. See Appendix A for a more comprehensive list of gender terminology and Appendix B for the genderbread person, which offers a pictorial representation of gender.

Concepts

To explore how NBGD individuals understand and experience health it is important first to define the key concepts of gender and health. Over time the definitions of both gender and health have evolved based on changing scientific knowledge and shifts in cultural norms. Both concepts are strongly influenced by geographic location, religion, culture, race, and ethnicity, and are often recorded in history through the lens of a prevailing dominant culture (Shoemaker, 1994). Consequently, it is difficult to establish universal definitions of gender and health. The following provides an overview of these concepts as they relate to the current study.

Gender

Gender is often defined as a social construct that individual societies ascribe to based on physical and/or biological traits and is centered on differentiating males and females (Mascia-Lees & Black, 2017; West & Zimmerman, 1987). When discussing gender and health, the World Health Organization currently defines gender as the characteristics of women, men, girls, and boys (World Health Organization, n.d.-b). Contrary to this binary narrative, in many Western and indigenous cultures, gender has historically been viewed as more expansive, including a revered third gender that combines both masculine and feminine characteristics (Matsuno & Budge, 2017). Gender has an immense impact on the ways people act, the things they believe, and how they make sense of themselves and the world around them (Mascia-Lees & Black, 2017). Depending on cultural narratives, gender can also significantly influence an individual's roles and responsibilities, quality of life, and life expectancy (Mascia-Lees & Black, 2017). Limiting gender to a binary construct based solely on sex characteristics is contrary to modern understandings of gender (Mascia-Lees & Black, 2017). It creates barriers for and makes invisible millions of people whose gender identity is more expansive.

Gender constructs are malleable, and it is possible to progress cultural and societal expectations around gender (Mascia-Lees & Black, 2017). In their classic work, West and Zimmerman (1987) put forth that gender is not something we are, but something we do, as we go about our day-to-day lives. Gender reflects our internal self-perception, contextualized within an interpretative lived experience. Regardless of gender identity, individuals “do gender” as they navigate their day-to-day lives. People change the way gender is done based on what is required in each situational interaction, whether they are aware of doing so or not (West & Zimmerman, 1987). For NBGD people, doing gender is a more intentional activity that entails displaying or challenging normative gender expectations (Darwin, 2017). For NBGD people, gender can become a salient narrative that influences their behaviors, health, and quality of life.

Health

Health is a lived experience that is influenced by the culture and environments in which a person lives. It is a life-long process of seeking order in bodily structure and function (Parse, 1981). Relative to the holistic nature of people, health incorporates physical, psychological, social, and spiritual well-being (Parse, 1981; Parse, 1992; Thorne et al., 1998; World Health Organization, n.d.-a). Definitions of health are individualized and cannot be prescribed or universalized (Parse, 1990). Consistent across several nursing theories is that health is a dynamic process in which individuals work towards a state of being an integrated, whole human being (Brouse, 1992; Parse, 1981). A key influence on health is access to quality healthcare (Healthy People 2030, n.d.). NBGD experience barriers to health due to discrimination and disparities in healthcare (Medina-Martinez et al., 2021). Consequently, it is important for nursing to explore how NBGD people understand and experience health to decrease disparities and better support their health and healthcare experiences.

Nursing Science and Practice Significance

Nursing’s knowledge and science is outlined by nursing’s metaparadigm. Professional disciplines use metaparadigms to provide a broad, overarching framework to describe the essential domains or relevant phenomena of the discipline (Fawcett, 1984). Nursing's metaparadigm describes the breadth of the profession as including knowledge, theory, and practice while also establishing nursing as a discipline (Lee & Fawcett, 2013). Fawcett (1984) identifies the four central concepts of nursing's metaparadigm as person, environment, health, and nursing. Exploring how NBGD individuals understand and experience health informs nursing knowledge and science by informing the concepts of person and health.

A person is any individual, family, community, or group who receive nursing care (Fawcett, 1996). Person is the central concept of the nursing metaparadigm to which all other concepts relate. Congruent with constructivist and phenomenological viewpoints, individuals interpret and find meaning within their environment in unique ways based on their consciousness, past experiences, and orientation to their environment. One's experience as a person is socially constructed and cannot be separated from that experience (Guba & Lincoln, 1994). Unique individuals and groups, including NBGD people, will have distinctive experiences and needs based on their orientation to the world.

Health, the purpose of nursing's interaction with people (Thorne et al., 1998), is the second concept informed by the current study (Fawcett, 1995; Parse, 1981). Health is an ever-evolving lived experience that is cocreated by persons and their interactions with social groups and the environments in which they live (Parse, 1981). As a holistic concept, health incorporates physical, psychological, social, and spiritual well-being. Prevailing definitions of health are impacted by normative social expectations (Thorne et al., 1998) and are therefore influenced by cisnormative narratives. This narrative can challenge the way NBGD people experience health. Exploring how NBGD individuals understand and experience health informs our knowledge of the population and illuminates the impact of normative expectations. It allows for identifying patterns in human behavior within the context of the environment to understand normal life events, critical life situations, and changes in health status for this population (Fawcett, 1984). The concepts of person and health are central to nursing's metaparadigm. A better understanding of these concepts provides a clearer foundation and understanding for its entirety.

Research Questions and Study Aims

Nonbinary and gender diverse (NBGD) people experience a higher burden of physical and mental health challenges, disparities, and discrimination in healthcare than cisgender people whose gender identity aligns with their sex assigned at birth. Despite the ANA's call to action, to date, nursing science and practice has failed to explore methods for improving the health and healthcare of NBGD people. The current study sought to address this gap by first understanding the lived experience of health for NBGD persons. The purpose of this study was to use interpretative phenomenological analysis to explore how NBGD individuals understand and experience health. The proposed research question was: How do NBGD individuals understand and experience health? The study aims included:

- Aim 1: Describe how NBGD individuals define health.
- Aim 2: Explore factors that affect NBGD individuals' experience of health.

CHAPTER II

LITERATURE REVIEW

Relevant to nursing's metaparadigm and practice, nursing is uniquely situated to influence the health of nonbinary gender diverse (NBGD) people. An extensive review of the literature was conducted to discover the current state of the science regarding the health and healthcare experiences of individuals who are NBGD. Understanding these experiences will assist healthcare providers in helping NBGD individuals achieve and maintain optimal health.

Search Strategy and Yield

Due to the overall paucity of knowledge regarding the health and healthcare experiences of NBGD individuals, all databases within Academic Search Complete were searched to cast a broad, multidisciplinary net. The literature was examined for results published between 2010 and 2020. Studies conducted before 2010 likely do not reflect the current health and healthcare experiences of NBGD individuals due to the rapid growth in societal awareness of issues faced by transgender individuals over the past ten years. Three separate key word searches were conducted and then combined. Terms were chosen based on the extant literature addressing transgender issues. Key words searched related to gender using "or" as a qualifier included: "Transgender", "trans", "transsexual", "gender variant", "gender nonbinary", "gender non-binary", "gender diverse", "gender nonconforming", "gender non-conforming", "GNC", "gender queer", "genderqueer", "gender fluid", "polygender", "agender", and "genderfuck". Terms searched related to healthcare interactions with "or" as a qualifier, included: "Needs", "access", "barriers", "disparities", "discrimination", and "stigma". The key words "health", "health care" and "healthcare" comprised the final key word search. The three search groups were then combined with "and" as the qualifier. The combination yielded 34, 172 results.

Exclusion Criteria

The search was limited to studies published in English, in peer reviewed journals, and in countries with Western social norms and customs, decreasing the total to 2, 242. One thousand one hundred and eighty-three results remained after removal of duplicates. Titles were then reviewed for relevance to the topic. Studies were removed from the sample if the population focus was the entire LGBTQ+ community or sexual minorities, were focused on sexual health and/or HIV/STI's, centered on gender affirming care, or investigated healthcare providers or the education of healthcare providers. Studies were eliminated that centered on pediatric populations, parenting, politics, policy or activism, or were about an entirely unrelated topic. Additionally, editorials, opinion pieces, informational articles, and best practice or policy statements were eliminated. Seventy-six studies remained after elimination of irrelevant studies. A secondary thorough examination of abstracts and results was conducted to exclude studies which either focused only on binary transgender identities or reported conglomerate results that did not distinguish between binary and nonbinary individuals. Ten studies remained, including eight quantitative, one qualitative, and one mixed methods study. One additional quantitative study was mined from the reference list of one of the studies (n=11). A follow up literature search, using the same criteria, was conducted in January 2023 to identify any new studies that were published between 2020 and 2022. Covid-focused studies were added to the exclusion list. An additional 9 quantitative (n=18) and one qualitative (n=2) study were subsequently added to the review (n=21). The following presents a critical analysis of the research methods of these studies.

Quantitative Studies

Eighteen quantitative studies were identified with findings related to the health or healthcare experiences of NBGD individuals that met inclusion and exclusion criteria (Burgwal et al., 2019; Cruz, 2014; Downing & Przedworski, 2018; Ferrucci et al., 2021; Gonzales & Henning-Smith, 2017; Harrison et al., 2012; Henderson, 2022; Jones et al., 2019; Kachen & Pharr, 2020; Kattari et al., 2019; Kattari et al., 2021; Kcomt et al., 2021; Klein et al., 2018; Lefevor et al., 2019; Reisner & Hughto, 2019; Rimes et al., 2019; Stanton et al., 2021; Thorne et al., 2019a). Studies originated from the United States (n=14), the United Kingdom (n=3), and Europe (n=1). The disciplinary affiliations of the first authors were health services and policy analysis (n=1), health policy and administration (n=1), medical sociology (n=1), social work (n=4), psychiatry (n=1), psychology (n=5), public/population health (n=2), social and psychiatric epidemiology (n=1), behavioral and community health sciences (n=1), and communication, culture, and technology (n=1). No studies were found with origins in nursing.

One study received NIH funding (Reisner & Hughto, 2019), one received funding from both the NIH and the National Institute on Drug Abuse (Stanton et al., 2021), one study reported funding from the National Institute of Mental Health (Henderson, 2022), one study received funding from The Big Lottery Fund, UK (Rimes et al., 2019) and one received funding from the Robert Wood Johnson Foundation (Gonzales & Henning-Smith, 2017). The remaining 13 studies did not identify a means of funding. The purposes of the studies were to explore six overarching phenomena: Experiences of stigma, discrimination, or victimization in healthcare (Cruz, 2014; Harrison et al., 2012; Kattari et al., 2021; Klein et al., 2018), healthcare access, utilization, and satisfaction (Downing & Przedworski, 2018; Ferrucci et al., 2021; Gonzales & Henning-Smith, 2017; Kachen & Pharr, 2020; Kattari et al., 2019; Kcomt et al., 2021; Reisner & Hughto, 2019), transgender-affirming healthcare (Kattari et al., 2019; Reisner & Hughto, 2019), the relationship between minority stress and health (Lefevor et al., 2019), mental health (Jones et al., 2019; Rimes et al., 2019; Stanton et al., 2021; Thorne et al., 2019a) and the overall health (Burgwal et al., 2019; Downing & Przedworski, 2018; Henderson, 2022; Reisner & Hughto, 2019) of both binary and nonbinary transgender individuals.

Philosophical Underpinnings and Theoretical Frameworks

None of the authors of the 18 quantitative studies delineated specific philosophical underpinnings, however, they could be inferred relative to methods. Six researchers introduced theoretical frameworks as guiding the course of their studies. Two used Minority Stress Theory (Ferrucci et al., 2021; Reisner & Hughto, 2019), one viewed the study through the lens of Intersectionality (Lefevor et al., 2019), and three studies used both Minority Stress Theory and Intersectionality (Burgwal et al., 2019; Henderson, 2022; Klein et al., 2018). The remaining 12 reports provided no information regarding a guiding theory or framework. Minority Stress Theory has been shown to be a valid and reliable measure of stress experienced by transgender and gender-nonconforming people (Testa et al., 2015) and the theory of Intersectionality facilitates the exploration of the complex experiences of individuals with multiple overlapping identities (Kassam et al., 2020).

Designs and Methods

Researchers for the 18 quantitative studies utilized non-experimental cross-sectional survey designs. Cross-sectional studies are suitable for investigating the prevalence of phenomena within populations and are therefore appropriate for exploratory studies (Sedgwick, 2014). Five studies collected data from databases with ongoing data collection, The Center for Collegiate Mental Health (Lefevor et al., 2019) and the Behavioral Risk Factor Surveillance

System (Downing & Przedworski, 2018; Ferrucci et al., 2021; Gonzales & Henning-Smith, 2017; Henderson, 2022). Three studies analyzed data from the National Transgender Discrimination Survey (Cruz, 2014; Harrison et al., 2012; Klein et al., 2018) and three studies analyzed data from the United States Transgender Survey 2015 (USTS 2015) (Kachen & Pharr, 2020; Kattari et al., 2021; Kcomt et al., 2021). The remaining seven surveys were conducted in the U.K. (Jones et al., 2019; Rimes et al., 2019; Thorne et al., 2019a), Europe (Burgwal et al., 2019) and across the U.S. (Kattari et al., 2019; Reisner & Hughto, 2019; Stanton et al., 2021). The use of common databases to collect information about this population has advantages and disadvantages. Transgender populations are historically difficult to access. Large data sets provide an opportunity to explore phenomena related to the population that may not otherwise be available. Using the same data set for multiple studies leaves the studies vulnerable to the same limitations created by the original study, including problems related to generalizability, and increases the risk of duplicate or redundant results (Trochim & Donnelly, 2007).

All researchers used convenience sampling which is appropriate and often necessary when studying transgender populations (Melendez et al., 2006). Six reported additional snowball sampling (Burgwal et al., 2019; Jones et al., 2019; Kachen & Pharr, 2020; Kattari et al., 2021; Kcomt et al., 2021; Rimes et al., 2019). Sample sizes ranged from 388 to 518,052. The studies with very large sample sizes (518,052 and 315,893) included both transgender and cisgender participants, the majority of which were cisgender (98% and 99%) (Downing & Przedworski, 2018; Gonzales & Henning-Smith, 2017). Across all 18 studies, participants were overwhelmingly White. The proportion of binary to nonbinary participants ranged from one to one (n=1) to nearly six to one (n=1). Sex assigned at birth was indicated in seven studies (Burgwal et al., 2019; Harrison et al., 2012; Kattari et al., 2021; Klein et al., 2018; Rimes et al., 2019; Stanton et al., 2021; Thorne et al., 2019a). The lack of diversity in the study samples is problematic in that the samples likely do not reflect the demographics and experiences of the entire transgender population.

Variables

The quantitative studies examined a variety of different variables surrounding the health and healthcare experiences of binary and nonbinary transgender individuals. It should be noted that all studies were correlational in nature and not experimental. As such, there were overlaps in how variables were considered. For example, six studies used demographics as independent variables (Cruz, 2014; Henderson, 2022; Kattari et al., 2019; Kattari et al., 2021; Kcomt et al., 2021; Klein et al., 2018) and six studies used demographics as dependent variables (Burgwal et al., 2019; Downing & Przedworski, 2018; Ferrucci et al., 2021; Harrison et al., 2012; Lefevor et al., 2019; Reisner & Hughto, 2019). Demographics examined included age, race/ethnicity, education, employment, income, relationship/marital status, sexual orientation, gender, sex assigned at birth, health insurance status, and housing situation. In all cases demographics were operationalized.

All 18 studies explored gender as a key variable. Gender was operationalized in a variety of ways. Five studies identified participants as either binary or nonbinary (Burgwal et al., 2019; Harrison et al., 2012; Klein et al., 2018; Reisner & Hughto, 2019; Thorne et al., 2019a). Three studies divided participants into binary and nonbinary genders and then further divided gender into four categories that included a designation for sex assigned at birth (Cruz, 2014; Kattari et al., 2021; Rimes et al., 2019). Six studies included cisgender and transgender individuals, two of which categorized participants as cisgender men, cisgender women, gender nonconforming, transgender men, or transgender women (Downing & Przedworski, 2018; Gonzales & Henning-

Smith, 2017), two divided gender into cisgender men, cisgender women, transgender men, transgender women, nonbinary assigned male at birth, or nonbinary assigned female at birth (Jones et al., 2019; Stanton et al., 2021), one combined gender groups into cisgender, genderqueer, and transgender (Lefevor et al., 2019), and one designated gender as cisgender man, cisgender woman, transgender man, transgender woman, or gender nonconforming (Ferrucci et al., 2021). Three studies divided gender into three categories, with transgender separated into male and female and one category for nonbinary genders (Henderson, 2022; Kachen & Pharr, 2020; Kcomt et al., 2021). The remaining study designated participants as either transfeminine, transmasculine, nonbinary, or transgender (Kattari et al., 2019). All authors explained their rationale for how genders were grouped and operationalized. The variety of different terms used to identify transgender individuals and those whose gender falls outside of the gender binary is problematic and contributes to the invisibility of NBGD people in the literature (Thorne et al., 2019b).

Other variables examined related to factors that impact health and/or healthcare experiences. This included general health, health behaviors, health related quality of life, and functional disabilities. Researchers also explored experiences related to engaging in healthcare such as the need for gender affirming care, barriers to care, healthcare access and utilization, and reasons for postponement of care. Finally, authors surveyed participants to explore stressors that impact health including stigma, discrimination, violence, incidences of trauma, harassment, and sexual assault, as well as mental health concerns such as anxiety, depression, alterations in eating, alcohol and substance use, suicidality and self-harm, social history, and social support. See Table 1 for a summary of variables explored in each quantitative study.

Table 1

Quantitative Study Variables

Study	Independent Variables	Dependent Variables
Burgwal et al., 2019	Gender	Age, education, economic situation, minority group status, SAAB, need of gender affirming medical interventions, self-reported health, general well-being
Cruz, 2014	Gender, personal identity, transitioning treatment, care location, level of being out, health insurance, race/ethnicity, age, income, relationship status	Postponement of curative care
Downing & Przedworski, 2018	Gender	Age, race/ethnicity, education, income, employment, health insurance, housing, marital status, children in household, sexual orientation, chronic medical conditions, health related quality of life, functional disabilities, health behaviors, healthcare access and utilization
Ferrucci, et al., 2021	Gender	Age, race/ethnicity, sexual orientation, marital status, education, health insurance, able to afford care, PCP, routine checkup past 12 months, general health status, number of chronic conditions
Gonzales & Henning-Smith, 2017	Gender	Health insurance, usual source of care, unmet medical, routine checkups
Harrison et al., 2012	Gender	Identity complexities, age, race/ethnicity, location, education, income, discrimination experiences in education, employment, health/healthcare, police, and violence
Henderson, 2022	Gender, race/ethnicity, sexual orientation, age	Health-related quality of life
Jones, et al., 2019	Gender	Mental health and quality of life
Kachen & Pharr, 2020	Gender	Healthcare insurance, routine healthcare provider, healthcare provider knowledge, healthcare visit past year, healthcare discrimination
Kattari et al., 2019	Gender, race/ethnicity, sexual orientation, age, education, PCP trans-inclusive care	Transition-related medical interventions, delay in accessing care
Kattari et al., 2021	Gender, income, race/ethnicity, age, disability, education	Healthcare provider verbal abuse, healthcare provider physical abuse, verbally harassed in a healthcare setting, unwanted sexual contact in a healthcare setting
Kcomt et al., 2021	Gender, healthcare need, race/ethnicity, poverty, identity disclosure, visual conformation, health insurance	Unmet healthcare need due to cost
Klein et al., 2018	Gender, age, race/ethnicity, income, education, employment, health insurance, SAAB, medical transition status, gender conformity, suicide attempts, substance misuse, HIV+ status, transactional sex, marginally housed	Social service discrimination
Lefevor et al., 2019	Gender	Age, race/ethnicity, religious/spiritual identity, academic status, victimization, suicidality, psychological distress
Reisner & Hughto, 2019	Gender	Age, race/ethnicity, sexual orientation, education, student status, income, health insurance, gender

Study	Independent Variables	Dependent Variables
		affirmation, healthcare utilization and experiences, social history, violence victimization, social support, mental health, substance use
Rimes et al., 2019	Gender	Mental health, self-harm, suicidality, substance abuse, abuse and victimization
Stanton et al., 2021	Gender	Depression, anxiety, substance abuse disorder, alcohol abuse disorder, behavioral health appointment, substance abuse appointment
Thorne et al., 2019a	Gender	Anxiety, depression, NSSI, self-esteem, perceived social support

Limitations

The quantitative studies exhibited several limitations. All 18 studies were correlational cross-sectional survey designs that utilized convenience sampling and as such, shared several limitations. These limitations included lack of generalizability, inability to determine cause and effect, and that data may not reflect reality over time (Trochim & Donnelly, 2007). All data was gathered via self-report introducing the risk for self-report and recall bias (Trochim & Donnelly, 2007). The study samples were overwhelmingly cisgender, binary transgender, White, well-educated, and did not account for intersectional identities, and therefore likely not representative of the entire population. Twelve of the 18 studies used online techniques for recruiting and data collection (Burgwal et al., 2019; Cruz, 2014; Harrison et al., 2012; Jones et al., 2019; Kachen & Pharr, 2020; Kattari et al., 2019; Kattari et al., 2021; Kcomt et al., 2021; Klein et al., 2018; Lefevor et al., 2019; Reisner & Hughto, 2019; Rimes et al., 2019). This limits the sample to individuals who have access to a computer. Online surveys also increase the likelihood for participants to misinterpret questions or for wording to influence responses (Trochim & Donnelly, 2007). Six studies conducted secondary analysis of commonly shared datasets (Cruz, 2014; Harrison et al., 2012; Kachen & Pharr, 2020; Kattari et al., 2021; Kcomt et al., 2021; Klein et al., 2018). Using the same data set for multiple studies leaves the studies vulnerable to the same limitations created by the original study, including problems related to generalizability, and increases the risk of duplicate or redundant results (Trochim & Donnelly, 2007). Five of the studies condensed all transgender identities into two categories which eliminates the ability to assess for differences in experiences across identities (Burgwal et al., 2019; Harrison et al., 2012; Klein et al., 2018; Lefevor et al., 2019; Reisner & Hughto, 2019). Two studies collected data via phone survey and used vocal timbre to determine sex assigned at birth for two-thirds of the study timeframe. This created the risk for gender misclassifications and inconsistencies in reporting gender (Downing & Przedworski, 2018; Gonzales & Henning-Smith, 2017).

Qualitative Studies

Two qualitative studies were identified with findings related to the health or healthcare experiences of NBGD people (Cosgrove et al., 2021; Taylor et al., 2019). The studies originated in the United Kingdom (Taylor et al., 2019) and the United States (Cosgrove et al., 2021) and the disciplinary affiliations of the first authors were gender studies (Taylor et al., 2019) and social work (Cosgrove et al., 2021). The authors of one study acknowledged funding from a University of Albany School of Social Welfare Dissertation Scholarship (Cosgrove et al., 2021) while the other study did not identify a means of funding (Taylor et al., 2019). The purpose of the studies was to understand the experiences of nonbinary people in their medical and social interactions (Cosgrove et al., 2021; Taylor et al., 2019). Cosgrove et al. (2021) reported that their photovoice study was grounded in critical feminist theory which is appropriate for an arts-based participatory action research study seeking to enact positive social change (Maguire, 1987). No philosophical underpinnings were identified by Taylor et al. (2019), which is not unusual for qualitative descriptive studies (Sandelowski, 2000).

Designs and Methods

Cosgrove et al. (2021) utilized purposive sampling while Taylor et al. (2019) used both purposive and snowball sampling to recruit nonbinary participants. Sample sizes were nine and eight, respectively (Cosgrove et al., 2021; Taylor et al., 2019). Both the sampling methods and sample sizes were appropriate for qualitative studies (Morse, 2007). Participants for both studies were majority White (Cosgrove et al., 2021; Taylor et al., 2019). Taylor et al. (2019) collected data via two focus groups with four participants each. Cosgrove et al. (2021) collected data over multiple participant and researcher group meetings that included journaling, group decision-making, and sharing of experiences. Participants used photography to express their answers to the research questions (Cosgrove et al., 2021).

Data analysis for Cosgrove et al. (2021) was a two-step process. The first step was a group analysis of photographs taken by the participants guided by a “SHOWeD” analysis worksheet common to photovoice studies (Wang & Redwood-Jones, 2001). Second, transcripts of the meetings and the SHOWeD worksheets were analyzed using Interpretative Phenomenological Analysis (IPA), a methodology well suited for discovering participants’ unique perspectives (Smith et al., 2009). Data was managed using ATLAS.ti version 1.6.0 software (Cosgrove et al., 2021).

Data analysis for Taylor et al. (2019) was conducted using Miles and Huberman’s method of qualitative descriptive analysis. The research team consisted of binary transgender and cisgender individuals. Procedures used to ensure trustworthiness included triangulation and reflexivity to establish credibility, member checking to facilitate confirmability, and keeping faithful to participants accounts to improve authenticity (Creswell, 2013).

Limitations

There were several limitations shared by these qualitative studies. These included the small homogeneous samples, the single recruitment sites, and the likelihood that those who agreed to participate were more confident in talking about their gender identity and therefore may not represent the entire nonbinary population. While the studies provided insight into the experiences of the participants, the results are not generalizable (Creswell, 2013).

There were also unique limitations identified for each of the studies. Cosgrove et al. (2021) acknowledged that use of participatory art and group-based methods limited participation to individuals who were comfortable both with engaging in these types of activities and those who were comfortable expressing their gender identity in public. Taylor et al. (2019) data was gathered via self-report introducing the risk for recall bias (Trochim & Donnelly, 2007). As a qualitative descriptive study, it lacked interpretation and the opportunity to discover the deeper meaning in the participants' experiences (Creswell, 2013; Smith et al., 2009). The authors also referred to limitations in transcription (Taylor et al., 2019). While the purpose of the study was to understand the experiences and medical needs of nonbinary individuals, the results were more reflective of general experiences rather than medical needs, likely due to the single question asked of participants, "How do you experience nonbinary gender identity?" (Taylor et al., 2019).

Mixed Methods Study

One mixed methods study was identified with findings related to the health or healthcare experiences of NBGD individuals (Goldberg et al., 2019). The disciplinary affiliation of the first author was psychology. The authors received no financial support for their research. The purpose of the study was to explore the mental health and healthcare experiences of transgender students in higher education, including investigating factors related to misgendering and less affirming treatment by providers (Goldberg et al., 2019). The authors reported framing the study within Hendricks and Testa's Gender Minority Stress Theory however, while the authors provide a definition of the theory, the concepts are not clearly explicated (Goldberg et al., 2019). Minority stress theory is often used to guide studies investigating the experiences of NBGD individuals (Burgwal et al., 2019; Griffin et al., 2019; Klein et al., 2018; Reisner & Hughto, 2019) and has been shown to be a valid and reliable measure of stress experienced by transgender and gender-nonconforming people (Testa et al., 2015).

Concepts

Concepts were explored with both open-ended and closed-ended questions. The concepts explored via open-ended questions and subjected to qualitative analysis were participants' understanding of their mental health, how societal norms surrounding gender create stress, and their experiences with mental healthcare. An additional goal was to gain insight into the participants' overall healthcare experiences. Concepts examined via closed-ended questions and subjected to quantitative analysis were participant characteristics related to perceptions of affirming treatment by campus providers and reports of misgendering by campus providers (Goldberg et al., 2019).

Variables

The researchers examined the influence of four independent variables, binary versus nonbinary status, sex assigned at birth, race, and student status on two dependent variables, perceived misgendering and perceived gender affirming treatment. The authors did not fully conceptualize all variables. Both dependent variables were operationalized by Likert-type scales and the independent variables were operationalized in a dichotomous manner (Goldberg et al., 2019) which is appropriate for design and methods (Trochim & Donnelly, 2007).

Design and Methods

The authors reported using a mixed methods design with a primarily qualitative approach (Goldberg et al., 2019). Both quantitative and qualitative data were garnered via an online survey. The survey was created by a member of the research team, was informed by trans-identified focus groups, and was pilot tested by members of the focus population. (Goldberg et al., 2019). There was no further discussion of validity or reliability. Online surveys with closed-ended questions are appropriate for garnering quantitative data. While open-ended questions in an online survey can add better understanding of concepts, they do not allow for follow up and full exploration of phenomena. As such, they do not produce the same results as traditional qualitative methodologies and limit the ability to identify this study as a true mixed methods design (Creswell & Plano Clark, 2011).

Sampling and Sample Characteristics

Convenience sampling was used to recruit participants from LGBTQ+ groups and support centers at college campuses in the United States. Listservs and social media groups for LGBTQ+ students were also used (Goldberg et al., 2019). The final sample consisted of 506 participants. Most of the participants were White, nonbinary, and reported their sex assigned at birth as female (Goldberg et al., 2019). Both the sampling methods and sample size were appropriate for the method (Creswell & Plano Clark, 2011).

Data Analysis

Data analysis for the qualitative portion of the study was reported as thematic analysis with open coding that was informed by relevant literature and gender minority stress theory (Goldberg et al., 2019). NVivo software was used to manage data. Two researchers participated in data analysis and intercoder agreement was calculated at two points during analysis to “clarify categories and definitions and confirm reliability" (Goldberg et al., 2019, p. 70). There was no further discussion of procedures to promote trustworthiness of the data. Data analysis for the quantitative portion of the study was conducted using Mann-Whitney U-tests, logistic regression, and t-tests which were appropriate for the variables (Polit & Beck, 2012). Data analysis software was not specified and there was no delineation of data cleaning.

Limitations

The study had several limitations including not specifying a time frame for diagnoses or the location of care, using single-item measures to assess misgendering, and allowing undiagnosed difficulties without exploring reasons for the lack of diagnosis (Goldberg et al., 2019). Other limitations of the study included the homogeneous sample and the likelihood that those who agreed to participate were more confident in talking about their gender identity and therefore did not represent the entire population. All data was gathered via self-report introducing the risk for recall bias (Trochim & Donnelly, 2007). The authors also acknowledge the tool used limited their ability to integrate results into existing literature (Goldberg et al., 2019).

Review of Findings

Transgender individuals continue to experience healthcare disparities at higher rates than their cisgender counterparts (James et al., 2016) and much of what we know about this population has been garnered through research that views transgender individuals as a homogenous group (Kattari et al., 2019). Only recently has science begun to acknowledge and explore the differences between binary and nonbinary transgender individuals. The current review reflects the immature state of the science as most of the studies are exploratory in nature. These studies sought to determine what factors were related to the health and healthcare experiences of binary and nonbinary transgender individuals. The key findings of the 21 studies centered on three themes that overlap and inform each other: Stigma and discrimination, healthcare access and utilization, and the overall health and mental health of binary and nonbinary transgender individuals.

Stigma and Discrimination

Discrimination and the fear of discrimination and violence are associated with negative psychosocial, social, and physical health-related outcomes (Goldberg et al., 2019; Klein et al., 2018). Both binary and nonbinary transgender individuals experience stigma and discrimination related to their gender identity or expression in both community and healthcare settings. This includes while on the job and when interacting with healthcare providers and police (Kachen & Pharr, 2020; Harrison et al., 2012). Examples of overt discrimination include denial of care, harassment, trauma, and sexual assault, all of which occur at much higher rates than experienced by cisgender individuals (Harrison et al., 2012; Lefevor et al., 2019). More subtle instances of discrimination include invisibility and invalidation of gender identity, (Cosgrove et al., 2021; Goldberg et al., 2019; Taylor et al., 2019) as well as gender inflation and the assumption of a single trans experience by healthcare providers (Cosgrove et al., 2021; Goldberg et al., 2019). Those who are visibly gender non-conforming or have had some form of gender-affirming medical intervention (GAMI) experience discrimination most frequently (Klein et al., 2018). Other factors associated with discrimination experienced by transgender individuals include younger age, lower education or income, unemployment, and having either public health insurance or no health insurance (Harrison et al., 2012; Klein et al., 2018). While these factors are not unique to this population, they serve to compound experiences of discrimination and exacerbate health disparities (Klein et al., 2018).

Evidence is beginning to emerge that nonbinary individuals carry an increased burden of stigma and discrimination than binary transgender people. They experience greater levels of unemployment and are more likely to have participated in informal and underground economies to survive (Harrison et al., 2012). They are subject to more frequent police harassment and are less likely to go to the police for help or access healthcare due to fear of discrimination (Harrison et al., 2012). Nonbinary people are more likely to experience physical and sexual assault, both during school age years and as adults (Harrison et al., 2012). They are also more likely than binary transgender individuals to be recognized as gender nonconforming (Reisner & Hughto, 2019). This may partially explain the increased instances of stigma and discrimination for nonbinary people; however, more research is needed to elucidate the reasons behind these phenomena.

Nonbinary people face additional challenges due to not fitting into the culturally accepted gender binary. They report increased invisibility, the need to hide their identity, and feeling alienated by the larger trans community (Cosgrove et al., 2021; Goldberg et al., 2019; Taylor et al., 2019). They also experience more gender dysphoria (Taylor et al., 2019), misgendering, more negative experiences with healthcare providers (Goldberg et al., 2019)) and are less likely to have family support for their gender (Reisner & Hughto, 2019). Contrary to these findings, Klein et al. (2018) and Kattari et al. (2021) report that binary transgender individuals are more likely than nonbinary individuals to experience discrimination and victimization in community and healthcare settings.

While the current studies describe the occurrence of stigma and discrimination for transgender people, they do not illuminate the nuances of the experiences and explicate the factors that are involved. Many of the studies continue to combine nonbinary identities into one group which conflates nonbinary gender experiences as a singular phenomenon. This discrepancy in findings, lack of clarity, and narrow focus on gender signals the need for further exploration of experiences of stigma and discrimination. In addition, a more in-depth examination is warranted of NBGD individuals to explore the impact of stigma and discrimination on their experiences of health and to look closer at variations in those experiences by gender identity.

Healthcare Access and Utilization

Stigma and discrimination experienced by binary and nonbinary transgender individuals also impacts their healthcare access and utilization. Both cisgender and transgender people postpone seeking care due to cost however, transgender individuals do so more often (Downing & Przedworski, 2018; Kcomt, et al., 2021) and are more likely to delay accessing healthcare due to discrimination (Cruz, 2014). Still, it is not clear whether binary or nonbinary individuals are more likely to avoid healthcare due to discrimination. Harrison et al. (2012) found that nonbinary people are more likely to postpone care due to fear of discrimination, whereas Kattari et al. (2019) reported that binary individuals are more likely to do so.

In addition to cost and discrimination, there are several other factors that impact healthcare access and utilization for transgender people. Transgender individuals have lower levels of education and income and are more likely to be unemployed than cisgender individuals (Downing & Przedworski, 2018). They also are more likely to have no health insurance (Downing & Przedworski, 2018; Gonzales & Henning-Smith, 2017) or use public health insurance (Klein et al., 2018; Reisner & Hughto, 2019) and have no primary source of care (Cruz, 2014; Gonzales & Henning-Smith, 2017). Other factors that impact healthcare access and utilization in this population include degree of outness (Cruz, 2014) and the availability of a trans-inclusive healthcare provider (Kattari et al., 2019).

Nonbinary people face challenges when accessing and using healthcare beyond those experienced by binary transgender individuals. They have more unmet medical care needs, less wellness visits, and are more poorly insured (Gonzales & Henning-Smith, 2017; Kachen & Pharr, 2020; Reisner & Hughto, 2019). They encounter additional barriers when accessing healthcare for GAMI due to not fitting into the accepted gender binary (Taylor et al., 2019). It should be noted that it is still not clear to what degree nonbinary individuals desire GAMI as compared to their binary counterparts. Kattari et al. (2019) found that nonbinary individuals desire GAMI with as much variation and frequency as binary transgender people, but other studies report the contrary (Burgwal et al., 2019; Kattari et al., 2019; Reisner & Hughto, 2019).

Like the findings regarding stigma and discrimination, the current studies describe the occurrence of barriers to healthcare access and utilization for transgender people but, they do not illuminate the nuances of the experiences or explicate the factors that are involved. There are also inconsistent findings regarding postponement of care and the need for GAMI. To resolve these discrepancies, further research is needed to better understand healthcare access and utilization for NBGD individuals, the need for GAMI, and the influence these factors have on NBGD individuals' experiences of health, including variations by gender identity.

Overall Health and Mental Health

Both binary and nonbinary transgender individuals consistently experience worse overall quality of life, health, and mental health than their cisgender counterparts (Jones et al., 2019; Kachen & Pharr, 2020). Burgwal et al. (2019) found that transgender people have worse self-reported health and general well-being than cisgender people that is aggravated by experiences of economic stress, disability, younger age, and minority statuses. They have more mental health challenges including generalized and social anxiety, depression, and psychological distress (Burgwal et al., 2019; Goldberg et al., 2019; Lefevor et al., 2019; Rimes, et al., 2019; Stanton et al., 2021) which is often related to trans-related stigma (Goldberg et al., 2019). Transgender people are more likely to have disordered eating, participated in self-injury, or have contemplated or attempted suicide (Klein et al., 2018; Lefevor et al., 2019; Rimes, et al., 2019). These factors are exacerbated by being marginally housed, having participated in transactional sex, and misuse of substances (Klein et al., 2018). All transgender groups are more likely than cisgender individuals to have disabilities with nonbinary individuals being the most vulnerable (Downing & Przedworski, 2018).

As with stigma, discrimination, and healthcare access and utilization, nonbinary individuals experience additional disparities in overall health (Henderson, 2022) and mental health compared to their binary counterparts. In a direct comparison of binary and nonbinary transgender people, Burgwal et al. (2019) found that nonbinary individuals have worse self-reported health, mental health, and general well-being. Mental health challenges include more generalized and social anxiety, depression (Reisner & Hughto, 2019; Stanton et al., 2021; Thorne et al., 2019a), psychological distress, and more disordered eating (Goldberg et al., 2019; Lefevor et al., 2019). Nonbinary people are more likely to abuse alcohol (Reisner & Hughto, 2019), have attempted suicide (Harrison et al., 2012), and have personality disorders (Goldberg et al., 2019). They are also more likely to be HIV+ or not know their HIV status (Harrison et al., 2012). Contrary to these findings, Reisner & Hughto (2019) found that binary transgender individuals are more likely than nonbinary individuals to self-harm, have anxiety and depression, and have diagnosed gender dysphoria.

It is clear transgender individuals experience disparities in overall health and mental health. The scope of the current studies does not allow for in-depth exploration of the personal and environmental factors that contribute to these disparities nor the meaning of health for NBGD people. There are inconsistencies in findings, particularly related to experiences by gender. Research is needed to better define these phenomena, understand factors related to these experiences, and better explain differences by gender.

Summary

The literature review identified several gaps and inconsistencies in knowledge regarding the health and healthcare experience of NBGD individuals. The state of the science is immature and lacks a solid foundation from which to build. Very few studies have explored the experiences of NBGD people separate from binary transgender individuals or examined differences between nonbinary gender identities. Methodologies have largely been quantitative and survey-based and do not fully explore the meaning of health for NBGD people. Only one of the two qualitative studies included interpretation of the deeper meaning of participant experiences. Of considerable note is the lack of nursing knowledge about the health and healthcare experiences of this population. Nurses are uniquely positioned to create change and improve the health and healthcare of the individuals under their care, including NBGD people. It is essential to develop qualitative nursing knowledge about the health of this population to build a foundation of knowledge to improve the health and healthcare experiences of NBGD individuals.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore how NBGD individuals understand and experience health. The research question was: How do NBGD individuals understand and experience health? The study aims included:

- Aim 1: Describe how NBGD individuals define health.
- Aim 2: Explore factors that affect NBGD individuals' experience of health.

Interpretative phenomenological analysis (IPA) was used to meet the aims of the study and answer the research question. IPA was first introduced in 1996 by Jonathan A. Smith to combine hermeneutics and phenomenology into a qualitative methodology that would better integrate into the existing body of largely quantitative psychological science (Smith, 1996; Smith et al., 2009). IPA is a qualitative methodology that allows for building foundational knowledge by exploring individuals' understandings of their experiences. IPA's ideographic perspective is suited for teasing out commonalities and differences in experiences of health across gender identities (Smith et al., 2009) and was an ideal methodology for exploring how NBGD individuals understand and experience health.

Philosophical Underpinnings

The philosophical paradigm that best informs NBGD individuals' experience of health is constructivism. Constructivism is a postmodern paradigm that emerged as a reaction to positivism and post-positivism. The ontology of constructivism is that of relativism (Guba & Lincoln, 1994). Reality takes multiple forms based on individuals and their environments. Knowledge is socially constructed. Humans cannot be separated from knowledge and the investigation of knowledge. Whereas positivists seek to remain detached from participants, constructivists acknowledge the integral role of the researcher and the participant and the reciprocity of that relationship (Forbes et al., 1999). The constructivist axiological stance places value on the individual perception, intuition, and voice of both researcher and participant. Constructive epistemology is therefore transactional and subjectivist (Guba & Lincoln, 1994). The goal of constructivist inquiry is to understand human behavior, experiences, and subsequent derived meanings. Methodologies are interactive and interpretive (Guba & Lincoln, 1994).

IPA is a methodological framework that falls under the worldview of constructivism. IPA has theoretical foundations in phenomenology, hermeneutics, and idiography (Smith et al., 2009). Like other interpretative phenomenological methods, IPA seeks to explore how people make sense of and find significance in lived experiences (Smith et al., 2009).

Phenomenology

Phenomenology is the study of how humans interpret experience (Mastin, 2008). Congruent with the constructivist world view, phenomenologists believe that phenomena cannot be separated from individuals' experiences of them and the best way to understand phenomena is to allow individuals to describe their experiences in their own words (Cohen, 1987). Smith, et al. (2009), describe the phenomenological aspects of IPA as being derived from the works of Husserl, Heidegger, Merleau-Ponty, and Sartre.

IPA's foundation is Husserl's modified positivist's perspective that took a descriptive and transcendental view of individuals' experiences (Smith et al., 2009). The goal of Husserl's phenomenology was for the individual to separate oneself from external experience and focus on the internal perception and reflection on that experience. Scientific rigor is maintained through researcher self-reflection and bracketing to remain separate and maintain the essence of an individual's experience (Wojnar & Watson, 2007).

Heidegger, Merleau-Ponty, and Sartre built on and moved past Husserl's descriptive phenomenology by acknowledging the contextualized, interpretative nature of human beings. Each sought to unearth a full understanding of individual lived experiences situated in the context of our world (Smith et al., 2009). While all three viewed phenomenology as an interpretive experience, each added unique perspectives to phenomenology that are brought together in the nuances of IPA (Smith et al., 2009). Heidegger described the worldliness of Dasein, the uniquely situated human being, Merleau-Ponty saw human perspective as separate from and yet embodied in the world, and Sartre viewed individuals as projects in the process of becoming, seeking meaning in the world, equally affected by the absence of things as with their presence (Smith et al., 2009).

IPA draws from the works of each of these phenomenological philosophers to create an in-depth, comprehensive phenomenological methodology. From Husserl, IPA acknowledges the importance of bracketing and derives its attention to the perception of experiences through description and reflection. Heidegger adds external factors such as objects, people, and languages as integral factors in how individuals experience phenomena. From Merleau-Ponty, IPA gains awareness of the primacy of individual perspectives, and Sartre brings recognition that people are developmental, process-oriented beings (Smith et al., 2009).

Hermeneutics

Simply stated, Hermeneutics is the art of interpretation. Historically hermeneutics has been described as a theory, a philosophical approach, and a methodology (Smith et al., 2009). As a word and a praxis, hermeneutics has its origins in the Greek exercises of interpretation and understanding (Crotty, 1998). For IPA, interpretation is a key component of understanding human experiences. Smith et al. (2009) describe the hermeneutic aspects of IPA as being derived from the works of Schleiermacher, Heidegger, and Gadamer.

Philosophers

Schleiermacher viewed interpretation as a holistic art that derives knowledge not only from written words but, the meaning ascribed to them by the author and the reader (Smith et al., 2009). Detailed and comprehensive interpretative analyses provide new perspectives and true understanding of the text and the author (Crotty, 1998; Smith et al., 2009). Heidegger was less concerned with text and focused on presented and hidden meanings of phenomena and human existence (Crotty, 1998; Smith et al., 2009). Knowledge can be derived from observing phenomena, but true understanding comes from the observer's interpretation of phenomena. The observer must be aware of the past experiences, knowledge, and point of view they bring to observation, even if awareness of that past only occurs after interaction with the new phenomena (Crotty, 1998; Smith et al., 2009). Gadamer's hermeneutics held similarities to both Schleiermacher's and Heidegger's. Like Schleiermacher, Gadamer's primary focus was the interpretation of text and like Heidegger, he acknowledged the relationship between history, foreknowledge, and the understanding of new phenomena (Crotty, 1998).

Hermeneutic Circle

Despite varying philosophical viewpoints, hermeneutics is consistently guided and actualized by the hermeneutic circle (Smith et al., 2009). In practice hermeneutics is a dynamic, holistic, multilevel examination of phenomena. The hermeneutic circle represents and actualizes this process. Phenomena are understood by examining both the whole of the experience and the parts that make up the whole. The whole and the parts are intimately interconnected and explicable only by moving back and forth between the two and reflecting on the process itself (Crotty, 1998; Smith et al., 2009).

The hermeneutic circle for IPA is applied by initially attempting to bracket foreknowledge, listening to an account, and then returning to foreknowledge in reflection, knowing that it may have been changed by having listened to the account (Smith et al., 2009). In addition, IPA makes detailed examinations of each participants accounts, looks for similarities and differences between the accounts, and then returns to the beginning to reflect on what each account brings to understanding the phenomenon as a whole (Smith et al., 2009). Finally, IPA is a double hermeneutic activity. Participants attempt to understand their experiences in order to share them. At the same time the researcher attempts to understand the participant. Together, both are attempting to make sense of the phenomenon (Smith et al., 2009).

As with phenomenology, IPA draws from the works of a variety of hermeneutic philosophers to create an in-depth, comprehensive hermeneutic phenomenological methodology. From Schleiermacher, the IPA researcher learns that interpretation offers meaningful insights into phenomena that exceed what is directly offered by participants. From Heidegger and Gadamer, IPA researchers gain the knowledge that the interplay between researcher and participant contributes to a higher level of understanding of the phenomena. From the Hermeneutic circle, IPA researchers gain a dynamic process that offers a comprehensive understanding of phenomena that otherwise would not be possible.

Idiography

In addition to description and interpretation, IPA takes an ideographic stance when investigating phenomena. Ideography is defined as the focus on the individual or the particular (Smith et al., 2009). This focus contrasts with a nomothetic generalized perspective which in turn, mirrors the distinction between constructivism and positivism. IPA focuses on the particular in both its faithfulness to exploring single cases and in its depth of analysis (Smith et al., 2009). It is committed to thorough and systematic exploration of phenomena at the individual level. Comparisons are made between individual cases to identify commonalities and differences and create a comprehensive picture of an experience (Smith et al., 2009). IPA moves from the specific to the general, allows for understanding of both individuals and groups, and creates a foundation of knowledge from which to build (Smith et al., 2009). It is a descriptive, reflective, interpretative methodology that seeks to reveal complex meaning and understanding of dynamic, situated, lived experiences and was an ideal methodology for exploring how NBGD individuals understand and experience health.

Sample

IPA was used to explore how NBGD individuals understand and experience health. IPA produces rich data through detailed examination of individual cases. Participants in IPA studies represent a perspective on phenomena of interest, as opposed to representing phenomena for an entire population. Small and homogenous samples are used to facilitate exploring “particular phenomena in particular contexts” (Smith et al., 2009, p. 49). Larger sample sizes can be problematic and limit the ability to stay true to the commitments of IPA (Smith et al, 2009). For the current study, five to eight individuals with gender identities outside the gender binary who have had an experience that caused them to explore their health or seek assistance related to their health were recruited. IPA studies with sample sizes within this range have been shown to be adequate for detailed exploration of phenomena while limiting extraneous data (Smith et al., 2009).

To further homogenize the group, participants were limited to individuals 18 years of age or older whose sex assigned at birth (SAB) was female and were living in the United States. While the literature is immature on this topic, based on prevailing binary gender norms and master narratives, it is safe to assume that there are differences in lived experience based on SAB (Bradford et al., 2019). Limiting the study population in this way helped maintain homogeneity and discover the differences that exist between gender identities (Smith, et al., 2009). Exclusion criteria included those who were unable to speak, hear, or understand English and those with cognitive impairments that may have interfered with their ability to understand informed consent. Prior to beginning the interview, informed consent was communicated both in writing and verbally using simple language. Comprehension of informed consent was assessed by asking the participants to verbalize the purpose of the research and their role in the process (Polit & Beck, 2012).

Sampling

To answer the research question and remain consistent with both the qualitative paradigm and the goals of IPA, referral, purposive, and snowball sampling were used to recruit individuals who had experience with and insight into the phenomena of interest (Smith et al., 2009). The NBGD population is often invisible under the larger transgender umbrella and is historically difficult to access (Freeman, 2018; Miller & Grollman, 2015; Nicholas, 2019). Referral via gatekeepers facilitated contact with individuals who represent particular perspectives on the phenomenon of interest and in turn, supported homogeneity and the ideographic approach of IPA (Smith et al., 2009). Purposive sampling is a frequently used, appropriate initial recruiting strategy for phenomenological studies and was inherently required for an IPA study (Creswell, 2013; Miles et al., 2014; Polit & Beck, 2012; Smith et al., 2009). Snowball sampling allowed for capitalizing on participants' social networks to recruit additional participants (Creswell, 2013;

Polit & Beck, 2012; Smith et al., 2009). At the conclusion of each interview, participants were asked if they knew of anyone who meets inclusion criteria and might be interested in participating in the study. If so, the participant was provided with the researcher's contact information to give to members of their social networks. This process allowed prospective participants to maintain privacy and control of their personal information (Trochim & Donnelly, 2007).

Following Kent State University Institutional Review Board (IRB) approval (Appendix P), participants were recruited via flyers (Appendix C) posted at the LGBTQ+ Center of a moderate-size Midwestern public university and at a nearby hospital-affiliated Pride Clinic. Additional in-person recruitment was conducted at area Pride events (Appendix D). Entrée into each location was via gatekeepers known to the student investigator. Limiting the number of sites and methods of recruitment facilitated homogeneity of the sample which supported a detailed examination of similarities and differences within the sample (Smith et al., 2009). See Appendix E for recruitment site contact information and Appendix F for permissions to post recruitment flyers.

Individuals interested in participating were asked to contact the investigator by phone or email. After initial contact, potential participants were screened for inclusion and exclusion criteria via telephone conversation (Appendix G). Participants were required to be able to articulate understanding, insight, and perspective of the phenomenon of interest (Smith et al., 2009). Prior to beginning the interview, informed consent (Appendix H) was communicated both in writing and verbally using simple language. Comprehension of informed consent was assessed by asking the participants to verbalize the purpose of the research and their role in the process (Polit & Beck, 2012). Participants signed the consent form before data collection began

(Appendix H). Participants received a twenty-dollar Amazon gift card for compensation in consideration of their time at the completion of each interview. The total compensation was forty dollars for the completion of both interviews. Forty dollars was selected as an amount that encouraged participation while not being so large as to be deemed coercive (Polit & Beck, 2012).

Protection of Participants

All efforts were made to protect the study participants. Protection of participants included activities to maintain respect for persons, beneficence, and justice (Office for Human Research Protections, 1979; Polit & Beck, 2012). Respect for persons includes both acknowledging individual autonomy and protecting those with diminished autonomy (Office for Human Research Protections, 1979). Autonomy is the ability of an individual to understand and deliberate available options, and act upon that deliberation (Office for Human Research Protections, 1979). For the study, autonomy was maintained via informed consent for voluntary participation, the right to withdraw from the study at any time, and the ability to decline to answer questions (Office for Human Research Protections, 1979; Polit & Beck, 2012). During informed consent, the purpose of the study was explained as well as any foreseeable risks of harm (Office for Human Research Protections, 1979). Participants were also offered the option of reviewing the interview questions before agreeing to participate in the study and the right to receive findings once the study was complete. See Appendix I for the Interest in Findings and Future Research form.

Respect for persons also included maintaining participant confidentiality (Office for Human Research Protections, 1979). Participant confidentiality was preserved through protection of data and personal information (Office for Human Research Protections, 1979). Only members of the research team, Amy Veney and Dr. Pamela Stephenson, had access to consent and demographic forms, audio recordings, field notes, and transcripts. Field notes and consent and demographic forms were stored in a locked cabinet in the faculty advisor's office separate from the audio recordings and transcripts. Audio recordings and transcripts were stored in a password protected Microsoft Teams site. Transcripts were numbered and all identifying information was removed to protect the identity of the participants. Once the study was completed, audio and digital files were deleted, and hard copies of transcripts and field notes were destroyed.

Beneficence is the ethical duty to minimize harm and maximize benefits (Office for Human Research Protections, 1979; Polit & Beck, 2012). The study posed no inherent risk of physical harm, however, there was the potential for emotional or psychological distress due to the in-depth nature of the interviews (Polit & Beck, 2012). To protect the participants, the investigator monitored for signs of distress throughout the data collection process. No undue distress was observed by the investigator or verbalized by any of the participants. If needed, the participants had the option to terminate the interview and receive appropriate referrals to support services. See Appendix J for mental health and crisis intervention referral information. While there was no direct benefit to the study participants, the information shared provides better understanding of the health experiences of NBGD people and can assist healthcare providers in providing health related care, support, and education and improve the healthcare experiences of NBGD people.

Justice refers to study participants' right to fair and equitable treatment (Office for Human Research Protections, 1979; Polit & Beck, 2012). Justice was protected by choosing subjects based on the established inclusion and exclusion criteria (Polit & Beck, 2012). This ensured that participants were chosen based on a clear, predetermined set of criteria and not individual characteristics. While there was no direct benefit to the participants, their involvement in the study contributed to the body of knowledge about the health of NBGD people and has the potential to inform healthcare practices for this population.

Data Collection

To develop rich data, IPA requires participants to be offered the opportunity to openly share their stories, reflect on the experience they are sharing, and have adequate time to develop their thoughts (Smith et al., 2009). This can necessitate multi-method and multi-time-point data collection (Polit & Beck, 2012; Smith et al., 2009). In-depth interviews are a frequently used means for gathering quality qualitative data (Munhall, 2007; Polit & Beck, 2012; Smith et al., 2009). For this study, two semi-structured interviews were conducted one week apart to allow time for a more in-depth reflection on the phenomena of interest. Participants were asked to journal to record their thoughts during that week. Journaling facilitates prolonged engagement and reflection and is an effective method of qualitative data collection (Filep et al., 2018; Hayman et al., 2012). Interviews were conducted by the student investigator via Microsoft Teams at a time that was convenient for the participants. Conducting interviews via online formats like Microsoft Teams has been shown to provide similar outcomes as face-to-face interviews while removing financial and geographic barriers (Jenner & Myers, 2019; Krouwel et al., 2019).

Following screening for inclusion and exclusion criteria, eligible and willing participants were asked to schedule a date for completing informed consent, the demographic form, and the interview. Every attempt was made to schedule the interview within one week to decrease the risk of attrition. Initial interviews lasted one to two hours and follow-up interviews lasted one hour or less. Prior to the interview date, the consent and demographic forms were completed by the participants via a Qualtrics survey. An opportunity was provided to ask questions prior to beginning the interview. At the completion of the interview, participants were asked if they were interested in receiving a copy of the research findings or if they were interested in participating in future research. See Appendix I for the Interest in Findings and Future Research form.

The student investigator conducted both the initial and follow-up interviews with the participants. The initial interactions began with the investigator establishing a conversational tone to build rapport, facilitate dialogue, and allow the participants to tell their stories in their own words (Smith et al., 2009). All questions and concerns were addressed before beginning the semi-structured interview. The first question, “What is your understanding of why I am talking to you today,” was meant to be a final confirmation of participant comprehension and as a launching point for exploring the participant’s experience of health. The Initial Interview Guide (Appendix L) was used to conduct the interview. The questions were broad and open-ended to encourage rich responses (Polit & Beck, 2012; Smith et al., 2009). Questions were modified based on the participants’ responses and the need to dive deeper into areas of interest (Smith et al., 2009). Prompts were used, when necessary, to assist the participants with further exploration of their thoughts and ideas. Examples included, “Tell me more about that,” and “How do you feel?” (Appendix L). The investigator used field notes to record observations, salient topics, and areas to return to for more in-depth exploration. At the conclusion of each interview, the participant was debriefed to assess for distress however, no referrals were necessary (Appendix J). All interviews were audio recorded within Microsoft Teams and with a supplemental digital recording device as back up. The interview was transcribed verbatim via the Microsoft Teams recording and then reviewed for accuracy.

Upon completion of the first interview, participants were asked to schedule a second follow-up interview to occur one week after the initial interview. During that week, they were asked to continue to reflect on their health experience. This allowed them time to return to the event itself and explore the experience further after having engaged with it during the interview process. At the completion of the interview, the student investigator reviewed the field notes, the transcription of the interview, and made note of ideas that required further exploration in the follow-up interview. Consequently, both the participant and the investigator engaged in the hermeneutic circle while exploring the phenomenon (Smith et al., 2009).

Participants were asked to email their journals to the student investigator prior to the second interview. Like the first interview, the second interview was scheduled via Microsoft Teams according to the participants' preferences. The Follow-Up Interview Guide (Appendix M) was used to direct the interview. Questions were modified based on the participants' responses and the need to dive deeper into areas of interest. The initial prompt, "Tell me about how the journaling process was for you" was used to allow the participants to re-engage in the interview process before exploring more difficult concepts. The second interview also served as pseudo-member checking as it allowed the investigator the opportunity to discuss initial thoughts on the data with the participant. Each participant received a $20 Amazon gift card at the completion of each interview ($40 total) as compensation for their time. At the completion of the second interview, the student investigator reviewed the field notes, journals, and the Microsoft Teams transcriptions. All recordings were listened to a second time and compared to the transcripts to clean the data and verify accuracy. Data analysis was informed by all field notes, journals, and the transcripts from both interviews.

Data Analysis

Smith, et al. (2009) support that there is no right or wrong way to conduct IPA data analysis. Because it is iterative and inductive and includes moving from the particular to the shared and from the descriptive to the interpretative, it makes sense to proceed in a stepwise fashion to facilitate illumination of emergent themes. Smith et al.'s (2009) recommended process for beginning IPA researchers was used for the data analysis. The six steps in the process are (1) reading and re-reading, (2) initial noting, (3) developing emerging themes, (4) searching for connections across emergent themes, (5) moving to the next case, and (6) looking for patterns across cases.

Data was first analyzed by a thorough reading and re-reading of the transcripts, journals, and field notes to facilitate immersion in the data (Smith et al., 2009). Careful attention was paid to the flow of the interview and any shifts in perspective or narration. Next, initial notes were made of anything of interest in the transcript including descriptions of things that mattered most to the participants and the meanings they ascribed to them (Smith et al., 2009). Particular attention was paid to the way things were described, the words used, and the concepts that emerged. This step was repeated multiple times until no new information of interest emerged. Next, emergent themes were developed (Smith et al., 2009). This step relied heavily on the hermeneutic circle as it required both abstraction and remaining grounded in the original data. Emergent themes reflected both the participant's original words and the investigator's interpretation of those words (Smith et al., 2009). Next, connections across emergent themes were identified. Once this process was completed for one participant, the process was repeated for the other participants. To remain true to IPA's ideographic commitment, care was taken to bracket individual cases until it was time to look for patterns across cases (Smith et al., 2009). To facilitate this, every attempt was made to complete data analysis steps one through four before interviewing subsequent participants. The final step of data analysis was to look for patterns across cases. This included identifying idiosyncrasies as well as commonalities and higher order concepts that described the phenomenon of interest (Smith et al., 2009).

Memos were kept during the entirety of data analysis to document the process, to track emerging themes, and create an audit trail. Data analysis began after the completion of the first interview and was conducted in collaboration with the student investigator's faculty advisor. The student investigator and faculty advisor met regularly during data analysis to review the data, the steps of the process, and decisions made regarding idiosyncrasies, emerging themes, and connections between themes. The faculty advisor therefore served as an independent auditor. An independent audit is a powerful tool for establishing the validity of a qualitative study (Smith et al., 2009). Data was managed and organized in Microsoft Excel spreadsheets. Using Microsoft Excel spreadsheets facilitated identification of emerging themes, exploring connections across themes, grouping of themes into higher order concepts, and searching for patterns across cases.

Trustworthiness

A variety of methods exist for establishing the trustworthiness of qualitative research. This arises from the plethora of ontological and epistemological approaches for producing qualitative data (Yardley, 2000). Smith, et al. (2009) recommend Yardley's (2000) four characteristics of quality qualitative research for establishing and assessing the trustworthiness of qualitative research. These four principles establish a broad, pluralistic method of evaluating qualitative research that is useful regardless of the philosophical and theoretical origins of the research (Smith et al., 2009; Yardley, 2000). According to Yardley (2000), the four characteristics of trustworthy qualitative research are sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance.

Sensitivity to context refers to both external and internal contexts of a study. External contexts include the prevailing sociocultural environment; other studies that either inform, support, or contradict a study; and the philosophical and theoretical frameworks that establish the lens through which data collection and analysis is conducted (Yardley, 2000). Internal context is the social interactions between the investigator and participants, including language used, the way dialogue unfolds, and the power balance between researcher and participant (Yardley, 2000).

For the current study, sensitivity to context began with the establishment of the need for and the planning of the study. The literature review identified several gaps and inconsistencies in knowledge regarding the health and healthcare experiences of NBGD individuals, as well as a sociocultural environment that renders NBGD individuals invisible. This both supported the need for the study and the requirement of a constructivist qualitative perspective to explore the phenomena and build foundational knowledge. Choosing IPA further supported sensitivity to context as it acknowledged the need for an idiographic approach related to the uniqueness of the NBGD population (Smith et al., 2009).

Sensitivity to context continued during data collection and analysis as well as the creation of the study narrative (Smith et al., 2009; Yardley, 2000). Close attention was paid to the interview process and the ways in which the participants reacted to and answered the interview questions. The student investigator was careful to show empathy, use language and behaviors aimed at putting the participants at ease, and remaining aware of challenges that can arise based on inherent power dynamics (Smith et al., 2009). Field notes were used to carefully track non-verbal data and the thread of conversations. The student investigator remained vigilant in assessing the flow of the interview and made changes to the interview schedule based on emerging data (Smith et al., 2009). During data analysis, sensitivity to context was maintained by remaining aware that IPA data analysis is a dual hermeneutic process where the investigator attempts to make sense of the participant while the participant is making sense of their experience. This sensitivity allowed for simultaneously remaining close to and separate from the data (Smith et al., 2009). Sensitivity to context was maintained during the creation of the study narrative by grounding analytical claims in the data and using verbatim extracts to support interpretations (Smith et al., 2009).

Commitment and rigor are also required when conducting a trustworthy qualitative study. Faithfulness to commitment and rigor necessitates comprehensive data collection, meticulous data analysis, and in-depth reporting of findings (Yardley, 2000). For the current study, this was accomplished through recruiting of an adequate sample size, inclusion and exclusion criteria that facilitated homogeneity of the sample, and prolonged engagement with the participants via two interviews, field notes, and participant journaling (Smith et al., 2009). Care was taken to remain attentive to the participants during data collection and committed to allowing the participants' experiences guide the interaction (Smith et al., 2009). Commitment and rigor continued during data analysis by verbatim transcription of the interviews, meticulous reading, and rereading of the data, remaining close to and yet separate from the data, attending to convergence and divergence, and by moving past superficial description to deep interpretation (Smith et al., 2009). An independent audit was conducted by the student investigator's advisor to evaluate the rigor of the data analysis. The independent audit provided a critique and verification of the step-by-step processes by which data analysis was conducted and decisions were made (Smith et al., 2009). In-depth reporting of the findings finalized the faithfulness to commitment and rigor. This included use of several verbatim extracts from the interviews and a thorough description of the data interpretation processes and decisions (Smith et al., 2009). Research reported in context maintains the connection between research and practice and allows research findings to become practical and useful (Nizza et al., 2021).

Thorough description of data interpretation processes and decisions also supported transparency and coherence (Yardley, 2000). Transparency and coherence allow the consumer of the research to clearly trace the stages of the research, understand decisions made during data analysis, and if desired, replicate the study with similar findings (Smith et al., 2009). For the current study this was accomplished at the end of data analysis through detailed reporting of how the participants were selected, a description of the interview guide and the interviews, and the steps that were used during analysis including rules for coding and the decision-making path (Smith et al., 2009). An in-depth narrative reported the philosophical framework, the investigator’s motivations for undertaking the study, and how the study aligns with the phenomenological and hermeneutic sensibilities inherent to IPA (Smith et al., 2009; Yardley, 2000). These processes allow the consumer to determine the impact and importance of the findings. An impactful and important study creates new understanding, adds to the theoretical framework from which it was initiated, has socio-cultural impact, or changes the way we think about phenomena (Smith et al., 2009).

CHAPTER IV

RESULTS

Health is a dynamic lived experience that is influenced by the culture and environments in which people live. As a result, health can vary from group to group and person to person. The unique health experiences of nonbinary gender diverse (NBGD) people have not been investigated. The purpose of this study was to address this gap in knowledge by using interpretative phenomenological analysis (IPA) to explore how nonbinary gender diverse (NBGD) individuals understand and experience health. IPA's ideographic perspective facilitates illuminating commonalities and differences in experiences of health across gender identities.

Participants were asked to participate in two semi structured interviews one week apart and to journal during the week between interviews. The open-ended interview questions inquired about the participants' definitions of health, factors that impact their health, and how they see their future health. The second interview focused on the participants' reflections after the first interview and revisiting topics from the first interview that required further exploration. Five of the seven participants journaled during the week between interviews. Two interviews combined with journaling and investigator field notes provided copious rich data and allowed both the participants and the student investigator to engage in hermeneutic reflection. The second interview was also invaluable for following up on concept threads missed during the first interview. Once completed, individual participant's accounts of their experiences were extensively considered through reading, re-reading, initial noting, and identification of emergent themes before exploring similarities and differences across cases.

Sample Characteristics

Interviews were conducted between October 2023 and November 2023. The final sample included seven NBGD people between the ages of 24 and 59 who were assigned female at birth. Six of the seven participants identified as White, and one identified as White and Native American. Three participants held master's degrees and four held bachelor's degrees. Four participants were married (two were married during data collection), one was ethically non-monogamous, one was polyamorous with a partner, and one was partnered. Annual household income ranges were \$10,000-\$19,999 (n=1), \$50,00-\$74,999 (n=3), \$75,000-\$100,00 (n=1), and greater than \$100,00 (n=2). Six participants lived in the Midwest and one had previously lived in the Midwest. See Table 2 for a list of the participants' ages and assigned pseudonyms. Due to the small sample size, age is the only demographic directly associated with the participants to protect their identities.

Gender Identities and Pronouns

There were similarities and differences in gender identities and pronouns among the participants. Four participants identified as nonbinary, but their pronouns varied. Two nonbinary participants used they/them pronouns although one switches to she/her when around family. One nonbinary participant used they/she pronouns and one participant identified as nonbinary/transmasculine and used he/they. One participant identified as gender nonconforming and used she/her, one identified as a demigirl and used she/they, and one identified as gendervague and used they/them pronouns. This participant also reported explaining their gender as nonbinary in situations where others had difficulty understanding gendervague. See Table 3 for participant gender identity definitions.

Table 2

Participant Ages and Assigned Pseudonyms

	Sam	Alex	Avery	Blake	Deb	Jesse	River
Age	35	45	31	37	59	33	24
Gender	Nonbinary	Gender-vague	Demigirl	Nonbinary/ Transmasculine	Gender Nonconforming	Nonbinary	Nonbinary
Pronouns	They/Them (NB, T/T)	They/Them (GV, T/T)	She/They (DG, S/T)	He/They (NB/TM, H/T)	She/Her (GNC, S/Hr)	They/She (NB, T/S)	They/Them (NB, T/T)

Table 3

Participant Gender Identity Definitions

Participant	Gender Identity	Participant Definition of Gender Identity
Sam	Nonbinary	“If you had a spectrum with male at one end and female at the other, kind of everything in between.”
Alex	Gendervague	“Gendervague is a term I found online when I was trying to explain to someone that I like, conceptually understand this idea of gender that society has, but personally, it makes no freaking sense to me. It is a weird, crazy thing that they have settled on doing. I kind of understand it, but I don't get it at all, at the same time, so gendervague.”
Avery	Demigirl	“If you’re thinking of it like a spectrum, you have cis female on one end and then nonbinary on the other end of the spectrum. I’m in the middle, so like I always put it as like if I were to order my gender off a wish list, it would technically be a girl, but it would be like kind of a shittier version of it or like maybe something’s like kind of off or like not what most would expect it to be. Another way I like to put it is like a LaCroix seltzer, how it has like essence of whatever fruit, it’s like essence of woman, like it’s kind of there but just a little bit, but I still feel kind of attached to, you know, being female, but I don’t feel entirely cis either. That’s what I like about demigirl is that it’s still technically nonbinary, but it also allows like that femininity to be present because nonbinary feels too nonbinary and cis feels too cis.”
Blake	Nonbinary/ Transmasculine	“I don’t like being called she. I don’t mind when I go places and I’m dressed masculine and people call me sir or he…. I kind of like it…. Like I still wear makeup once in a while. Like if I go out, I’ll wear makeup and I’ll wear a

Participant	Gender Identity	Participant Definition of Gender Identity
		heel. I will do those things and still have femininity to it and that's not a big deal."
Deb	Gender Nonconforming	"Just the whole spectrum from one end to the other, I guess…. [but for me] only like from the middle over to masculine, never, never towards the feminine side.... I'd rather be a butch lesbian any day than to be a guy…. but I don't like being feminine."
Jesse	Nonbinary	"I like being very fem. I like being sparkly, but also, a lot of times, I just look like Adam Sandler…. I want to find a good in between that represents me and I just haven't because I usually don't have a label for it. I'm usually like this is how I feel today and it's always all over the map so that's why I kind of ended up with nonbinary."
River	Nonbinary	"I don't identify as female or male. Outside of the binary genders. I don't really identify as either of those."

Participant Health Conditions

The purpose of this study was for the participants to share their lived experiences of health. Participants' health conditions were not elicited directly but were instead allowed to emerge through the telling of their stories. This permitted them to share a condition only if it was significant to them. The health conditions most frequently shared during the interviews related to the participants' mental health. All seven participants revealed experiencing some form of trauma including sexual, physical, psychological, and/or emotional abuse or neglect as a child and/or as an adult. Four participants described subsequent post-traumatic stress disorder and panic attacks. Five of the seven participants experienced depression and/or anxiety. Three reported suicidal ideation or attempts, chronic pain, and Ehlers-Danlos Syndrome (EDS), a group of genetic connective tissue disorders that cause joint, skin, and tissues issues (The Ehlers-Danlos Society, 2024). Four participants recounted disordered eating, three of which also described Avoidant Restrictive Food Intake Disorder (ARFID), a food-limiting eating disorder characterized by lack of interest in food and/or sensory sensitivity (Eddy, 2023). Two participants reported possible borderline personality disorder. Six of the seven participants had neurodivergent diagnoses such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) and were currently or had previously been obese. Other reported medical conditions included irritable bowel syndrome (n=1), diabetes mellitus (n=1), postural orthostatic tachycardia syndrome (POTS) (n=1), arthritis (n=2), hypothyroidism (n=1); fibromyalgia (n=1), sciatica (n=1), “heart issues” (n=1), “lung issues” (n=1), and transient ischemic attacks (n=1).

Findings

The following describes the findings of the data analysis in relation to the research question and aims of the study. The research question was: How do NBGD individuals understand and experience health? The study aims included:

- Aim 1: Describe how NBGD individuals define health.
- Aim 2: Explore factors that affect NBGD individuals’ experience of health.

Aim One: Describe How NBGD Individuals Define Health

At the beginning of each interview, participants were asked to define health in their own words. Each participant’s definition of health reflected their lived experiences and current state of health. Most participants noted the different components of their health, two coupled their definitions of health with the activities needed for them to feel healthy, and three participants included the impact of chronic illness. Definitions varied but all participants described health as comprising of mental and physical attributes, with two participants including emotional (Sam & River) and two participants including spiritual (Alex & Deb) elements. They also shared the intrinsic connection between their physical health, mental health, and their lived experiences.

Blake (NB/TM, H/T) and Deb (GNC, S/Hr) (see Table 2 to review participant descriptors) highlighted this connection while also describing the influence of healthcare providers. Blake explained how every aspect of his lived experience affects his health:

> So, it's kind of all of those intersections as well as like, when it comes to mental health, not only how my provider and I work together but then, how I interact with the world, right. Like how everything around me affects my mental health as well as like, then that affects my physical health. So, really health is a broad term, and little facets affect everything, all the time.

Deb expressed the intrinsic connection of her physical and mental health as a holistic experience and described the significance of healthcare interactions:

> I'm more of a believer in a holistic approach, body, mind, spirit. Mental health certainly affects physical health and how we are treated or not treated among healthcare professionals can play out in so many ways. Not just how we feel inside about ourselves or anyone else, but if we ever return for treatment or if we have trust in what we're doing or encouraged to do.

Avery (DG, S/T) and River (NB, T/T) coupled their definitions of health with the activities needed for them to feel healthy. They included the need to find balance and how sometimes that can be difficult. Avery stressed the importance of sleep in her definition of health:

> It's finding that balance between physical and mental wellness, which is easier said than done, right? Having healthy emotional, physical coping skills, things like that. Physical health to me would be, you know, different forms of selfcare, like having good sleep hygiene, you know, getting enough sleep, having a healthy sleep schedule. You know,

> incorporating things like physical activity, listening to my body, you know, knowing when I need to eat or when I need to take a nap or like if I've had too much caffeine that day, you know what I need to do to help myself regulate better.

River echoed Avery's thoughts:

> Physical health. So, like, the regular physical stuff and then also like mental, emotional health. I think that all relates. I think it's just a combination of like physically taking care of yourself, making sure you have the right nutrition, amount of exercise, and then also mentally taking care of yourself, making sure that you have proper rest, proper self-care, stuff like that.

For Sam (NB, T/T), Alex (GV, T/T), and Jesse (NB, T/S), their definitions of health were shaped by their experiences living with chronic health conditions. They revealed how these conditions impacted the way they perceived their health and their ability to live their day-to-day lives. This was reflected in how Sam defined health through the lens of illness and isolation:

> How sick or not sick you are, but health can be physical and emotional and mental health. Relationships are [part of your total health], but I think that also plays into emotional and mental health… I don't think isolated people are healthy.

Sam's sick-focused view of health not only influenced their day-to-day experience of health but also shaped the way they perceived and anticipated their health experiences. An example of this came when they shared the good news of a clear follow-up ultrasound only to immediately invalidate that positive experience with a negative one:

> I had a BIRADS 3 mammogram back in April and they were like, it's either cancer or fibroadenoma. We will tell you in six months. [The follow up ultrasound was clear] but instead, they found suspicious moles that I have to go get removed, so it all balances out.

Alex's definition of health similarly reflected a focus on illness by revealing that they accept a baseline of health that is not the same for people without chronic illness. They shared, "If you have disabilities, like chronic illnesses like I do, health looks different for me than it would for someone who doesn't have those." Alex further expressed the burden of masking their chronic health conditions and having to hide their pain and needs:

> People actually think I'm this really positive, happy all the time person…they don't realize inside I'm like having, you know, horrible thoughts to hurt myself or die or whatever…it's such an energy drain to try and mask all the time.

Alex went on to use Spoon Theory to describe the impact of living with chronic illnesses daily. Spoon Theory is a metaphor sometimes used by individuals who suffer from chronic illnesses to represent a measure of the amount of mental and physical energy available to expend at any given moment (Miserandino, 2003). Alex explained how Spoon Theory manifests in their life:

> So, it's a lot of like ignoring the dizziness when I stand up or when I start walking and being cheerful and smiley, instead of dragging my feet like I really want to do. Dressing well, you know, being clean, even though I have no spoons to actually shower and go to work on the same day…. I have an awesome partner so I can just say to them, sorry, I've got one spoon left. If I cook, I'm going to be at negative spoons. If I clean, negative spoons. What do you want me to do with my one spoon?

Jesse, the third participant to relate their definition of health to chronic illness, also acknowledged Spoon Theory when comparing their physical and mental health to bars in a video game:

> Just kind of my physical and mental status… I like viewing my health like in bars in a video game. I've got my mental and physical parts of the bars. Some people talk about

> spoons... I've got my little mental and physical health bars...just kind of tracking my status.

The participants' definitions of health revealed the intrinsic connection between their physical and mental health, the ways in which they feel like they can influence their health, and the impact of chronic conditions and healthcare experiences. As they shared their stories, it became clear that their health was much more intricate and nuanced and was deeply influenced by their lived experiences. The following highlights the key factors that influenced the participants' experiences of health.

Aim Two: Explore Factors that Affect NBGD Individuals' Experience of Health

To address aim number two, emerged themes were examined across cases revealing 34 themes and health conditions common to the majority of the participants. Connections and patterns between the themes and health conditions were considered and an initial five higher order themes were identified, *gender as a salient narrative*, *finding support and validation for gender*, *healthcare trauma and/or bad experiences*, *family and interpersonal trauma*, and *the impact of gender experiences and trauma on the body*. After further consideration of these themes, it was determined that a higher level of abstraction was required. A follow up review of initial coding, the participants' definitions of health, and investigator field notes was conducted. Subsequently, the higher order themes *gender as a salient narrative* and *finding support and validation for gender* were collapsed into the theme *Gender*. The significant supporting themes related to gender were then subsumed into *relating to others*, *lack of peers*, *unsupportive parents*, *assumptions and binary cisnormative healthcare*, and *support and validation*. The themes of *healthcare trauma and/or bad experiences* and *family and interpersonal trauma* were combined into the theme *Trauma*. The themes of *gender* and *trauma* were then combined with *the impact* *of gender experiences and trauma on the body* into the overarching theme, *The Body Keeps the Score*. *The Body Keeps the Score* reflects the profound way the participants' lived experiences were stored in their bodies and manifested in their physical and mental health. *Gender* and *trauma* represent the two most significant factors contributing to the participants' experiences of health. See Appendix N for the thematic analysis summary.

The participants directly and indirectly named their lived experience of health as *The Body Keeps the Score*. The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma is a book by Bessel van der Kolk, M.D. (2014) which describes the ways in which human bodies hold on to previous traumas and manifests those traumas in physical, mental, and emotional symptoms as well as impacting responses to future stimuli. The participants' stories reflected this, by revealing how life events contributed to their overall mental and physical health, with each experience building upon previous ones, creating their current state of health and impacting their perceptions of new experiences. They began by sharing childhood events and trauma that laid the foundation for their health. Those foundations were then built upon by their day-to-day lives, including interactions with healthcare providers. Alex (GV, T/T) and Avery (DG, S/T) directly mentioned Dr. van der Kolk's book. Alex shared that their trauma response often includes panic:

> Are you familiar with the book, The Body Keeps the Score? So, it's like that, in your body. The triggers may not, you know, bring back actual memories of it because trauma short circuits your short-term memory and it's harder to hold on to those memories because they were too scary, you know? So, it's mostly just physically in the body like tension or sadness or panic. Panic's a huge one for me.

Avery related discovering she had been holding on to trauma from a childhood sexual assault after starting pelvic floor physical therapy:

> I did pelvic floor PT… just realizing how much like tension and trauma was like built up there and like how I didn't know was there until I started to actually like working and releasing tension from that part of my body… like you know The Body Keeps the Score, right? Your body holds on to trauma and certain ways your nerve endings and muscles literally contract based on repetitive stress and stay that way but experiencing that was definitely a new perspective for me… But you know, when something's there for so long, you kind of accept it as your normal.

Blake (NB/TM, H/T) indirectly portrayed his body keeping the score, as "taking hits." The hits he experienced were the result of experienced fear and discrimination related to his gender. He emotionally shared the fear he feels navigating the world and the toll it takes on his physical and mental health. He compared the hits building up to the accumulation of debt and that the healthcare system, seemingly a safe place to find support, often is not:

> So, like at any given moment, I'm prepared to have a mental health or like a physical health crisis of like being stabbed or shot or whatever. And then that all taxes on your mental health… my mental, my physical health are so intertwined that those things are just like riding a roller coaster differently all the time. Then, that burden that you have to bear for the lack of knowledge in the healthcare community is so intense that it holds you back from seeking out healthcare. So, then again, mental health hit, physical health hit, and it just keeps hitting you back, and then it's like those hits that you need help with, you get deeper and deeper and it's just like when you dig yourself in debt, right. Like I'm in a mental and physical health debt that I can't dig out of because what do you do? If I

> reach out for help, you don’t know the hand that’s gonna come help you. Like, is it gonna be a friendly one or is it someone who’s going to push you under the water and try to drown you?

Jesse (NB, T/S) disclosed how their body keeps the score through sharing the long-term impact of the trauma of being sexually assaulted by an acquaintance, “It’s always lingering in there. It’s hard to fully get rid of it.” Other participants indirectly revealed how their bodies keep the score by sharing life events and relating them to their current health and experienced symptoms. Through the sharing of these life events, they revealed two significant factors that contribute to their experience of health and their bodies keeping the score, *gender* and *trauma*.

Gender

As their stories unfolded it became clear that gender was a salient narrative that framed their lived experiences and influenced their overall health. Gender played a role in their growth and development and in their ability to navigate the world around them. Gender-related factors that contributed to their bodies keeping the score were (1) *relating to others,* (2) *lack of peers*, (3) *unsupportive parents,* (4) *assumptions and binary cisnormative healthcare*, and (5) *support and validation*. Participants described difficulty understanding who they were in relation to other people and the impact of growing up without examples of NBGD peers with whom they could identify. Their stories further revealed the influence of unsupportive parents and the effect of assumptions and binary cisnormative expectations in healthcare spaces. While these experiences led to feelings of isolation and invalidation, the participants also shared the ways in which they found support and validation.

Relating to Others. River (NB, T/T) shared how gender affected their lived experience from a young age. Their earliest memories about gender were an inability to relate to their peers and to the concept of gender. River's peers who were also assigned female at birth (AFAB) seemed to be comfortable with what it meant to be a woman, sharing similar behaviors, clothing, and feelings about the world around them:

> I didn't understand why I didn't fit in with other people. I tried my best to like fit the role, like you know, do like the girly stuff. I was feminine in high school because I was trying to like fit the thing that I thought I should. I guess I didn't even like consider that there was an option other than doing that…

River, however, did not understand what it meant to be or feel like a woman. This incongruence led them to perceive gender as a performative act. By adulthood, River realized that they could not continue to "act" like something they were not and began to explore what this meant for them:

> I just didn't ever feel like I really understood what it meant to be like a woman. I didn't relate to those feelings that people would say, like with the sexuality side of it, but also the gender side of it. I just didn't feel like I could relate to anybody… So, I just thought I was like having weird feelings because, you know, that's how everybody feels. But then growing up and realizing like not everybody is like putting on an act. That was when I was like, OK, that's something I should unpack.

Jesse (NB, T/S) voiced similar struggles understanding the behaviors and conversations of their peers who were assigned female at birth. Jesse however, associated their inability to relate to a preference for activities normally associated with individuals assigned male at birth:

> I got along with the guys better than girls a lot of the time. Just probably more because I like playing video games and having similar interests and the girls were all on the same sports teams and all those kinds of things and I had absolutely no idea what they were talking about, ever.

Like River and Jesse, Alex (GV, T/T), who was neurodivergent, voiced difficulty relating to gender norms and expectations. For Alex, gender was an obligatory concept that created expectations around their body that they could not relate to and felt arbitrary and unnecessary:

> I think it’s rather common in people who are autistic to find the whole gender idea just kind of like, society’s idea of gender, if you have these body parts, you have to act and behave and wear and do these specific things, it’s just like really meaningless… and autistic people and neurodivergent people in general tend to find these rote behaviors and expectations just very strange in general.

In addition to expressing difficulty understanding the concept of gender, Alex included the impact of the pervasiveness of gender; expressing frustration with the limitations placed on people that have little to do with their capabilities or who they are as a person:

> Just being a human with body parts that society has expectations about is just really difficult to navigate sometimes… We have so much focus on the future and having to fit into certain paradigms like, you know, there's this expectation that you're going to find a career and stay in that career and advance in your career and then retire. And then, at the same time, it looks different based on your body parts. And that has an effect on people's mental health and wellbeing as well.

Lack of Peers. The participants inability to relate to others and to the concept of gender was reinforced by the absence of diverse gender representations beyond normative binary cisgender individuals and a subsequent lack of terminology with which to describe themselves. This scarcity of relatable examples hindered River's (NB, T/T) exploration of gender identity and made it challenging to form connections with others, leaving them isolated:

> I didn't really know any queer people or trans people growing up… I thought about it, but it was more like everybody around me was so like cis and straight, it just wasn't a consideration for anybody… I felt like, OK, well, if I'm not a man, then I must be a woman. I didn't even know anything else existed besides that.

Avery (DG, S/T) described a similar struggle with finding others with which to relate and a lack of terminology with which to describe herself. Growing up, she had a vague idea that the LGBTQ+ community existed but only related to sexuality. So, for her, her gender identity was not a consideration:

> I'm a 90's kid so it was more focused on like specifically gay and lesbian people and that was pretty much the extent of my exposure… I identify as kind of a woman but like, I didn't have the terminology.

Blake's (NB/TM, H/T) exploration of who he was also began with an awareness of sexual orientation. Through therapy, Blake came to realize that his gender was part of the reason why he felt different from other people. At that time, his knowledge of who he could be was limited to the binary transgender identities for which he had been exposed. It was only after further exploration that he realized he could be something different. He shares how he initially felt limited by binary transgender expectations, thinking he had to be a transman, even though that did not feel right to him:

> Back then, I was using only he/him pronouns… I felt like at the time I had to pick, like it had to be. You can be a girl, or you could be a boy. Everybody wanted you, if you were trans, you had to pick one.

Deb (GNC, S/Hr), who recently discovered a distant cousin was also gender nonconforming, summed up the feelings of isolation and invalidation felt by the participants' lack of peers with which they could relate. "This sure as hell would have been nice to know back then. You know what I mean? That there was somebody else who had something similar and all this other stuff… [I would have felt] like I belonged."

Unsupportive Parents. The feelings of isolation felt in their peer groups were further strengthened by a lack of support and validation from their parents, delaying the normal exploration that adolescents and young adults engage in regarding their gender. This delay and lack of understanding also significantly impacted their mental health. River (NB, T/T) and Avery (DG, S/T) best described the feelings of the participants. River shared how their home was not a safe place to explore their gender identity and how that impacted their mental health:

> I grew up in a home that wasn't like accepting so it wasn't like a safe place to like explore that stuff, you know… My mom barely started understanding the sexuality thing, so she definitely doesn't understand the gender thing… same with my dad… And I went to a Catholic high school, that was also another factor. And I think like that was part of the reason my mental health was so bad. It was just not being able to understand those kinds of feelings.

Avery (DG, S/T) added that, although her parents tried to understand who she was, their inability to accept her identity had a negative impact on her health:

> My family tries but does not understand… I identify as queer as does my sister and that's been a point of contention with my parents for like, as long as we have both been out and that kind of very negatively impacts my health because you know, not feeling understood or helped by my parents, you know, that sucked.

Assumptions & Binary Cisnormative Healthcare. The participants went on to describe how interactions with the healthcare system further invalidated their gender and personhood. They described being made to feel invisible by gender-based assumptions and the gendering of healthcare spaces. For them, healthcare encounters were framed by healthcare professionals' assumptions about their identity and their failure to inquire about who they are and what their needs might be. River (NB, T/T) expressed a lack of consideration for their very existence:

> People just like assume when you present a certain way like, you must be like male or female, no matter what, even if you look pretty androgynous. They don't think of someone who's not like actively identifying as a woman… It's not like they are trying to exclude me, it's just like you can tell that it wasn't even a thought in their mind.

River depicted how the lack of consideration for their personhood was further exacerbated by the gendering of healthcare spaces:

> Especially like when it's related to like… the gynecologist, they're very gendered, you know like, they very much speak like women's health, like it's called a women's health center, you know, so that can feel super uncomfortable… [and] the terms they use at the gynecology office like are just so gendered… it tends to make you less proactive [about your health].

Alex (GV, T/T), echoed River's sentiments about gender-based assumptions and added another layer of complexity. They shared that, in addition to assuming who a person is and what their needs might be, providers further miss the nuances of gender dysphoria and the significant impact it can have on an individual's experience of health:

> They attribute whatever I'm experiencing to being a female. It's just in your head or you're a woman, this is normal for a woman. There are very, very few medical professionals who even ask you what your gender is, and they assume that what you physically look like is your gender and that you're comfortable with it… I wish a doctor had been more cognizant of not assuming that I'm comfortable being this person in this body.

Jesse (NB, T/S), who like Alex is neurodivergent, communicated a similar frustration with gender-based assumptions in healthcare. Jesse shared their journey to discovering why, their whole life, they felt like they were a "weird person" who "could not understand people." They described how gendered research and healthcare delayed discovering their neurodivergent diagnosis:

> Someone assigned female at birth who has had to deal with ADHD doesn't exist. Female autism doesn't exist. All these different health issues… it's oh, you're a woman, so that's just normal. Or you could just listen to me for a minute… There's a lot of doctors that just assume… especially men.

Jesse added that, in addition to the lack of knowledge around the health experiences of persons who are assigned female at birth, there remains an undercurrent of misogyny in healthcare spaces. Jesse voiced feeling not listened to, a sentiment shared by the majority of the participants:

> I'm still being told I'm not allowed to do what I want with my body… [I get asked], What does your husband think? I made an appointment specifically to talk to you about

> this thing, and you barely took the time to acknowledge me or make eye contact or listen to a word I said. Ah, it's just so frustrating… At doctor's appointments, it's become increasingly difficult to not just yell at people that I don't want any of this and navigating who will even listen to me. No one listens to me.

Frustrations with gender-based assumptions were expressed by every participant in the study. When describing these frustrations, they often added that gender-based assumptions were not experienced in isolation and were frequently combined with other assumptions that significantly impacted their healthcare experiences. The most common one described by the participants was assumptions about weight. Avery (DG, S/T), who had been an athlete most of her life, shared an instance when she had to convince a healthcare provider that the pain she was experiencing was due to something other than her weight:

> He was immediately under the assumption that because I was a bigger person now doing a sport, oh, your back hurts you just because you're not used to exercising and I tried to explain to him, like I've been exercising consistently for years. I took a break from Derby for two weeks and came back and this pain is starting and it's not like a sore muscle pain, but I don't think that got through to him ever, and he then just out of the blue, without explaining why, asked me to touch my toes… So, it was almost like I had to prove that I was flexible, and I was athletic instead of him just believing me.

For Sam (NB, T/T), providers making assumptions about their weight was a frequent occurrence. It often delayed treatment and made them feel dismissed and not believed. Sam described one instance when they had a lipoma on their back that was causing incontinence, pain, and leg weakness:

> It took me a good six to nine months to get anyone to do anything or even look at it because it is just because you are overweight. I felt very written off. I feel like I am the expert on my own experience. You can't tell me whether or not I'm in pain. I can. I'm the only person that can tell you whether or not I'm in pain. So, having doctors not even be willing to look at it, I felt very dismissed and not believed.

In addition to weight bias, Sam (NB, T/T) related several stories about how their gender impacted their healthcare experiences. They spoke with a tone of frustration as they shared a story about a healthcare provider at an LGBTQ+ clinic which, on the surface, is a safe space for NBGD people. The provider misgendered them and their wife and used incorrect pronouns, despite being corrected. This experience highlighted the invalidation in healthcare settings described by several of the participants:

> He managed to misgender both of us. My wife is a cis woman. She is a butchy lesbian but still cis. He used they/them for her, the entire appointment, even after she corrected him twice. He didn't even ask my pronouns and used she/her for me the entire visit… So, how you present must be your gender. Because my wife has buzzed hair, if one of us is going to use they/them, it obviously is going to be her.

While sharing her story, Deb (GNC, S/Hr) frequently expressed her frustration with the binary gender narrative, including binary transgender normativity. So, for her, frustrations with healthcare and gender centered around the binary narrative that is reinforced by medical forms:

> Only more recently has there been any other option other than male or female but, then [the choice is] nonbinary, blah, blah, like nonbinary is binary… so I just put gender nonconforming… I didn't wanna be put in that type of box… And when things evolved

> as far as being transgender, like to me that was the same kind of box that they're talking about and I didn't want to be in that box [either], it's really frustrating.

Unlike the other participants, Avery (DG, S/T) portrayed gender as having a limited influence on her healthcare experiences. She attributed this to her appearance and the privilege that comes with passing as a cisgender person.

> I pass as a cis person, so I think a lot of times people just assume that and because of that it doesn't impact me or give people the chance to maybe negatively stereotype or act on an assumption. I do use she/they so, for me, if people use she, that's fine. So, I think in a lot of ways, because I have these privileges, maybe I haven't had to think about the connection much.

Support and Validation. While binary cisnormative gender expectations caused the participants to experience isolation and invalidation, many of the participants were able to cope by finding support and validation in counseling and by finding like-minded people and safe spaces. Avery (DG, S/T) and Blake (NB/TM, H/T) described the validation they found in counseling. For Avery, finding a counselor who understood her gender identity provided her with a supportive parental surrogate:

> I feel validated, so like how I was talking about earlier, like sometimes I don't feel supported or understood by my parents. Like, I think she can kind of fill that gap for me because she is an older woman, like she could be my grandma. So, I have like that wiser adult figure who's able to like understand my gender identity, understand the fact that I'm queer a lot more, and I have someone who is able to give kind of like that older adult parental type of guidance in a way that doesn't have judgment around it.

For Blake, taking the time to find the right counselor played a crucial role in helping him figure out his gender identity:

> And then there was me discovering [my gender identity]. At the time I was female identifying, so I was in a what presented as like a lesbian relationship and trying to figure out my sexuality there, and then it was gender. And I'm like, this doesn't fit. I don't feel like this, and really discovering that, so going on that journey with like two or three different providers and then finally finding one that was like, no, it's OK, like all of these things, these pieces and parts of things that you're finding. She's like, you know, there's a term for that. And like it's normal. There's nothing wrong with you.

Alex (GV, T/T), Avery (DG, S/T), and Jesse (NB, T/T) expressed how they find support and validation by gravitating towards like-minded people and safe spaces. Alex explained the reasons why one of their favorite places is a safe space:

> I tend to gravitate more towards environments that support me as a person. And, like one of my favorite places to go they tend to ask what your pronouns are. They welcome you as a human being and not necessarily one gender or the other, or they don't really have any expectations of you, and they're happy to help you out with their service. I tend to shy away from places where that isn't really done.

Avery expressed finding an unspoken understanding and comfort with a group that consisted solely of queer and neurodivergent people:

> We all did improv in the same troupe. We all just support each other and we're all neurodivergent, so I think that helps. We've kind of cultivated this safe space amongst each other that you know, we're all queer. We're all neurodivergent… We all are kind of

> under this umbrella and I think it gives us a like unspoken understanding of each other and like how we work.

For Jesse, their solace was found at drag shows. Jesse shared how drag culture not only provided them with safe spaces, but gave them a way to express themself while taking away the fear of judgment:

> I feel like drag is helping me find ways to express myself without feeling like I have to match or fit in anywhere versus just getting dressed to go to the grocery store. I'm like some people are gonna perceive me. I have to figure out how I want to be perceived today and I don't like it versus when I'm putting on a show.

Through the sharing of their experiences, the participants revealed how the binary normative structures within their environment created an internal struggle, invalidated the possibility of their identity, and delayed their ability to understand and define their identity. Although there were differences in their experiences, a comprehensive picture emerged of the impact of gender on their lived experiences of health. Gender was pervasive in their families, communities, and healthcare settings. They experienced a lack of others with whom they could relate, an inability to position themselves in society, and the stress of binary cisnormative, transnormative, and gender-based expectations. They felt isolated and struggled to understand why the rest of the world didn’t understand gender the way they do. Their experience of gender framed how they interacted with new experiences and created a foundational health status not experienced by those who conform to cisnormative and heteronormative expectations. This foundational health status was further built upon by the participants’ experiences of trauma.

Trauma

All seven participants experienced varying degrees of trauma, either as a child, as an adult, or both. Their stories revealed the profound impact these experiences had on their physical and mental health. Manifestations of their traumas included PTSD, depression and suicidality, anxiety, chronic pain, and disordered eating. To best reflect the participants' powerfully recounted lived experiences of trauma and the overlapping nature of those traumas, the following findings are presented in a narrative format as opposed to discrete categories.

Pervasive Childhood Traumas: The Stories of Sam and Alex. Sam (NB, T/T) and Alex (GV, T/T) disclosed stories of pervasive physical and psychological traumas that occurred throughout their childhoods. They related unstable and unsafe family units and early awarenesses of violence and illness. Their experienced traumas had a lasting influence on their physical and mental health. Sam, who now receives ketamine infusions to cope with subsequent depression and PTSD, shared:

> I grew up in a very abusive household. My stepfather was heavily abusive to all four of us. I have a scar over my right eye where I got 30 stitches from him throwing a pop can at my head in the 4th grade. He threatened to kill my brothers and I and chased me with a butcher knife when I was in high school.

Sam further described the impact these traumas had on their brothers. As they recounted these events, the effect their brother's experiences had on Sam was revealed in the emotional manner in which they shared the events:

> The oldest [of my brothers] was five years younger than me and when he was nineteen, he was murdered on Christmas Eve. The middle brother, who is now the oldest, is on heroin, meth, cocaine, you name it. He says he's clean, but he doesn't act clean. The

> youngest was an alcoholic, killed his best friend in a car accident on Halloween and spent two and a half weeks in ICU and ended up going to rehab and is now sober but he has lifelong disfigurement and disability from it.

In addition to physical and psychological abuse, Sam was further traumatized by the events surrounding their mother's sexual assault. Sam describes their mother's sexual assault as the way they learned about sex:

> I got the sex talk because my mom got raped when I was in the fifth grade, and they had to explain to me what the evening news was talking about and why there were news crews on our front lawn. It was a kind of surreal thing, so they played the security footage that happened when she was at work on the evening news every night trying to find this guy. And we had news at our home, and we had news crews in our front yard. My mother has PTSD. She completely shut down and my stepfather encouraged her to not get treatment.

These and other traumas led to Sam leaving their childhood home at a young age, ongoing estrangement from their family, and chronic health conditions. In addition to depression and PTSD, Sam reported anxiety, panic attacks, and struggling with obesity. And, as revealed in Sam's illness-focused definition of health, these traumas also framed their outlook on life, giving their stories negative connotations and negating positive outcomes.

Although the circumstances were different, Alex (GV, T/T) also experienced extensive childhood trauma. They reported experiencing neglect and abuse at the hands of their mother that continued until they moved out when they were in their early twenties. Alex described their first memory of physical abuse. They remember it as their mother being frustrated with them for expressing their needs as an infant:

> I remember like being in my crib and my mom picking me up and shaking me out of frustration, probably because I was crying and needed a diaper change or food or something and it’s more, it’s more of a memory of a feeling, I remember being picked up by her and I remember being shooken and not understanding what was going on and being scared.

Like Sam, the abuse Alex suffered at the hands of their mother was exacerbated by their stepfather’s physical, psychological, and sexual abuse:

> They were probably the worst nine months of our lives… like actual physical torture… everything was just scary and bad… This tooth is missing because he stuck a revolver in my mouth and whacked the back of my tooth… he would pin us down with martial arts, pull guns on us, yell at me scaring the crap out of me when my mom is locked in a room and he is outside pounding on the door and practically breaking it in, and like if I move, the tension gets turned on me. And then there was also sexual abuse… It was nine months of hell. My mom got very, very sick… so I couldn’t get away from him. After my mom kicked him out, he continued to stalk me for nine years. I would work on [my mental health] and then he would do his moment of stalking and then I would be right back to where I was.

The impact of the abuse Alex suffered was compounded by neglect and having to care for their mother from a young age. Alex recalled an instance when they were five years old:

> I had to take care of my mom a lot growing up. Like, when I was five, she had pneumonia, and she refused to call 911… so I had to watch her struggle, and I had to figure out how to cook for myself and how to make what she needed. So, sickness was something I learned to think about pretty early on.

The long-term effects of the traumas Alex experienced as a child were wide-ranging and were expressed in their physical and mental health as well as their relationships. They struggled daily with chronic pain, PTSD, depression, anxiety and panic attacks. Alex also described searching to find a sense of security and the need to partner with a person who would advocate and stand up for them; two crucial things that were missing from their childhood. Perhaps the most positive thing to emerge from their trauma was a deliberate intention to be aware of how they respond in situations so as not to perpetuate the traumas they experienced growing up, a sentiment shared by several of the other participants:

> I try to take a step back and look at it from someone else's perspective to see if the way I'm interpreting it is the way that it's actually happening, or if it's healthy and appropriate, or if maybe something else is happening, so that I can respond in a way that I want to, because my intention is to respond with kindness and compassion, no matter what. It's not always easy to do in the moment, but I try. That's my game. But it's also part of my practice of learning how to separate myself from the conditioning I grew up with.

Degradation and Disordered Eating: The Stories of Blake and Avery. Several participants reported disordered eating that arose from their childhood traumas. Blake (NB/TM, H/T) and Avery's (DG, S/T) stories best exemplified the relationship between the participants' experiences of trauma and their unhealthy eating patterns. Blake, who was the oldest of three siblings, shared how, throughout his life, he was made to feel unworthy of love and was often the target of his father's anger and verbal abuse. Significantly, his coming out to his family was received much differently than it was for a younger sibling. As described by Blake, the disparity in this instance was representative of a lifetime of feeling less worthy than his other siblings:

> It's funny because I'm the oldest and my youngest sibling just came out as nonbinary and is talking about possibly like taking T (testosterone) and things like that. And it was received very differently. When I did it, it was just cut your hair shorter. Just be a lesbian. Just wear masculine clothing, and now they're doing it and it's, we're fully in support. If you need top surgery, we'll help pay for it. I'm like OK, so it's been a routine like, that's how it's been for 37 years.

In addition to feeling less loved and supported by his parents, Blake was verbally abused by his father. During his parents' tumultuous divorce, his father's anger with his mother was often redirected at him during family meals. For Blake, the result of this treatment was a pattern of disordered eating and feeling the need to earn food:

> It would be my dad and my mom starting to argue at dinner, and then my dad would redirect it… so he would sit there and make fun of me. Or like just make me feel really bad until I wouldn't eat dinner and he'd be like, just go to your room if you're gonna pout. Well, you're telling me I'm fat. You're telling me I'm stupid. You're telling me I'm all these things… I'll do the thing now where like if I'm having a bad day… I'll not eat or I'll go days where I forgot to eat. So, if I had a bad day, or I didn't do well at work… then at night I hyper focused on cleaning or things that I thought needed to get done that could have waited instead of eating because it's like a system where you feel like you have to earn it.

Although he didn't understand it at the time, the turmoil in Blake's home life left him feeling like he had to earn love. He related several stories of how he pathologically felt the need to put other people's needs first and to care for and protect the people he loves. Several of the stories he shared revolved around caring for and protecting his sisters. An early instance of this was when he was in kindergarten. His innocent assessment of the prevailing issues in his family led him to attempt to protect his mom by providing care for his new sister:

> When my mom was pregnant, I told everyone at the school that I had to quit school to take care of my sister. I was like telling everybody because my dad worked a lot. While he was, I didn't know at the time, but he was cheating on my mom. And I was like, I'm gonna have to quit school because I have to go home and take care of my sister.

Blake’s need to protect and care for his sisters was so substantial that it led to him experiencing sexual abuse at the hands of an older male cousin. He described the first instance when he and his sister were left alone with the cousin, and he engaged with the cousin to protect his sister:

> I walked into the room and my sister, that's 22 months younger than me, was in there with him and he had her pants off… I was like, what are you doing? And he was like really taken aback. And then it turned into essentially, like I don't remember the exact words, but it was like either he was going to do that to her, or it was going to be me. So, like I walked (her) out of the room and sat her down with toys and went back in there and he was like early 20s, late teens and I would have been like seven.

Now, as an adult, Blake recognizes the impact that his childhood traumas have had on his mental and physical health. He described choosing abusive relationships that mimicked his parents’ relationship, chronic anxiety, depression, panic attacks, and suicidality, and a deep-seated fear of male healthcare providers:

> If there are things wrong and the option is to see a male provider, I'll opt to not go… or if I go in and you have to go to urgent care and if it's a male provider I will leave before I

> will be seen. I'm like, I will go home and die at home before I go get seen at an urgent care with a male provider.

Like Blake, Avery (DG, S/T), who also experienced childhood sexual abuse and had a parent that was critical of her appearance, recalled the first time she remembered her mother mentioning her weight:

> I remember my mom bringing up Weight Watchers at like 10 years old and being like, oh, I think this is something you should do because you're not healthy and you need to be more healthy… My mom's views of health are very like, skinny, thin focused and very fat phobic. So, like if you're fat, there's no way you could be healthy.

For Avery, the impact of her mother's comments was extensive, influencing her self-worth and reinforcing her struggles with her gender identity. She related feeling as though she was always doing something wrong and somehow needed to "fix" who she was:

> I immediately felt like I was doing something wrong… I didn't take it as I just need to improve myself. It was more. I took it as here's what's wrong with you and here's how you can fix it… And it also kind of reinstalled this idea of like, oh, I'm not really a girl properly because I'm not thin.

Over time, Avery began to associate being thin and food restriction with being healthy and successful. "I kind of grew up with this mentality of like if you don't eat as much or you eat a little, that's a good thing and should be rewarded." When Avery left home for the first time and was struggling to build her life and identity, food restricting became a way for her to feel like she had control of her life:

> I was restricting food a lot because I had control over it… I used that as a means of controlling my adulting but also controlling things like anxiety. So, like if I had a bad

> anxiety day, as a means of like feeling like I was in control, maybe I would restrict that day. Or like if I was out with friends on the other side of the spectrum, you know, if I was out with people socializing, I would use that as an excuse to eat. And because I wasn't really eating on my own time, my body was telling me to make up for it. So it was kind of this weird, like I don't want to say punishment or reward system, but that's the only term I can think of really, because I did develop a pattern over time as I like, put myself out there more and made friends that if I was around people I then had permission to eat because I was rewarding myself.

In addition to disordered eating, Avery struggled with anxiety, chronic pain, and obesity because of her childhood traumas. As she got older, she began to consciously work on having a better relationship with her body and with food. Part of that process was to “rebel” against her mother’s expectations for her body:

> Like being OK with having more weight on my body, body modification. And umm, you know, I have tattoos. I have piercings. I dye my hair funny colors like, I feel like I've had to find different opportunities to allow me to have control in a more positive and constructive way. So doing things like exercising because I want to or like using it as a healthy coping mechanism if I'm like really mad or upset. You know, eating a salad because I want to, because it tastes good. Not because I feel like I have to or, eating something else besides salad. Things like that.

Avery wasn’t the only participant to express their identity through body modifications. All of the participants had body piercings, tattoos, or both and many of the participants had haircuts and hair colors that signaled them as members of the LGBTQ+ community. Blake

(NB/TM, H/T) revealed the importance of body modifications when he described the impact of having to remove his piercings for a new job:

> I interviewed via teams with them like I didn't visit the site, so they didn't like actually know. My first day on site, like I normally have my nose piercings and all of that, I had to take it all out. That's just their company rule, so I had to, like day three of my job, I had to walk in and, essentially like that is part of my queerness and I had to like, take it all off. So, essentially stripped of being queer. And I was like, really, really naked. Like I don't like my face now, and that's a whole other thing. Like it's an identity crisis on top of like being in a new place and things like that.

Mental Health Repudiation: The Stories of River and Jesse. For River (NB, T/T) and Jesse (NB, T/S), much of their childhood trauma arose from existing mental health issues that went untreated and undiagnosed. Both of their families denied that mental health was a valid concern or that it could possibly need treatment. Like other participants, River’s mother was critical of their weight and both parents psychologically manipulated them during their divorce. River described their experience navigating mental health with parents who had their own mental health issues:

> Having parents who actively don't believe in mental health but are very mentally ill is a weird thing. As far as back as middle school I was always very anxious, and I would almost like black out because I would have like these really bad anxiety attacks and my mom like for a long time thought it was like something physical and would take me to the doctors like made me do all these things. But then eventually they were like no, like we think it's just anxiety. And she's like, that's not a real thing.

River further explained the immense impact their mother’s behaviors around medications had on their physical and mental health:

> I was put on medicine when I was like pretty young… my mom was always wanting to take me off the medicine. So, it was like I was on it for a while, and off of it for a while, and then like back on it, but I think that like impacted me a lot like physically and mentally because like I would have like physical symptoms like after you stop taking medication, you've been taking a long time. Like you have withdrawal symptoms, you know, and also like, the physical symptoms of anxiety that I still experienced and me not even understanding like cause the doctor's telling me that it's anxiety, but my mom's like, no it's not… That's been something that I've actively had to like really work on in my adult life, you know? Like, I think that that's had like a really big impact on me since I was a kid. And I think finally, like I'm to the point where I feel like I'm more of a stable human. But I think for a long time, like I was very, very unstable because of that… And part of me wanted to just, like, give up and be like, well, I tried, but now I'm glad that I didn't do that (die by suicide).

Jesse (NB, T/S), who as an adult grew to have a better understanding of, and relationship with, their parents, described what it was like for them to struggle with mental health issues with parents who were undiagnosed themselves:

> Mental health wasn't a thing. It was just, people are making it up. It's all fake. They're just getting in their emotions. That's how my mom grew up. So, she definitely did not get diagnosed with any of the things she had… So, I think the first time anyone recognized anything was when my depression got really bad for the first time. Late middle school, I had started cutting a little bit and the school counselor saw my cut and called a meeting

> with my mom... So instead of talking to me about it, pulling me aside, he goes straight to my parent, which is one of the primary causes of it at that time. And then I just get in trouble for it. No one takes me to therapy. No one sets up anything with the doctor. I just get in trouble.

Jesse also described struggling with their weight and body image. Jesse felt a hyper focused attention on their body due to the activities they participated in. In addition, they were given conflicting messages about their appearance and weight from their parents and healthcare providers:

> I was always told to lose weight and watch what I'm eating, but at the same time I wasn't being shown how to do it. I started modeling in middle school and I was a competitive baton twirler from 4th grade all the way through and the end of high school. So, between pageants, baton, modeling, all that kind of stuff growing up, I have people telling me I'm too thin and I have people telling me I'm not allowed to gain weight. So, the unhealthy relationship with food started in middle school.

Jesse shared how the constant critiques of their body left them hypercritical of themself and feeling inadequate, leading to disordered eating:

> Like there was no right answer, like I was gonna fail no matter what. Because when someone’s telling you you’re too thin and go eat 15 cheeseburgers and someone else is telling you you're only one pound away from the max you are ever allowed to weigh. On top of that, it turns out I have ARFID (Avoidant/Restrictive Food Intake Disorder). I don't know if that was developed or if I've always had a texture thing, but I don't know if it just got worse from all my eating problems then, but it just felt like there was no winning because everyone had an opinion and none of them lined up and made sense.

Jesse also described feelings of guilt and being at fault for the things that happened in their life. These feelings came to a head when Jesse was sexually assaulted in college and their boyfriend accused them of being a willing participant and the cause of the sexual assault:

> My whole life is things being my fault. Like I just, I mean, growing up as the eldest child, it was my fault for everything. Anyway, that was already pretty set before anything happened, so it just got worse after that when it was already that ingrained in me. And then the person that you're with says it's all your fault. You're like, OK, well, you just confirmed it.

Profound Neglect and Isolation: Deb's Story. Alex wasn't the only participant to experience neglect in their childhood. Deb (GNC, S/Hr), who was born to teenage parents, described an absent mother and parents that were ill-equipped to care for her and her siblings:

> They weren't really equipped at all, you know, to take care of kids or anything… My aunt would come by and check on me or my sister to make sure we either had food in the house or were being taken care of… It was probably just more neglect, you know.

Deb's lack of parental care led to feelings of abandonment and isolation which were exacerbated by the birth of her siblings. With the arrival of each new sibling, Deb felt more discarded and less important:

> Shortly after she had me, she had my sister… then she was doing whatever she was doing [and not caring for me] and so then maybe like later, like yeah, I forgot about her. And then by that time I was just like, I don't want anything to do with you, you know? And that was most of my, you know, growing up… And then after she had my sister, she had my brother… And then my youngest brother… And she didn't like, really take care of any of her kids… And with my dad, a lot of times I would go with him when he'd go to

> his friend's garages and work on cars… and just kind of hang out there… And a lot of times in the summertime, we used to go to (XX Lake) and he'd bring his motorcycle… And he would take us on motorcycle rides and I'm like sitting in front of him, you know, and then, he would let me ride it… But then you know once my oldest younger brother [was born] you know, after that we didn't, there wasn't much stuff together. So, yeah, I kind of became more distant after that, I guess. And then I just kind of, you know, went into my own little isolation.

Deb's experiences of neglect and isolation as a child led her to search for love and validation through early sexual relationships and later, abusive relationships. Deb described the experience of losing her first romantic relationship and subsequent suicidal ideation:

> The first time I broke up with a girlfriend, and we had been together for like 3 years at that time and, you know, being 13, everything's so drama anyway, and to have been, you know, in a family that I couldn't stand. And then, you know, I had somebody who did accept me, and I was very close to [leave me], it felt devastating. It was then that I first, you know, considered [suicide]. Less than a month later, one of my friends from school was on a field trip and he drowned. And then, like a month later, somebody else who was in my class… hung himself in his basement. And I didn't wanna be a copycat. So that was the only thing that that saved me at that time… But still, that thought and that feeling, you know, carried on for a long time.

As a young adult, Deb found support and acceptance when she became part of a strong lesbian community. Deb described her new community as "gay everything," including work, school, and recreational activities. The community provided her with the family she wished she had as a child. Unfortunately, she later became isolated from that supportive community by an abusive partner:

> I was in a somewhat of a, you know, abusive type relationship, so I became isolated from like the whole community I had been in, and I have always been kind of, you know, a little bit, estranged from my family growing up, you know that that wasn't all that particularly great… And yeah, it was not the best situation.

As a result of her experiences, Deb described life-long mental health issues including depression, suicidality, and PTSD, and at one time, was told she had borderline personality disorder. She spent a good portion of her life severely obese and spent years in a wheelchair. However, in her journal, Deb shared how she had started to heal from her earlier traumas through creating her own family:

> I've been reflecting back more on what my childhood was like growing up, all the coming outs, how 'we' make our own families… I mean I feel really good about how things are in my life right now; they've never been better. But if I think about the road I took to get where I'm at now, I don't know that I could do that again… I went on to see this counselor… for 18 years… It was a huge connection for me within the boundaries of a counseling relationship that probably saved my life. I know it's such an AA cliché but 'to thine own self be true' has been something that has stuck with me for quite some time. Although not necessarily a huge AA fan, though I can't deny it has been helpful, that was like part of my other 'family', besides my 'LGBTQ+" family. I think because a lot of folks were unconditionally welcoming, and I think it's cause they'd probably been to hell and back and know what it's like to be alone/isolate/or whatever the hell else there is when you're no longer or if ever felt like you belonged.

The narratives of all seven participants revealed the profound and lasting impact of trauma on their physical and mental health and how *Their Bodies Keep the Score*. Each participant experienced trauma to varying degrees, whether in childhood, adulthood, or both, leading to conditions such as PTSD, depression, suicidality, anxiety, chronic pain, and disordered eating. Their experiences navigating binary cisgender normative structures left them feeling isolated and invalidated. The impact of their lived experiences of gender and trauma was further revealed through their perceptions of their future health and their requests for healthcare professionals.

Additional Findings

While gender and trauma were the two most significant factors that affected the health of the participants, additional findings were worthy of discussion. During the interviews the participants were asked how they see their future health and what they want from healthcare professionals and the public. What they shared revealed how their health was overwhelmingly impacted by their lived experiences, including their interactions with the healthcare system.

How They See Their Future Health

Many of the participants expressed a negative outlook on their future health, anticipating a decline in their well-being and a shortened lifespan. This bleak perspective demonstrated decreased resiliency resulting from their lived experiences of trauma, the isolation and invalidation of living in binary cisnormative environments, and their struggles with mental health and other chronic health conditions. Interesting patterns in the outlooks of the participants emerged based on their ages and generations, with some outlooks more positive than others. According to the generation classifications by Pew Research Center (Dimock, 2019), the study sample consisted of one person who was Generation Z (River), four Millennials (Sam, Avery, Blake, and Jesse), one Generation X (Alex), and one Baby Boomer (Deb).

The participants with the poorest outlook on their future were Millennials. They expressed feeling like they had limited control of their bodies and their future health.

For Jesse (NB, T/S), a 33-year-old Millennial, their struggle with chronic health conditions colored their outlook on the future and their thoughts about how much they could impact that future:

> That's really up in the air because I'm not optimistic necessarily. I would like to be, and I will continue putting plans in place to do what I can to grow my health both mentally and physically… I'm trying to think positively about my health moving forward but I'm not default optimistic about it just because I know the number of health issues I already have at 33 doesn't bode well for how many I will have as I age… I try not to dwell on it necessarily… I'm also trying to just be OK with where I am in my body.

Sam (NB, T/T), who was a 36-year-old Millennial, and Blake (NB/TM, H/T), a 37-year-old Millennial, echoed Jesse's concerns. Sam shared, "I see my health declining in the future because I do have so many chronic health conditions that I think they're just going to catch up to me." Blake described having a bleak outlook on his future health from the time he was a young adult:

> I didn't really see myself living a long time… in my 20's I was like, it doesn't matter if I live or die, like I really didn't think it mattered at all… For a while I didn't feel like I had any [control over my future health].

Alex (GV, T/T), born in 1978, who was a younger Gen X on the cusp of being a Millennial, also doubted their ability to live a healthy long life, including living long enough to see their children grow to adulthood. They expressed a deep sense of helplessness and feeling as though they had no control over their body and health:

> So, originally, when my youngest was maybe in the second grade, I told myself, I just have to make it until they turn 18 years old. I just gotta make it until they turn 18 years old. So, I really didn't think my health was gonna hold up… I definitely had this idea and still sort of have this idea that when I turn 60, somewhere around there is my due date and I'm going to expire. My body does whatever it does and I don't really have a say in it… I do have dreams about my plans for the future, so it's not like I'm not thinking it out. I just don't know if they'll be able to happen, so we'll see when I get there.

Avery (DG, S/T), who was a younger Millennial on the cusp of being Gen Z, shared a slightly more optimistic outlook on her future health, "I don't know. I think it'll be better. It's just because I feel like I have the tools and I'm slowly getting the motivation to make more changes, and I do have those tools to make more changes."

The two participants with the most positive outlooks on their future health were Deb (GNC, S/Hr) and River (NB, T/T). Deb was a 59-year-old Baby Boomer on the cusp of being Generation X and River was a 24-year-old Generation Z. When asked how she saw her future health, Deb acknowledged that it took time for her to develop a positive outlook:

> Pretty good. I think it's a constant upkeep process. The past five years I've been better than I've ever been, you know all the way around. And it's like, why did it take so long, you know, and just taking a day at a time.

In her journal, Deb reflected more about the difference between the generations and why younger generations may have a poorer outlook on their future:

> More recently, in the past decade or so, there seems to be more allies than ever, more kids coming out earlier, more supports for kids, but more mental health issues. Maybe growing up in an underground gay world gave us a little more resilience? Or maybe, having more supports for our youth, has allowed for more survival and less suicides, but still having the fallout of going through those stages of, not only coming out, but surviving in a world that is far from total acceptance.

Like Deb, River recognized that getting to where they are today and where they see themselves in the future has been a growth process:

> I guess I feel like my health has been, like steadily increasing. I think maybe a few years ago, like it would have been very bad. I think hopefully it'll continue to increase."

River described a turning point was when they started "figuring out my authentic self instead of basing myself off like what other people think it should be… I just feel more prepared to like take on the world… to survive and thrive… living as my authentic independent self."

The participants' perceptions of their future health emerged in interesting patterns based on generational differences and demonstrated the influences of gender and trauma and their bodies keeping the score. While some of the participants shared bleak outlooks and feelings of helplessness for controlling their health, others acknowledged that health is an ongoing process with continuous opportunities for improvement. Healthcare professionals share an important role in supporting NBGD individuals in improving and maintaining their health. The following outlines what the participants asked of healthcare professionals to assist them in living healthier lives.

What They Want

At the conclusion of their interviews, the participants were asked if they could stand on a soapbox and have the world's undivided attention, what they would say to healthcare professionals and the public. They expressed a strong desire for more trauma-informed care, emphasizing the importance of understanding all people's, not just NBGD people's lived experiences, including complex trauma histories that many people carry. Participants also asked for gender-neutral healthcare environments free from gendered symbols like pink gowns and women's health centers, which often make them feel excluded and uncomfortable. They wanted compassionate care that honors each person's wishes and avoids making assumptions based on appearance. Participants stressed the importance of healthcare providers educating themselves about NBGD identities and health needs, rather than placing the burden of education on patients. Below the participants share their hopes for a more inclusive, respectful, and affirming healthcare experience for all people.

Sam (NB, T/T):

> I don't think I need anything special. I think healthcare providers should do better for everyone. [We need] more trauma-informed care and more personalized care because the problems that I've had with healthcare providers are things like… the provider who refused to even shake my hand due to alternative lifestyles. Yeah, like, that didn't need to happen… And, maybe make your gowns not pink and not call it women's health pavilion and not make everything so feminine.

Alex (GV, T/T):

> [Gender] is important. I know a lot of people don't understand it, but you don't have to understand something to honor someone's wishes. And you don't have to be perfect

about it. It’s really more about the attempt… Just making the effort is a huge deal. If someone wants to go by a different name, it’s important to do that because the previous name can hold a lot of trauma… And stop making a big deal about our body parts… we all have body parts, and the body parts are for procreation, as in making new human life so we can continue our species. But they really have very little to do with being a human and experiencing life and just being a human being. So, you know, it really shouldn't matter what body parts we have, but what should matter is that we know how to behave appropriately, kindly, and compassionately with the individuals around us, you know, and that everyone needs to be heard and seen.

Avery (DG, S/T):

Someone else’s identities aren’t your problem. If they want to be called by certain pronouns, certain names, just do it and move on. Just be nice, dude. I don’t like the golden rule because the golden rule always says treat others how you want to be treated but, in actuality, you should be treating someone else how they want to be treated, right?

Blake (NB/TM, H/T):

You have to educate yourself. It’s no different in any field you go into, you have to be constantly learning all the new information... Your entire premise as a physician is do no harm and you’re harming, you’re actively harming people when you don’t have the knowledge and you’re not willing to take care of them.

Jesse (NB, T/S):

I just want them to keep learning because I feel like so many health professionals may technically have their patients’ best interests in mind and their health. But if they stopped learning when they left medical school, however many years ago, and they stopped

> improving and researching and learning more, and they're set in their ways, that's not how science works. That's not how any of this works…. I feel like, especially when it comes to the healthcare stuff, any of the doctors who learn and listen are just drastically better experiences then those who walk in and say, nope, this is how it is…. [It causes] so much frustration.

River (NB, T/T):

> I think it's important to consider like, people who don't fit into those boxes and you know, you can need the same kind of like healthcare but not identify the same way. And it's not just about gender affirming care. Trans people also need all types of healthcare. So, it's important to have like affirming healthcare providers in every field… There needs to be more education on that and more like, just like mindfulness because I think a lot of times people just like assume… especially in like a medical setting. You know, just because I feel like I'm not really like a person who likes to like, educate everybody. Like I would rather people just respect it.

Deb (GNC, S/Hr):

> Don't be an ass… The mental health part in having those, you know, positive connections or experiences with other people can go a long way. You may give them the right, you know, treatment or medicine. But if you're gonna be shitty to them, you know, it's not probably gonna be as effective… The more acceptance, the more empowerment, the better we help ourselves and each other.

Summary

This study sought to reveal how NBGD individuals understand and experience health by describing how NBGD individuals define health and exploring factors that affect their health. The participants' definitions of health included the components of their health, activities needed for them to feel healthy, and the impact of chronic illness. Participants also highlighted the intrinsic connection between their physical health, mental health, and their lived experiences. *The Body Keeps the Score* emerged as the predominant way that the participants experienced health which reflects how the participants' life events contributed to their overall mental and physical health, creating their current states of health and impacting their perceptions of new experiences.

The participants revealed two significant factors that contributed to their experience of health and their bodies keeping the score, *gender* and *trauma*, which in turn influenced how they see their future health. Gender was a salient narrative that was influenced by difficulty relating to others, a lack of peers to which they could relate, unsupportive parents, and assumptions and binary cisnormative healthcare. The participants also shared finding support and validation in counseling, like-minded people and safe spaces. All seven participants experienced varying degrees of trauma, either as a child, as an adult, or both. These traumas impacted their physical and mental health which manifested as PTSD, depression and suicidality, anxiety, chronic pain, and disordered eating. While many of the participants felt helpless to control what they foresaw as poor future health, others acknowledged that there is always an opportunity to affect your future health in a positive way.

The participants provided a clear picture of their lived experience of health and how their bodies keep the score. They shared insight into how healthcare professionals can better support the health of NBGD people by providing trauma-informed care, gender-neutral healthcare environments, and compassionate care that honors each person’s wishes and avoids making assumptions based on appearance. Perhaps most importantly, the participants stressed the significance of healthcare providers educating themselves about NBGD identities and health needs, rather than placing the burden of education on patients.

CHAPTER V

DISCUSSION

Well over one million lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ+) people in the United States identify as nonbinary or gender diverse (NBGD) (Williams Institute, 2021). NBGD people are a disparate group that experiences a higher burden of physical and mental health challenges, disparities, and discrimination in healthcare than cisgender people (Goldberg et al., 2019; Harrison et al., 2012; Lefevor et al., 2019). Compared to their cisgender LGB counterparts, transgender, nonbinary, and gender diverse people experience higher rates of depression, anxiety, suicidal ideation, chronic conditions, poor quality of life, and unmet healthcare needs (Downing & Przedworski, 2018; Ferrucci et al., 2021; Goldberg et al., 2019; Gonzales & Henning-Smith, 2017; Haire, et al., 2021; Harrison et al., 2012; Howell & Maguire, 2019; Jones et al., 2019; Kachen & Pharr, 2020; Klein et al., 2018; Lefevor et al., 2019). While these disparities are clear, previous studies frequently considered binary transgender people and NBGD people an amalgamate, making it difficult to discern the unique health experiences of NBGD people. As a result, NBGD people have been an invisible population in the existing health literature.

To address this issue, the current study sought to build foundational knowledge about the health of NBGD people by exploring how NBGD individuals understand and experience health. The research question was: How do NBGD individuals understand and experience health? The study aims were:

- Aim 1: Describe how NBGD individuals define health.
- Aim 2: Explore factors that affect NBGD individuals’ experience of health.

Interpretative phenomenological analysis (IPA) was employed to meet the aims of the study and answer the research question. Grounded in constructivism, IPA's ideographic perspective was ideal for exploring the unique lived experiences of NBGD individuals (Smith et al., 2009). Referral, purposive, and snowball sampling were used to recruit seven NBGD participants assigned female at birth who had an experience that caused them to explore their health or seek assistance related to their health. Referrals via trusted community members and word of mouth within the NBGD community about the trustworthiness of the student investigator were crucial to recruitment. Although data saturation typically is not the goal of IPA (Smith et al., 2009), no new insights were identified after the first five participants.

Data analysis proceeded in a case-by-case stepwise fashion beginning with reading and re-reading, followed by initial noting, development of emergent themes, and identifying connections across themes. Finally, patterns across cases were explored and idiosyncrasies were identified. Microsoft Excel was used to organize the data and assist with developing themes. The following reviews the findings related to the specific aims of the study.

Specific Aim One: Participant's Definitions of Health

To address study aim one and create context for attending to study aim two, the participants' definitions of health were considered first. Consistent across all participants' definitions was the intrinsic connection between their physical and mental health and how both were shaped by their lived experiences. The participants shared that healthcare encounters, sleep, exercise, nutrition, and relationships were noteworthy factors in their definitions of and experiences of health. Their initial definitions of health mirrored traditional normative definitions. As the participants shared their stories, they revealed more intricate and nuanced aspects of their health that were not initially revealed in the solicited definitions, including the influences of gender and trauma.

A surprising finding was the significance and prevalence of chronic conditions in their definitions of health, experiences of health, and outlooks on their future health. All seven participants reported chronic physical health conditions, chronic mental health conditions, or both. Common conditions included chronic pain syndromes (n=4), depression and anxiety (n=5), PTSD (n=4), obesity (n=6), disordered eating (n=4), and neurodivergent conditions such as ADHD and autism (n=6). While the increased incidence of depression, anxiety, and other chronic conditions in transgender, nonbinary, gender diverse individuals is documented in the literature (Downing & Przedworski, 2018; Ferrucci et al., 2021; Goldberg et al., 2019; Gonzales & Henning-Smith, 2017; Haire, et al., 2021; Harrison et al., 2012; Howell & Maguire, 2019; Jones et al., 2019; Kachen & Pharr, 2020; Klein et al., 2018; Lefevor et al., 2019), the prevalence and significance of chronic conditions in the participants' definitions and experiences of health was unexpected. Their stories revealed that their chronic conditions were omnipresent, shaping their day-to-day activities, informing how they interacted with their environments and in relationships, and framing the way they perceived and integrated new encounters and experiences.

There is a lack of studies exploring how NBGD individuals define health. One previous study was identified that provided "women and gender minorities" the opportunity to share their definitions of sexual health (Rubinsky & Cook-Jackson, 2018). The study sample consisted of 186 geographically, racially, and sexually diverse women and gender minorities from the United States and eight other countries. The age range of the participants mirrored the current study (18 to 69). More than half of the participants identified as White. Women and gender minorities were defined as anyone who identifies as a woman and those who were assigned female at birth but do not identify as a woman. Eight of the 186 participants reported gender identities that would have met inclusion criteria for the current study.

Like the results of this study, the findings suggested that definitions of health are often initially constrained by heteronormative and cisnormative structures and systems. Only when individuals are allowed to express themselves beyond those constraints and share their lived experiences do full and rich definitions of health emerge (Rubinsky & Cook-Jackson, 2018). The study findings also contributed that health for women and gender minorities is grounded in communication, identity, and physical and emotional health (Rubinsky & Cook-Jackson, 2018), further supporting that gender identity is a significant factor in gender diverse individuals' experiences of health.

While other studies have explored the health of transgender and NBGD individuals, none solicited their definitions of health. The findings, therefore, were built on an a priori assumption of the universality of the concept of health. As such, the current study, introduces into the literature a previously unexplored and developing concept of health unique to NBGD individuals assigned female at birth.

Specific Aim Two: Factors that Affect the Participants' Experiences of Health

The overarching theme *The Body Keeps the Score* depicts the significant ways in which the participants' mental and physical health were shaped by their lived experiences. The two most noteworthy factors that contributed to their bodies keeping the score were their experiences of gender and trauma.

Gender

Gender has an immense impact on the ways people act, the things they believe, and how they make sense of themselves and the world around them (Mascia-Lees & Black, 2017). Depending on cultural narratives, gender can substantially influence an individual's roles and responsibilities, quality of life, and life expectancy (Mascia-Lees & Black, 2017). For NBGD individuals, their lived experiences are framed by cultural narratives that defend binarism and erase gender identities that are anything other than cisnormative (Cosgrove et al., 2021). The findings of this study indicate that NBGD adults are socialized early to question their fit within society. This was evidenced by the participants' difficulty relating to others (n=6), their lack of peers (n=5), and their experiences with unsupportive parents (n=5). Pressures to conform to normalized cisgender and transgender stereotypes were immense and left them feeling isolated and uncertain about their identities. Interactions with healthcare professionals who adhered to traditional gender norms and placed predetermined expectations on them exacerbated their feelings of invalidation and misalignment with the world around them (n=6) (Goldberg et al., 2019; Taylor et al., 2019). Consequently, NBGD individuals are made to fight for acknowledgement of their very existence and are burdened with the responsibility of evolving current cultural narratives of gender.

Contributing to this experience is a unique confluence of gender-based assumptions and cisnormativity not experienced by other gender minority groups (Murchison et al., 2023). NBGD individuals assigned female at birth are subjected to binary cisgender, female cisgender, and binary transgender assumptions, as well as the invisibility of NBGD gender identities. Binary cisgender assumptions (cisgenderism, cissexism, or cisnormativity) put forth that a person's gender must align with their sex assigned at birth and that there are only two valid genders, male and female (Goldberg & Kuvalanka, 2018; Matsuno et al., 2024; Schwab & Stamper, 2024). Female cisgender assumptions (sexism) are generally negative assumptions and beliefs about people assigned female at birth based on their gender (Swim & Hyers, 2009). Binary transgender assumptions (transnormativity) are those that defend only two valid transgender identities, transgender female or transgender male (Goldberg & Kuvalanka, 2018; Johnson, 2016; Matsuno et al., 2024; Murchison et al., 2023; Schwab & Stamper, 2024). Cisnormativity and transnormativity often position NBGD individuals in a place where they are neither cisgender nor transgender enough to be recognized by either group (Goldberg & Kuvalanka, 2018; Matsuno et al., 2024; Murchison et al., 2023; Schwab & Stamper, 2024). The participants reported that their NBGD gender identities were rarely considered in healthcare and other community spaces leading to feelings of invisibility and invalidation (Colson et al., 2024; Goldberg & Kuvalanka, 2018; Johnson et al., 2024; Matsuno et al., 2024; Schwab & Stamper, 2024).

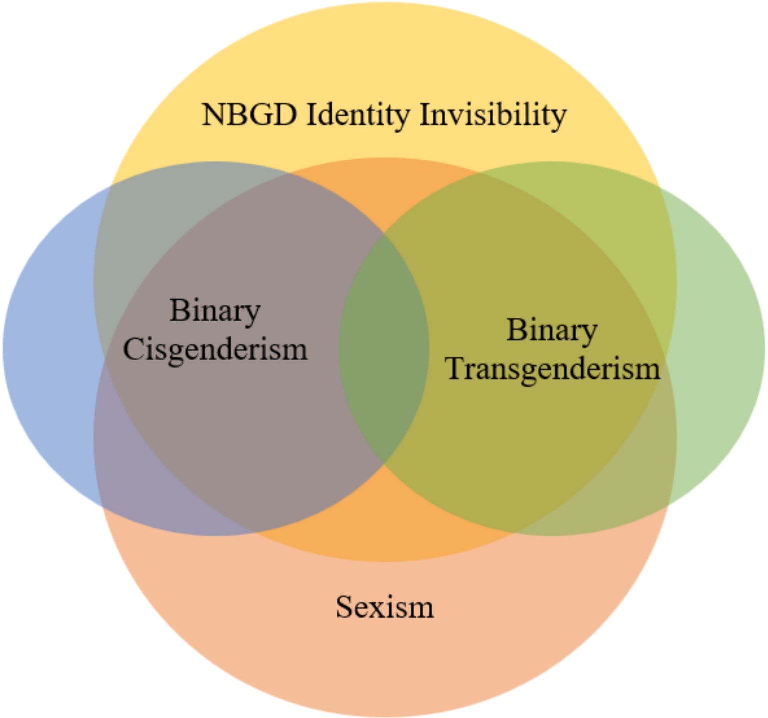
The evidence supporting transnormativity and its impact on the lived experiences of transgender individuals is clear (Bradford & Syed, 2019; Czuy Levine, 2018; Garrison, 2018; Johnson, 2015; Johnson, 2016; Murawsky, 2023; Murchison et al., 2023; Schwab & Stamper, 2024; Vipond, 2015) however, there is a paucity of data on the intersectional impact of normative gender structures on the lived experience of NBGD individuals assigned female at birth. Schwab & Stamper (2024) interviewed 19 majority White transgender (n=11) and nonbinary (n=8) young adults between the ages of 18 and 26 to explore their gender stories. Like the current study, the participants shared struggling to relate to others and the importance of identifying nonbinary peers for both support and facilitating identity formation. Most significantly, their narratives revealed the persistent impact of cisnormativity and transnormativity on their wellbeing.

Another study conducted by Murchison et al. (2023) explored differences in experiences of cissexism (cisnormativity) related stressors across gender identities for 714 transgender and nonbinary young adults between the ages of 18 and 30; the majority of which were White and assigned female at birth. Findings demonstrated that nonbinary people face unique challenges related to having their gender acknowledged and that gender invalidation is closely linked to depression and suicidality. The participants assigned female at birth experienced a unique convergence of cissexism, sexism, and gender binarism not experienced by other participants, contributing the influence of female-based sexism on the gender experiences of NBGD individuals assigned female at birth.

Combined, Schwab & Stamper (2024) and Murchison et al. (2023), contribute the impact of cisnormativity, transnormativity, and sexism on the experience of gender for NBGD individuals assigned female at birth. Missing from these findings is the influence of the invisibility of NBGD gender identities. The current study, therefore, introduces into the literature the most comprehensive picture to date of the experience of gender for NBGD individuals assigned female at birth including the influences of cisgenderism, transgenderism, sexism, and the invisibility of NBGD identities. See Figure 1 for a visual depiction of the intersectional gender experiences of NBGD individuals assigned female at birth.

Figure 1

Intersectional Gender Experiences of NBGD Individuals Assigned Female at Birth



Trauma

It is well documented that experiences of trauma are common among transgender, nonbinary, and gender diverse individuals. Findings regarding the relative prevalence and significance of traumas across binary transgender and NBGD identities has been mixed (Colson et al., 2024; Grant et al., 2011; Harrison et al., 2012; James et al., 2016; Kattari et al., 2021; Lefevor et al., 2019; Newcomb et al., 2020; Reisner & Hughto, 2019; Rimes et al., 2019; Testa et al., 2012; Valentine et al., 2024). Although experiences of trauma were not required to participate in the current study, 100% of the participants reported experiencing trauma, either as a child, as an adult, or both. Across their lifespans, the participants endured multiple instances of physical and psychological abuse (n=5), neglect (n=2), childhood sexual abuse (n=2), and sexual assault (n=2) either in isolation or in combination. They also reported enduring gender-related traumas including misgendering (n=5), invalidation (n=6), labeling (n=5), and discrimination (n=6). The participants reported subsequent PTSD and panic attacks (n=4), depression and anxiety (n=5), disordered eating (n=4), and suicidality (n=3).

Few studies have explored experiences of trauma for NBGD individuals separate from those of binary transgender individuals (Lefevor et al., 2019; Reisner & Hughto, 2019; Rimes et al., 2019). Reisner & Hughto (2019) compared 185 non-binary and 267 binary majority White transgender adults in Massachusetts to identify differences in their health and wellbeing. When exploring violence victimization, they found that non-binary respondents reported fewer lifetime instances of intimate partner violence and no differences in other types of victimization compared to their binary transgender counterparts. Non-binary participants reported less lifetime self-harm and anxiety, however, more depression and hazardous alcohol use.

Unlike Reisner & Hughto (2019), when evaluating difference in stressors and health outcomes between equal numbers of genderqueer (nonbinary), binary transgender, cisgender male, and cisgender female college students (N= 3,568), Lefevor et al. (2019) observed that genderqueer individuals were harassed, sexually abused, and experienced more traumatic events than both binary transgender and cisgender individuals. These experiences correlated with more frequent anxiety, depression, psychological distress, disordered eating, self-harm and suicidality than the binary transgender and cisgender respondents.

Rimes et al. (2019) added another layer of intricacy by comparing differences in sex assigned at birth when exploring experiences of mental health, self-harm, suicidality, substance use, and victimization in a group of 677 mostly White nonbinary and binary transgender individuals between the ages of 16 and 25. The findings supported that those assigned female at birth experienced more childhood sexual abuse, domestic violence, and other forms of violence than both nonbinary and binary transgender participants assigned male at birth. They also reported more mental health conditions that interfere with daily activities, self-harm, and suicidality. While the findings of Lefevor et al. (2019) and Rimes et al. (2019) support the findings of the current study, the incongruences with Reisner & Hughto (2019) and the overall scarcity of evidence signal the need for further investigation of the prevalence and significance of experiences of trauma for NBGD individuals.

The Body Keeps the Score

The overarching theme *The Body Keeps the Score* depicts the immense way in which the participants' mental and physical health were shaped by their lived experiences, including their experiences of gender and trauma. The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma is a book by Bessel van der Kolk, M.D. (2014) which describes the ways in which human bodies hold on to previous traumas and manifests those traumas in physical, mental, and emotional symptoms as well as impacting responses to future stimuli. Since its release, the book has been widely cited and quoted, becoming imbedded in popular culture and lexicon, making it a logical metaphor for the way the participants understand and experience health.

As the participants' narratives revealed, there was a cyclical, bolstering connection between their gender and experienced traumas, their heightened awareness of reinforcing experiences, and their somatic and psychological responses. These findings align with the concepts of Minority Stress Theory and add to the body of literature that supports the experiences of minority stress for binary transgender and NBGD people (Burgwal et al., 2019; Cogan et al., 2021; Colson et al., 2024; Dolezal et al., 2023; Goldberg et al., 2019; Griffin et al., 2019; Johnson et al., 2024; Lefevor et al., 2019; Matsuno et al., 2024; Murchison et al., 2023; Pease et al., 2022; Valentine et al., 2024; Wilson & Jones, 2023).

Minority Stress Theory was first proposed to describe how distal stressors contribute to proximal stressors in cisgender sexual minorities (Brooks, 1981; Meyer, 1995; 2003). Since its inception the theory has been further developed and validated to include the experiences of gender minorities (Hendricks & Testa, 2012; Pellicane & Ciesla, 2022; Testa et al., 2015). Distal stressors are environmental and external events that occur due to a person's minority status that cause the individual to experience stress (Hendricks & Testa, 2012; Meyer, 1995; Pellicane & Ciesla, 2022). Examples of distal stressors include discrimination, rejection, and victimization. Proximal stress is the anticipation and expectation of external stressful events and the subsequent vigilance it creates (Hendricks & Testa, 2012; Meyer, 2003; Pellicane & Ciesla, 2022). Proximal stressors include internalized stigma, anticipated rejection, and concealment. Distal and proximal stressors therefore work to magnify the influence of each on an individual's health. Both distal and proximal stressors contribute to negative physical and mental health outcomes (Brooks, 1981; Hendricks & Testa, 2012; Meyer, 2003; Pellicane & Ciesla, 2022). This mirrors the narratives of the current study's participants, including their experiences of gender-based traumas, their vigilance and anticipation of new traumas and poor outcomes, and their lived experiences of health.

Minority Stress Theory does not fully account for the experiences of the participants of this study. In addition to the experienced distal and proximal stressors related to their gender minority status, 100% of the participants suffered non-gender related traumas that contributed to their lived experience of health and their vigilance and anticipation of new traumas and poor outcomes. This expands on Minority Stress Theory and highlights the need to consider non-gender related traumas and how they intersect with distal and proximal stressors to shape lived experiences for NGBD individuals (Charak et al., 2023; Valentine et al., 2024). This includes childhood, adolescent, and adult experiences of physical abuse, sexual abuse, and emotional and psychological abuse perpetrated by acquaintances, parents, and other family members (Dworkin et al., 2018; Estrada et al., 2021; Livingston et al., 2019; Salomaa et al., 2023; Shipherd et al., 2019; Valentine et al., 2024). Considering distal and proximal stressors related to minority status in isolation overlooks these and other significant factors and oversimplifies complicated intersectional experiences. (Burgwal et al., 2019; Colson et al., 2024; Henderson, 2022; Klein et al., 2018; Valentine et al., 2024). The current study underscores this and supports the need to further explore these experiences and their relationship with Minority Stress Theory.

What They Want and Implications

During data collection, the participants were provided the opportunity to express what they wanted in their healthcare experiences. Their requests mirror the study findings and provide a foundation for attending to the subsequent practice, policy, and education implications. First and foremost, the participants asked for acknowledgement and validation of their personhood and gender identity. To satisfy this request, recognition of individual identities needs to be integrated into all aspects of healthcare interactions. This includes individual level responsibility to avoid assumptions and view gender more expansively, health system level duty to purposefully implement policies, protocols, and practices that support diverse identities, and government level obligation to develop policies the defend the rights, identities, and healthcare of all people.

The participants also asked for more inclusive healthcare nomenclature. Terminology used to describe anatomy, assessment findings, procedures, and care environments had a significant impact on the healthcare experiences of the participants and their willingness to engage in healthcare. A pointed effort should be made to evaluate ways to make medical encounters more inclusive, including physical spaces, electronic health records, intake forms, and conversations. Nurses and other healthcare professionals should engage in implicit bias and knowledge assessments to identify opportunities for improvement and seek out learning opportunities to address identified gaps in knowledge.

Finally, the participants requested better trauma-informed care that recognizes the varied and often hidden traumas that people carry. This necessitates creating safe and supportive environments and providing trauma-informed care for all people regardless of their reasons for engaging in healthcare. Like gender validation, the creation of trauma-informed care environments should be intentional with implementation of evidence-based policies, protocols, and practices that are coordinated with ongoing education and support. Education on gender diversity and trauma-informed care should be a foundational part of nursing, medical, and other allied health curricula. As the majority profession in healthcare, nurses are uniquely positioned to lead these initiatives and answer the American Nurses Association’s 2018 call to provide culturally congruent care and eliminate healthcare discrimination and disparities experienced by gender diverse people. Only then can we move towards a more inclusive, respectful, and affirming healthcare experience for all people.

Limitations

Throughout the research process, efforts were made to foster the trustworthiness of the study, including remaining sensitive to context and maintaining commitment, rigor, transparency, and coherence to demonstrate the impact and importance of the findings (Smith et al., 2009; Yardley, 2000). As a qualitative study with a small homogenous sample, the results are potentially transferable but not generalizable (Creswell, 2013). Transferability is judgment-based and up to the consumer to determine the relative applicability of the findings (Creswell, 2013). The purpose of IPA is not to discover universal truths, but to examine how people understand and make sense of life experiences. The goal is to build foundational knowledge from which a body of knowledge can be created (Smith et al., 2009). The participants of the study were all White and well-educated. Although attempts were made to recruit underrepresented people, time constraints limited the ability to build trust within marginalized communities to support recruitment. It is likely that those who agreed to participate in the study were more confident in talking about their gender and health, introducing volunteer bias. The findings of the study likely are not representative of all NBGD people assigned female at birth, potentially limiting transferability.

Additional limitations arose related to the participants in the study. All data was gathered via self-report introducing the risk for recall bias. Participants likely considered what to disclose and may have been impacted by social desirability and wanting to control how they were perceived. Situational context was also considered as a possible limitation. During the interviews, several of the participants mentioned the prevailing political climate as concerning and a potential factor in their future health. Several of the participants were navigating new health issues, testing, and doctors' appointments, and two of the participants were married during data collection. The impact of these situational contexts was possibly evidenced by variation in some of the participants' openness and willingness to talk between the first and second interviews. The student investigator intentionally reflected on the possibility of recall bias, social desirability, and situational contexts during data analysis.

Possible limitations also arose out of factors related to the student investigator. There was potential that the interview guide was not adequate and that questions were asked in a manner that influenced responses. Every attempt was made to be consistent in the way the questions were asked and to allow the participants to control the flow of the conversation. The student investigator was careful not to lead or interrupt the participants to limit the investigator's influence on the data. There also was the possibility that topics were not explored to a depth needed to fully reveal their significance or that errors were made during data analysis. To support the trustworthiness of the findings, the faculty advisor partnered in the data analysis and served as an independent auditor. The role of the independent auditor is to follow the chain of evidence to validate findings and evaluate the rigor of the claims (Smith et al., 2009). As the independent auditor, the faculty advisor reviewed all notes, annotated transcripts, the Microsoft Excel spreadsheets, tables of themes, and all drafts of the analysis.

Future Research

There continues to be little in the current literature that describes the unique health experiences of NBGD people separate from those of binary transgender people. The findings of this study contribute new knowledge, introduce the topic to nursing's body of science, and provide a foundation for future research about the health and healthcare needs of NBGD individuals. More research is needed to expand on these findings and delve deeper into NBGD individuals' definitions of health, their experiences of health, and how these may vary across gender identities and sex assigned at birth. Additional research should explore the combined impact of cisgenderism, transgenderism, sexism, and invisibility on the health and lived experiences of NBGD individuals assigned female at birth. Experiences of the intersections of minority stress, non-gender-based traumas, and adverse childhood experiences should be investigated in the context of both gender identity and sex assigned at birth. It is essential to focus future research on the experiences of black, indigenous, and other people of color, as well as additional intersectional identities to build a more diverse and comprehensive body of science regarding the health of NBGD people.

The findings of this study also highlighted healthcare professionals' lack of knowledge about NBGD identities and providing culturally competent, trauma-informed care. Supplemental research exploring healthcare professionals' knowledge and attitudes about caring for NBGD people is needed. Finally, it is important to investigate how trauma-informed care may need to be adapted to meet the needs of NBGD populations. Evidence-based practice recommendations can then be created, and educational offerings can be developed to address gaps in knowledge.

Conclusion

Nonbinary and gender diverse (NBGD) people experience a higher burden of physical and mental health challenges, disparities, and discrimination in healthcare than cisgender people whose gender identity aligns with their sex assigned at birth. Nursing science had previously failed to explore the health of, or disparities experienced by, NBGD people. Very few studies had examined the experiences of NBGD people separate from binary transgender individuals rendering them an invisible population. The findings of this study address these omissions by providing insight into the lived experience of health for NBGD individuals assigned female at birth. Introduced was their emerging conceptualization of health, including the significance of gender and trauma. Also highlighted was the unique intersection of cisgenderism, transgenderism, sexism, and the invisibility of NBGD identities on their experiences. Finally, their pervasive experiences of trauma emphasize the need to expand on Minority Stress Theory by considering non-gender related traumas and other intersectional experiences that impact NBGD individuals’ experiences of health.

APPENDICES

APPENDIX A

GENDER TERMINOLOGY

Appendix A

Gender Terminology

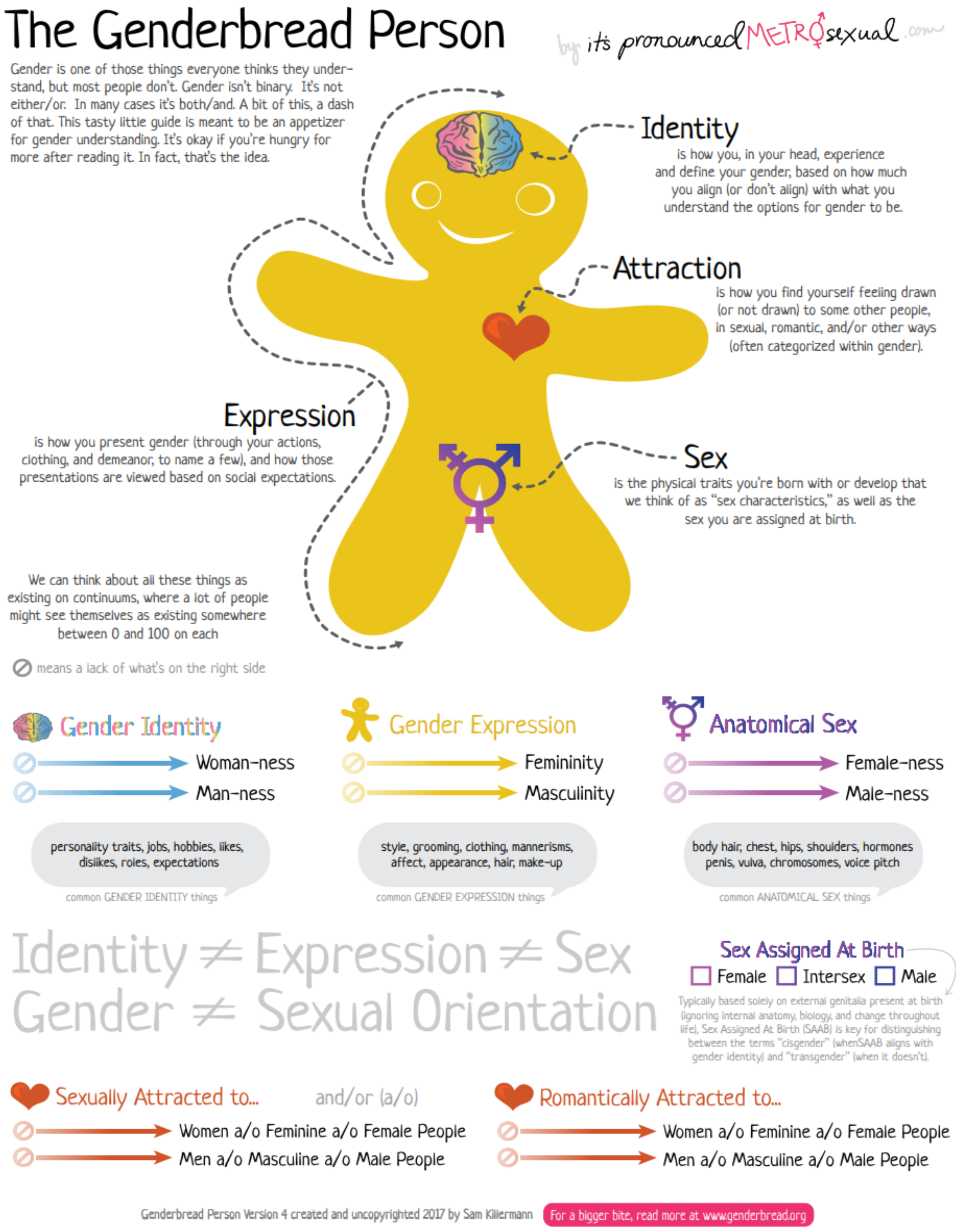
Term	Definition
Agender/genderless/ neutrois	Being neither man nor woman or not having any gender
Cisgender	Someone whose gender identity matches the sex they were assigned at birth
Demigirl	Someone who identifies with being a girl or a woman on some level but not completely
Demiguy	Someone who identifies with being a boy, guy, or a man on some level but not completely
Femme	A feminine gender expression or identity
Gender binary	Pervasive social system that puts forth that there can only be masculine cis men and feminine cis women and that there can be no alternatives in gender identity or expression
Gender diverse	Umbrella term used to describe gender identities that demonstrate a diversity of expression beyond the binary framework
Gender dysphoria	Distress caused when a person's assigned birth gender is not the same as the one with which they identify
Gender expansive	A person with a wider, more flexible range of gender identity or expression than typically associated with the gender binary
Gender expression	External appearance of one's gender identity expressed through behavior, clothing, body characteristics, and/or voice
Gender fluid	A person who does not identify with a single fixed gender or who has a fluid gender identity
Gender fuck	Act of intentionally messing with gender expectations
Gender identity	One's intrinsic sense of self, how they perceive themselves and their gender
Gender non-conforming	Broad term referring to people who do not behave in a way that conforms to binary gender expectations or whose gender does not fit into one category; considered offensive by some and intentionally empowering by others, should be used only if chosen by an individual
Genderqueer	Can be used as an umbrella term for nonbinary people; can also refer to people who are gender fluid, identify as both male and female or neither male or female, whose gender is outside of any of these categories, or people who reject notions of static gender categories
Intergender	Persons with a gender identity that is between a man and a woman, both a man and a woman, or outside the binary of man and woman
Intersex	A person born with any of a variety of differences in their sex traits and/or reproductive anatomy, can include genitalia, sex organs, gonads, chromosomes, hormones, and secondary sex traits
Non-binary	Adjective describing persons with a gender identity that is between a man and a woman, both a man and a woman, or outside the binary of man and woman; may also be used as an umbrella term for all gender identities outside of the gender binary
Polygender	Gender identity in which a person experiences multiple genders
Queer	Originally used as a slur but has been reclaimed by parts of the LGBTQ+ community; can be used to indicate gender or sexual orientation, expresses a spectrum of identities and orientations that counter the mainstream; continues to be considered a slur by some members of the community
Questioning	Term used to describe people who are in the process of exploring their sexual orientation or gender identity
Third gender	Culturally oriented word used to describe a third gender (or fourth, etc.); often associated with indigenous cultures but can be seen in western cultures as well
Transgender	Umbrella term for people whose gender identity or expression does not match their sex assigned at birth
Two Spirit	Term used to describe gender diversity and gender variance in different Native American groups

APPENDIX B

THE GENDERBREAD PERSON

Appendix B

The Genderbread Person



The Genderbread Person

by it's pronounced METROsexual.com

Gender is one of those things everyone thinks they understand, but most people don't. Gender isn't binary. It's not either/or. In many cases it's both/and. A bit of this, a dash of that. This tasty little guide is meant to be an appetizer for gender understanding. It's okay if you're hungry for more after reading it. In fact, that's the idea.

Identity is how you, in your head, experience and define your gender, based on how much you align (or don't align) with what you understand the options for gender to be.

Attraction is how you find yourself feeling drawn (or not drawn) to some other people, in sexual, romantic, and/or other ways (often categorized within gender).

Expression is how you present gender (through your actions, clothing, and demeanor, to name a few), and how those presentations are viewed based on social expectations.

Sex is the physical traits you're born with or develop that we think of as "sex characteristics," as well as the sex you are assigned at birth.

We can think about all these things as existing on continuums, where a lot of people might see themselves as existing somewhere between 0 and 100 on each

⊘ means a lack of what's on the right side

Gender Identity

⊘ → Woman-ness

⊘ → Man-ness

personality traits, jobs, hobbies, likes, dislikes, roles, expectations

common GENDER IDENTITY things

Gender Expression

⊘ → Femininity

⊘ → Masculinity

style, grooming, clothing, mannerisms, affect, appearance, hair, make-up

common GENDER EXPRESSION things

Anatomical Sex

⊘ → Female-ness

⊘ → Male-ness

body hair, chest, hips, shoulders, hormones penis, vulva, chromosomes, voice pitch

common ANATOMICAL SEX things

Identity ≠ Expression ≠ Sex
Gender ≠ Sexual Orientation

Sex Assigned At Birth

☐ Female ☐ Intersex ☐ Male

Typically based solely on external genitalia present at birth (ignoring internal anatomy, biology, and change throughout life), Sex Assigned At Birth (SAAB) is key for distinguishing between the terms "cisgender" (whenSAAB aligns with gender identity) and "transgender" (when it doesn't).

Sexually Attracted to... and/or (a/o)

⊘ → Women a/o Feminine a/o Female People

⊘ → Men a/o Masculine a/o Male People

Romantically Attracted to...

⊘ → Women a/o Feminine a/o Female People

⊘ → Men a/o Masculine a/o Male People

Genderbread Person Version 4 created and uncopyrighted 2017 by Sam Killermann

For a bigger bite, read more at www.genderbread.org

APPENDIX C

RECURITMENT FLYER FOR PHYSICAL LOCATIONS

Appendix C

Recruitment Flyer for Physical Locations

The Nonbinary Gender Diverse People's Health Research Study

- **Are you 18 years of age or older?**
- **Do you currently live in the Midwest?**
- **Is your gender between, outside, or beyond the male/female gender binary?**
- **Were you assigned female at birth?**
- **Have you had an experience that caused you to explore your health or seek assistance related to your health?**

If you answered yes to all these questions, you may be eligible to participate in a research project that is designed to explore how nonbinary gender diverse people understand and experience health.

You will be asked to fill out a brief information sheet and participate in one in-depth interview and one short follow-up interview with the primary researcher. You will receive financial compensation as a gesture of gratitude for your time as a participant.

Participation provides the benefit of helping healthcare providers better understand the health experiences of nonbinary gender diverse people.

If you would like to learn more, please contact Amy Veney at

330-554-3917 or aveney@kent.edu

Amy Veney: 330-554-3917

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Amy Veney: 330-554-3917

Amy Veney: 330-554-3917

Amy Veney: 330-554-3917

APPENDIX D

RECRUITMENT SCRIPT FOR FACE-TO-FACE RECRUITMENT

Appendix D

Recruitment Script for Face-Face Recruitment

Hi, my name is Amy Veney, I am a Kent State University PhD candidate, and I am here to talk to you about The Nonbinary Gender Diverse People's Health Research Study. NBGD people are often seen as having the same health needs as other transgender people without consideration for how they may be different. The purpose of this study is to explore NBGD people's understanding and experience of health. You are eligible to participate in the study if you are 18 years of age or older, your gender is between, outside, or beyond the male/female gender binary, you were assigned female at birth, and you have experienced an event that caused you to explore your health or seek assistance for your health. Participation provides the benefit of helping healthcare providers better understand the health experiences of NBGD people.

If you are interested, I am available to speak with you now or we can arrange a time for me to call you to determine if you are eligible to participate. I am happy to answer any questions you may have. Thank you for allowing me to speak with you today.

APPENDIX E

RECRUITMENT LOCATIONS

Appendix E

Recruitment Locations

Kent State University LGBTQ+ Center
800 East Summit Street, 024 Kent Student Center, Kent, OH 44242
330-672-8580
lgbtqsc@kent.edu
Contact: Ken Ditlevson

Summa Health Pride Clinic
1260 Independence Avenue, Akron, OH 44310
234-867-7740
prideclinic@summahealth.org
Contact: Hollie Kozak

Cleveland Pride
Malls B & C
Cleveland, OH
Saturday, June 3, 2023

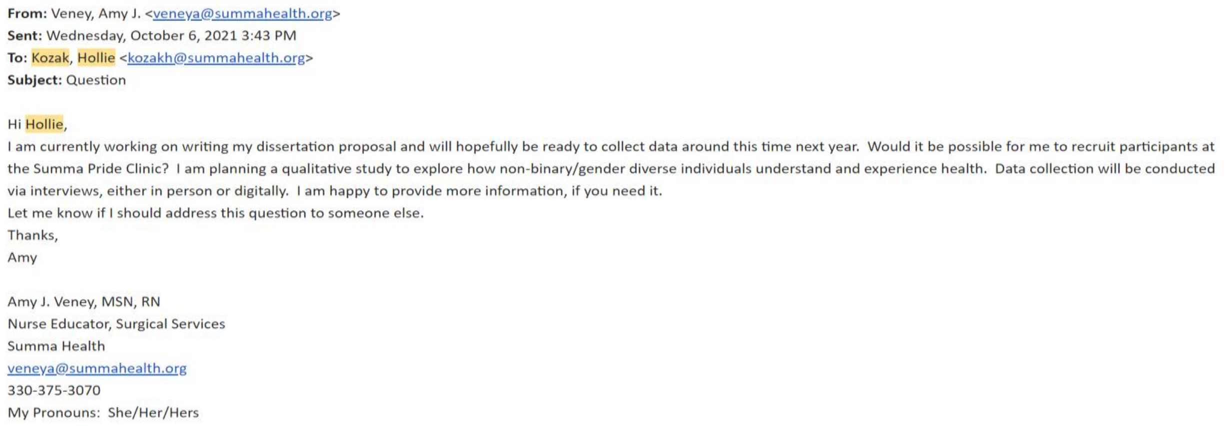
Akron Pride
Lock 3
Akron, OH
Saturday, August 26, 2023

APPENDIX F

PERMISSION TO POST RECRUITMENT FLYERS

Appendix F

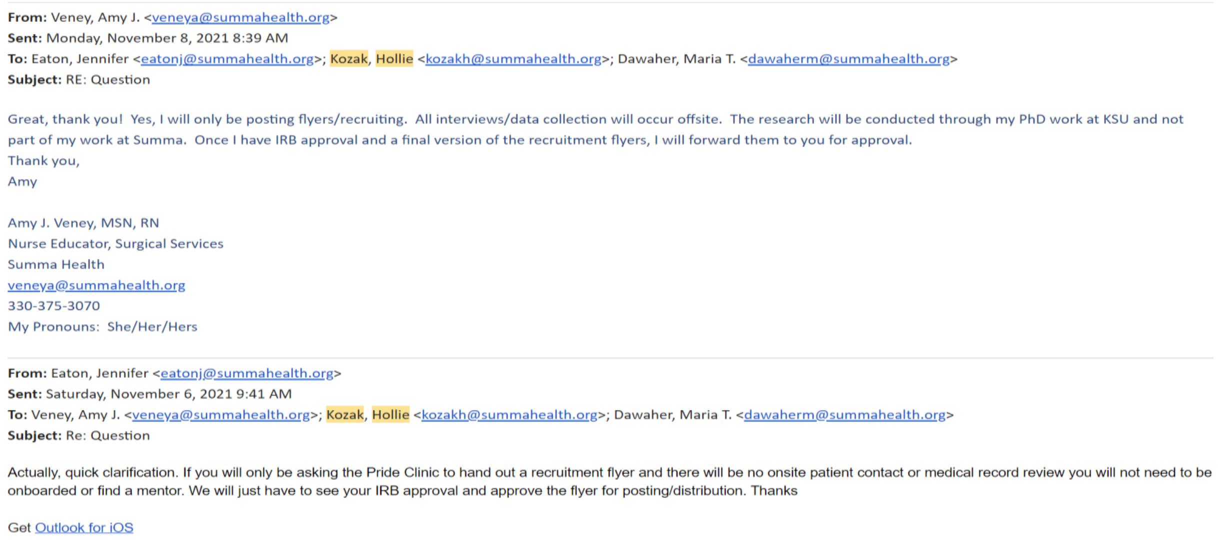
Permission to Post Recruitment Flyers



From: Veney, Amy J. <veneya@summahealth.org>
Sent: Wednesday, October 6, 2021 3:43 PM
To: Kozak, Hollie <kozakh@summahealth.org>
Subject: Question

Hi Hollie,
I am currently working on writing my dissertation proposal and will hopefully be ready to collect data around this time next year. Would it be possible for me to recruit participants at the Summa Pride Clinic? I am planning a qualitative study to explore how non-binary/gender diverse individuals understand and experience health. Data collection will be conducted via interviews, either in person or digitally. I am happy to provide more information, if you need it.
Let me know if I should address this question to someone else.
Thanks,
Amy

Amy J. Veney, MSN, RN
Nurse Educator, Surgical Services
Summa Health
veneya@summahealth.org
330-375-3070
My Pronouns: She/Her/Hers



From: Veney, Amy J. <veneya@summahealth.org>
Sent: Monday, November 8, 2021 8:39 AM
To: Eaton, Jennifer <eatonj@summahealth.org>; Kozak, Hollie <kozakh@summahealth.org>; Dawaher, Maria T. <dawaherm@summahealth.org>
Subject: RE: Question

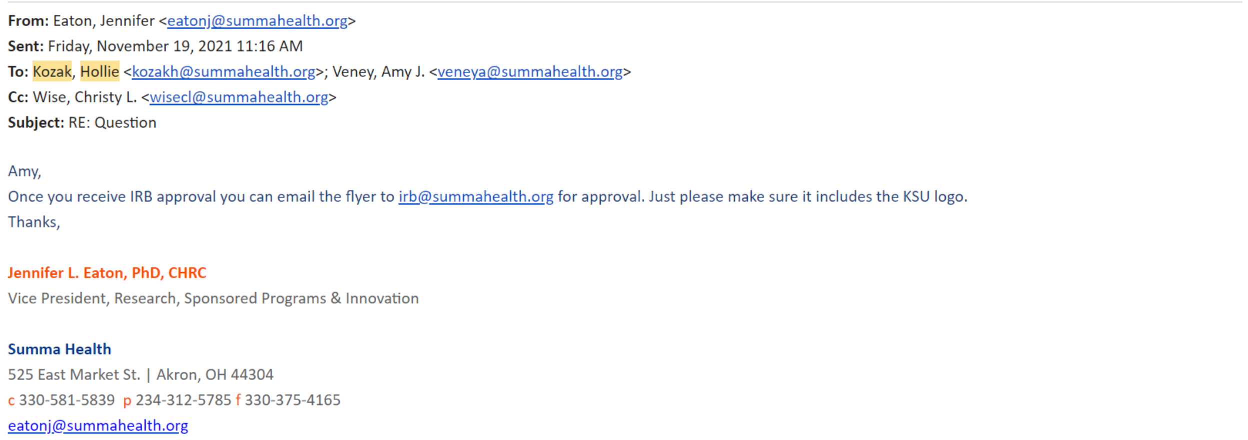
Great, thank you! Yes, I will only be posting flyers/recruiting. All interviews/data collection will occur offsite. The research will be conducted through my PhD work at KSU and not part of my work at Summa. Once I have IRB approval and a final version of the recruitment flyers, I will forward them to you for approval.
Thank you,
Amy

Amy J. Veney, MSN, RN
Nurse Educator, Surgical Services
Summa Health
veneya@summahealth.org
330-375-3070
My Pronouns: She/Her/Hers

From: Eaton, Jennifer <eatonj@summahealth.org>
Sent: Saturday, November 6, 2021 9:41 AM
To: Veney, Amy J. <veneya@summahealth.org>; Kozak, Hollie <kozakh@summahealth.org>; Dawaher, Maria T. <dawaherm@summahealth.org>
Subject: Re: Question

Actually, quick clarification. If you will only be asking the Pride Clinic to hand out a recruitment flyer and there will be no onsite patient contact or medical record review you will not need to be onboarded or find a mentor. We will just have to see your IRB approval and approve the flyer for posting/distribution. Thanks

Get Outlook for iOS

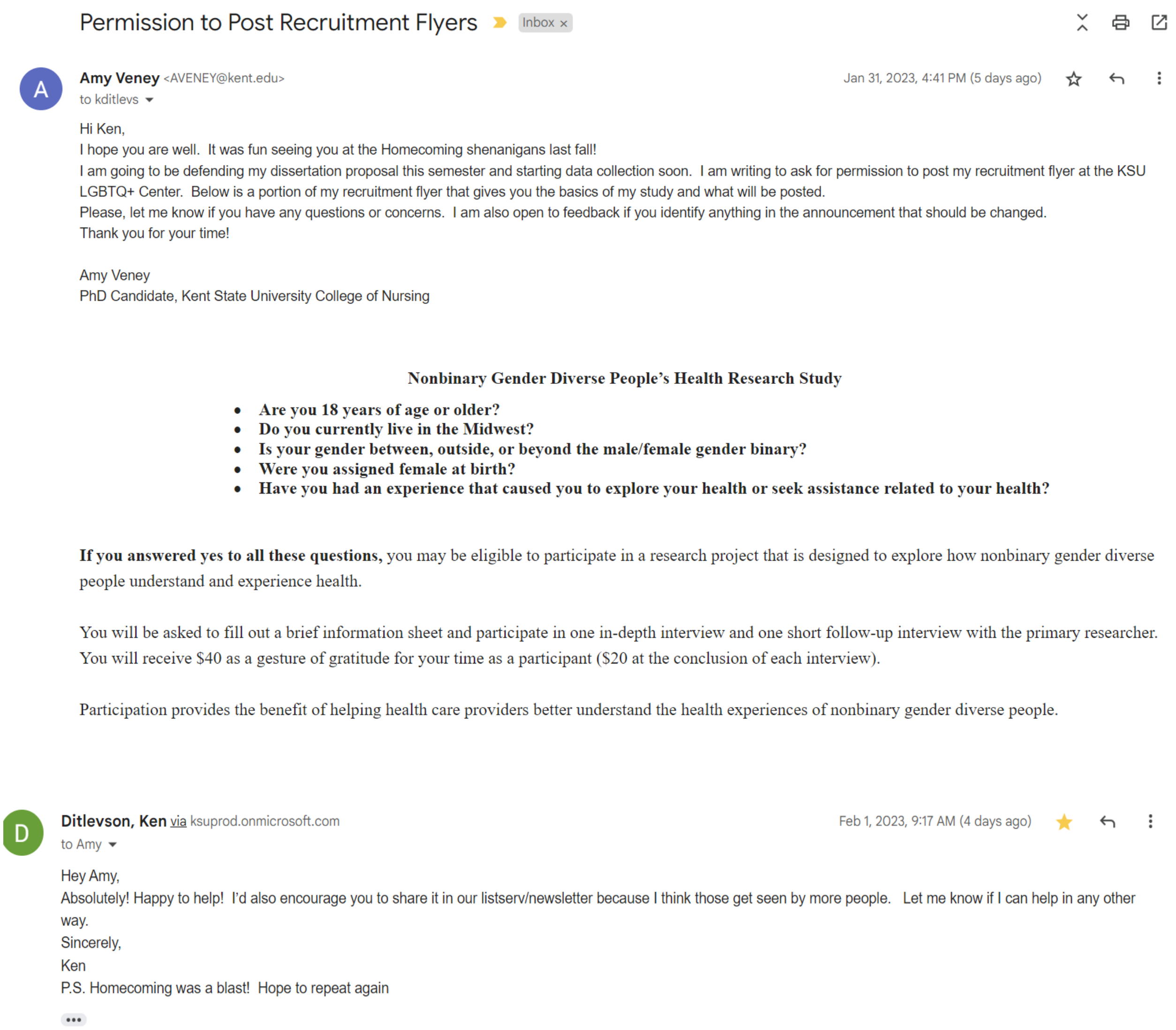


From: Eaton, Jennifer <eatonj@summahealth.org>
Sent: Friday, November 19, 2021 11:16 AM
To: Kozak, Hollie <kozakh@summahealth.org>; Veney, Amy J. <veneya@summahealth.org>
Cc: Wise, Christy L. <wisecl@summahealth.org>
Subject: RE: Question

Amy,
Once you receive IRB approval you can email the flyer to irb@summahealth.org for approval. Just please make sure it includes the KSU logo.
Thanks,

Jennifer L. Eaton, PhD, CHRC
Vice President, Research, Sponsored Programs & Innovation

Summa Health
525 East Market St. | Akron, OH 44304
c 330-581-5839 p 234-312-5785 f 330-375-4165
eatonj@summahealth.org



Permission to Post Recruitment Flyers

Amy Veney <AVENEY@kent.edu>
to kditlevs
Jan 31, 2023, 4:41 PM (5 days ago)

Hi Ken,
I hope you are well. It was fun seeing you at the Homecoming shenanigans last fall!
I am going to be defending my dissertation proposal this semester and starting data collection soon. I am writing to ask for permission to post my recruitment flyer at the KSU LGBTQ+ Center. Below is a portion of my recruitment flyer that gives you the basics of my study and what will be posted.
Please, let me know if you have any questions or concerns. I am also open to feedback if you identify anything in the announcement that should be changed.
Thank you for your time!

Amy Veney
PhD Candidate, Kent State University College of Nursing

Nonbinary Gender Diverse People's Health Research Study

- **Are you 18 years of age or older?**
- **Do you currently live in the Midwest?**
- **Is your gender between, outside, or beyond the male/female gender binary?**
- **Were you assigned female at birth?**
- **Have you had an experience that caused you to explore your health or seek assistance related to your health?**

If you answered yes to all these questions, you may be eligible to participate in a research project that is designed to explore how nonbinary gender diverse people understand and experience health.

You will be asked to fill out a brief information sheet and participate in one in-depth interview and one short follow-up interview with the primary researcher. You will receive $40 as a gesture of gratitude for your time as a participant ($20 at the conclusion of each interview).

Participation provides the benefit of helping health care providers better understand the health experiences of nonbinary gender diverse people.

Ditlevson, Ken via ksuprod.onmicrosoft.com
to Amy
Feb 1, 2023, 9:17 AM (4 days ago)

Hey Amy,
Absolutely! Happy to help! I'd also encourage you to share it in our listserv/newsletter because I think those get seen by more people. Let me know if I can help in any other way.
Sincerely,
Ken
P.S. Homecoming was a blast! Hope to repeat again

APPENDIX G

TELEPHONE SCREENING SCRIPT

Appendix G

Telephone Screening Script

Hello, my name is Amy Veney, a Kent State University PhD candidate. I'm calling about a research study. Am I speaking to ____________ (name)?

If "no," wait for the person to pick up or ask for a time to call back; information about the study not to be shared with others to protect privacy.

If "yes":

Is this a good time to talk? I expect this phone call will take about 10 minutes.

Arrange to call at another time, if appropriate.

I'm calling about a research study of nonbinary gender diverse people who have had an experience that has caused them to explore their health or seek assistance related to their health. The study is called The Nonbinary Gender Diverse People's Health Research Study. The purpose of this study is to explore NBGD people's understanding and experience of health.

I received your (message/e-mail) expressing interest in participating in the study. I am calling to see if you are still interested and to determine if you are eligible to participate. If you agree, I will ask you some brief questions to see if you can be in the study. If are eligible, we can begin the interview now or schedule it for a time that is more convenient for you. If you consent to participate, you will then be interviewed twice by me, either online using Microsoft Teams or in person. The first interview will take approximately 60-90 minutes. The second follow up interview will take less than 60 minutes.

Before we go on to the questions, let me tell you a little bit about your rights as a research subject. You don't have to answer any questions that you don't want to, and you can choose to stop at any time without penalty. The main risk of answering my questions today is loss of confidentiality, meaning I will know your answers. However, we will our best to keep your information confidential within the limits of the law. Any identifying information will be kept in a secure location and only the researchers will have access to the data. Research participants will not be identified in any publication or presentation of research results; only aggregate data will be used.

Your research information may, in certain circumstances, be disclosed to the Institutional Review Board (IRB), which oversees research at Kent State University, or to certain federal agencies. Confidentiality may not be maintained if you indicate that you may do harm to yourself or others.

If you have questions about the study, you can call me at 330-554-9630, or my faculty advisor Dr. Pamela Stephenson at 330-672-3704. If you have questions about your rights as a research subject or research-related injuries, you can call the Kent State University Institutional Review Board at 330-672-2704. May I go ahead with the eligibility questions?

If no, thank the individual and end the call.

If yes start the questions:

I am going to ask you several questions that will help determine if you are eligible to participate in the study.

- Are you 18 years of age or older?
- Do you currently live in the Midwest?
- Is your gender between, outside, or beyond the male/female gender binary?
- Were you assigned female at birth?
- Have you experienced an event that caused you to explore your health or seek assistance related to your health?
- Do you have any difficulties with speaking, hearing, or understanding English that prevent you from participating in an interview?
- Do you have cognitive difficulties or impairment that may interfere with making an informed decision? For example, is it difficult for you to follow written or verbal instructions or to understand explanations?

If eligible and interested in participating, discuss location, time, and date to obtain informed consent and conduct the interview. If ineligible or the answer is no, thank them for their time.

APPENDIX H

INFORMED CONSET TO PARTICIPATE IN A RESEARCH STUDY

Appendix H

Informed Consent to Participate in a Research Study

Study Title: The Nonbinary Gender Diverse People's Health Research Study
Co-Investigator: Amy Veney Principle Investigator: Dr. Pamela Stephenson

You are being invited to participate in a research study. This consent form will provide you with information on the research project, what you will need to do, and the associated risks and benefits of the research. Your participation is voluntary. Please read this form carefully. It is important that you ask questions and fully understand the research to make an informed decision. You will receive a copy of this document to take with you.

Purpose

The purpose of this research is to understand how nonbinary gender diverse people understand and experience health. This research is important because nonbinary gender diverse people are often seen as having the same health experiences and needs as other transgender people. However, there is lack of consideration for how they may be different. By studying nonbinary gender diverse people who have had an experience that caused them to explore their health or seek assistance for their health, healthcare providers will gain understanding of the unique health experiences of nonbinary gender diverse people. With this knowledge, healthcare providers have the potential to be better able to provide health related care, support, and education to nonbinary gender diverse people.

Procedures

If you choose to participate in this research, you will be interviewed by one of the investigators, Amy Veney. Interviews will be conducted in person or online using Microsoft Teams, at a time that is convenient for you. If you meet with the researcher in person, the interview will be conducted in a private room within a public space that is accessible to you. You will be responsible for any transportation needed to get to the interview site. Your interview will be recorded using Microsoft Teams and an additional digital recording device. The initial interview is expected to last about 90 minutes. At the time of the interview, you will be asked to provide some information about yourself, including age, race, gender, relationship status, occupation, education level, and household income level. Collecting basic information to describe a group of study participants is a standard research practice. At the end of the interview, you will be asked to reflect on your responses to the initial interview and consider additional information that may add insight into your health experiences. You will be provided with a notebook to record your thoughts. The time taken to record your thoughts will vary based on your individual experiences but is anticipated to take approximately 10 to 15 minutes per day. One week after the initial interview, a second, shorter interview will be conducted to allow you to share the information recorded and answer clarifying questions. The second interview is anticipated to last one hour or less. The notebook will be collected at the second interview and included in data analysis. If you choose an online interview, your thoughts can be submitted by email. There are no follow-up requirements after the second interview.

Audio Recording

Interviews will be audio recorded and transcribed using Microsoft Teams. Access will be password protected. Only members of the research team will be able to listen to the recording. A transcript will be made of the recorded interview. The transcript will not contain your name or any other identifying information. After this study is completed, the recording will be deleted.

Benefits

This research will not benefit you directly. However, your participation in this study may help nurses better understand the health experiences of nonbinary gender diverse people. With this knowledge, nurses will be better able to provide health related care, support, and education to nonbinary gender diverse people.

Risks and Discomforts

Overall, there are no anticipated risks for participating in this research, beyond those encountered in everyday life. However, depending on your personal experiences, some of the questions asked may be upsetting, or you may feel uncomfortable answering them. If you do not wish to answer a question, you may skip it and go on to the next question. You also have the option to see the questions before deciding whether you would like to participate in the study. If you become distressed during the interview, a list of mental health resources will be provided.

Privacy and Confidentiality

Your identity will be kept private. Your signed consent form will be kept separate from your study data, and responses will not be linked to you. Any identifying information will be kept in a secure location and only Amy Veney and Dr. Pamela Stephenson will have access to the data. Your signed consent form will be stored in a locked filing cabinet, separate from the data. Written information sheets will be kept in a separate, locked filing cabinet. Electronic data will be kept in a secure, electronic file to which only the researchers will have access. The interview audio recording will be transcribed without any information that could identify you. When the study is completed, the recording will be deleted. If the results of this study are written in a scientific journal or presented at a scientific meeting, your name will not be used. Your records will be kept confidential and will not be released without your consent except as required by law. Your research information may, in certain circumstances, be disclosed to the Institutional Review Board (IRB), which oversees research at Kent State University, or to certain federal agencies. For example, confidentiality may not be maintained if you indicate that you may do harm to yourself or others.

Compensation

After completing your first interview, you will receive $20 as compensation for your time. After completion of the second interview, you will receive an additional $20 compensation for your time spent participating in the study ($40 total compensation for both interviews). Journaling during the week between interviews does not impact compensation.

Voluntary Participation

Taking part in this research study is entirely up to you. You may choose not to participate, or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. You will be informed of any new, relevant information that may affect your health, welfare, or willingness to continue your study participation.

Contact Information

If you have any questions or concerns about this research, you may contact the student investigator, Amy Veney, at 330-554-3917 or the university faculty advisor, Dr. Pamela Stephenson at 330-672-3704. This project has been approved by Kent State University Institutional Review Board (IRB). If you have any questions about your rights as a research participant or complaints about the research, you may call the IRB at 330-672-2704.

Consent Statement and Signature

I have read this consent form and have had the opportunity to have my questions answered to my satisfaction. I voluntarily agree to participate in this study. I understand that a copy of this consent will be provided to me for future reference.

_________________________________ _____________________
Signature **Date**

APPENDIX I

INTEREST IN FINDINGS AND FUTURE RESEARCH

Appendix I

Interest in Findings and Future Research

1. Are you interested in receiving a copy of the research findings of this project?
    a. Yes ______
    b. No ______

2. Are you interested in participating in future research on this topic?
    a. Yes ______
    b. No ______

If you responded Yes to any of these questions, how would you like to be contacted?

Name: ____

Email: ____

Phone: ____

Address: ____

APPENDIX J

MENTAL HEALTH/CRISIS INTERVENTION SHEET

Appendix J

Mental Health/Crisis Intervention Sheet

Kent State University LGBTQ+ Center:
Kent Student Center Room 024
LGBTQSC@kent.edu | Phone: 330-672-8580

Townhall II:
Main Number: 300-678-3006 | 24/7 Crisis Hotline: 300-678-HELP
155 North Water St, Kent OH 44240 | townhall2.com

CANAPI (Akron Pride Initiative):
759 W. Market St (1st Floor), Akron, OH 44303 | 330-252-1559 | canapi.org

Summa Health Pride Clinic:
1260 Independence Avenue, Akron, OH 44310 | 234-867-7740 |
www.summahealth.org/specializedservices/pride-clinic

The LGBT Center of Greater Cleveland:
6705 Detroit Ave, Cleveland, OH 44102 | 216-651-5428 | lgbtcleveland.org

MetroHealth Pride Clinic:
Thomas F. McCafferty Health Center | 4242 Lorain Ave, Cleveland, OH 44113
Schedule an appointment: 216-957-4905 | metrohealth.org/lgbtqi-pride-network

The Trevor Project: 1-866-488-7386

National Suicide Hotline: 1-800-273-8255

National Gay and Lesbian Hotline: 1-888-843-4564

APPENDIX K

DEMOGRAPHIC SHEET

Appendix K

Demographic Sheet

Instructions: Please provide a response for each of the following questions. You may skip any questions you prefer not to answer.

1. What is your age? _______
2. What is your postal zip code? ____________
3. With what gender do you identify most often? __________________________________
4. With what additional genders do you identify? _____________________________________
5. What are your preferred pronouns? ____
6. What is your partner/marital/relationship status? _________________________
7. With which racial or ethnic category do you identify? Choose all that apply.
    a. African American or Black ______
    b. Asian or Pacific Islander ______
    c. White ______
    d. Latinx or Hispanic ______
    e. American or Alaskan Native ______
    f. Multiracial ______
    g. Additional: _______________________
    h. Choose not to respond: ____________
8. What is your highest level of education achieved?
    a. No formal education credentials ______
    b. High school diploma or equivalent ______
    c. Some college, no degree ______
    d. Technical program/trade school diploma or certificate ______
    e. Associate degree ______
    f. Bachelor’s degree ______
    g. Master’s degree ______
    h. Doctoral or professional degree ______
    i. Choose not to respond: ____________

9. What is your annual household income?
    a. Less than $10,000 ______
    b. $10,000-$19,999 ______
    c. $20,000-$49,999 ______
    d. $50,000-$74,999 ______
    e. $75,000-$100,000 ______
    f. Greater than $100,000 ______
    g. Choose not to respond: ____________

APPENDIX L

INITIAL INTERVIEW GUIDE

Appendix L

Initial Interview Guide

1. What is your understanding of why I am talking with you today?
2. What does the word health mean to you?
3. What are the things that you feel most impact your health?
    a. Prompts/areas to explore: Family, friends, work, school, home environment, diet, exercise, mental health, daily activities
4. How does your gender relate to your health?
5. How do you think other people view your health?
6. Tell me about the first time you remember thinking about your health.
7. Is this the same event that caused you to explore your health or seek assistance related to your health? If not, please describe that event for me.
8. Tell me about some of the things that were going on in your life at the time this happened.
9. Did you ask for help with your health because of this event? If so, tell me about it.
    a. Prompts/areas to explore: Healthcare providers, dieticians, exercise specialists, specialty care like physical therapy, environment change, family, friends?
10. Tell me about your life since this happened.
11. Did this event change the way you view health/your health?
12. How do you see your future health?

Generic prompt to be used as needed:

1. Can you tell me more about that?
2. Why?
3. How?
4. Tell me what you are thinking.
5. How do you feel?

APPENDIX M

FOLLOW-UP INTERVIEW GUIDE

Appendix M

Follow-Up Interview Guide

1. Talk to me about how the journaling process was for you.
2. Can you share with me some of the things you wrote in your journal?
3. How have your thoughts about health developed over the past week?
4. During the first interview, you shared with me (xxx). Can you clarify your thoughts about that? (This may be asked about one or more items).
5. Is there anything else you would like to share?

APPENDIX N

THEMATIC ANALYSIS SUMMARY

Appendix N

Thematic Analysis Summary

Names	Emerged Themes & Health Conditions		Connections Across Emerged Themes & Health Conditions	Patterns Across Cases
Sam	Not seen/invisible Unheard/not listened Written off/dismissed Isolation Labeling/Assumptions (weight & gender) Misgendering Obesity PTSD/panic attacks	Gendering Dehumanized/humiliated Trauma/abuse/loss Healthcare trauma Disengaging from HC Bleak outlook Validation/advocacy Anxiety/depression IBS	**Gender as a salient narrative** -Labels -Assumptions -Inability to relate to others -Lack of peers -Lack of NBGD examples -Unsupportive parents -Gendering of HC -Combined female, binary cisgender, & binary transgender frustrations -Not being seen -Not being listened to -Invalidation **Finding support & validation for gender** -Counseling -Safe spaces -Supportive/like-minded people -Chosen families **Healthcare trauma &/or bad experiences** -Mistreatment -Procedural trauma -Assumptions/labels **Family & interpersonal trauma** -Physical abuse -Psychological abuse -Verbal abuse -Neglect -Sexual abuse -Sexual assault -Abusive relationships **Impact of gender experiences & trauma on the body** -Taking hits/body keeping score -PTSD -Depression -Anxiety -Panic attacks -Chronic pain -Disordered eating -Obesity -Negative outlook	**The Body Keeps the Score** Gender Trauma
Alex	Assumptions (gender) Being labeled Dehumanized Gendering Gender confusion Unheard/not listened Trauma/abuse/neglect Lack of validation Not protected Chronic pain/EDS PTSD Depression/Anxiety	Disengaging from HC Advocacy/validation Masking Food issues The Body Keeps the Score Safe spaces Counseling Gender dysphoria Bleak outlook Feeling judged by others Healthcare trauma Autism/ADHD Panic attacks		
Avery	Not understood Not believed Body Keeps the Score Food issues/Obesity Finding support Chosen family Counseling Isolation Sexual abuse Cis privilege Anxiety	Weight bias All or nothing behaviors Need to feel in control Adulting Neutral health outlook Lack of NBGD peers Unsupportive parents Validation ADHD Chronic pain/EDS		
Blake	Shame Fear of male HCP Sexual & verbal abuse Abusive relationships Disengaging from HC Putting other's needs first Adulting Invalidation/not seen Binary trans box/ privilege Depression/suicidality Autism/ADHD Anxiety/panic attacks	Not being seen/gendering Healthcare trauma Lack of support Finding support Counseling Validation Bleak health outlook Food issue Not understanding own gender Unsupportive parents Taking hits		

APPENDIX O

CITI CERTIFICATION

Appendix O

CITI Certification

CITI PROGRAM

Completion Date 12-Jan-2022
Expiration Date 11-Jan-2025
Record ID 46521130

This is to certify that:

Amy Veney

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

Social & Behavioral Research - Basic/Refresher
(Curriculum Group)
Social & Behavioral Research
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

Kent State University

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?wb6b97683-f422-404d-80eb-9db7f1989d37-46521130

APPENDIX P

IRB APPROVAL

Appendix P

IRB Approval

IRB Approval
672
The Nonbinary Gender Diverse People's Health Research Study

To: Stephenson, Pamela L

I am pleased to inform you that the Kent State University Institutional Review Board reviewed and approved your Expedited request for Approval to Use Human Research Participants.

Please refer to the study number 672 when communicating with us about this study.

Approved on: Monday, April 24th 2023
Approval type: Initial
Expiration date: Friday, April 24th 2026
Continuing review: Friday, April 24th 2026
If "No date provided" the study has not been assigned continuing review and does not expire.

View the protocol: kent.kuali.co/protocols/protocols/643945147ec281002a3fe2db

IMPORTANT:
Open the protocol to review any approval comments.
You must report any external funding or contract to our office (as well as Sponsored Programs).
You must use the IRB approved consent form(s) that can be accessed via Kuali.
This study was reviewed for compliance with Title 45 Part 46 of the Code of Federal Regulations, and if applicable, rules for the conduct of clinical trials and use of HIPAA regulated information.

Kent State University has a Federal Wide Assurance on file with the Office for Human Research Protections (OHRP); FWA Number 00001853.

To search for funding opportunities, please search Pivot at https://pivot.proquest.com/

If you have any questions or concerns, please contact the Office of Research Compliance at Researchcompliance@kent.edu or 330-672-8058.

On behalf of the IRB, thank you for your dedication to human subjects compliance,

Kevin McCreary, Director
Sarah Pfeiffer, Assistant Director

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