Investigating the Lived Experience of Asexual Identifying Individuals Navigating Healthcare

Mohima Meera

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Abstract

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Historically, health services have pathologized individuals because of their sexual orientation or gender identity, which contributes to avoiding or delaying seeking care and consequent later-stage diagnoses when many treatments are less effective. One determinant of seeking health care is the extent to which people feel accepted and welcome by health care providers. In recent years, progress has been made in some settings by improving patient experiences among people with different sexual orientations and gender identities. But there are few published studies on the healthcare experiences of people who identify with asexuality. This exploratory study aims to understand asexual (ace) individuals' experiences to inform ways to improve patient experience and health promotion. Grounded in phenomenological theory, a semi-structured qualitative interview was conducted via Zoom with 43 ace participants recruited from social media platforms. Through reflexive thematic analysis, it was concluded: (1) The continued lack of knowledge and understanding of asexuality and influence of compulsory sexuality in healthcare results in non-affirmative approaches to care, which negatively impacts ace patients' healthcare experience, (2) Patients report having positive healthcare experiences with providers who exercised cultural competency and humility, providing care in a patient-centered, trauma-informed approach, and (3) Institutional factors drive patients' overall healthcare experience. Implications of the findings and ideas for how healthcare practices and policies can be improved to be welcoming to ace patients are discussed. More empirical research

is needed to understand the health needs of the ace community, with the long-term goal of improving the availability and accessibility of healthcare services.

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Acknowledgments

"Our histories never unfold in isolation. We cannot truly tell what we consider to be our own histories without knowing the other stories. And often we discover that those other stories are actually our own stories." – Angela Davis (2015)

During the very little time I had to read for pleasure, *("reading for pleasure? You're saying people read for* displeasure?" Why, yes – ask anyone in academia.), I had the privilege of picking up Angela Davis's book "Freedom is a Constant Struggle: Ferguson, Palestine, and the Foundations of a Movement," from where I found this quote. I was recently asked by an acquaintance to share one thing that best summarized my dissertation experience. Aside from wanting to hand them a chewed-up dog toy – the toy representing me being chewed up and spat back out by life – this quote came to mind. Completing a dissertation is not an easy feat. And doing so in a post-pandemic world ravaged by ongoing structural and systemic violence – especially having to helplessly witness your tax dollars funding the most documented genocide in history in occupied Palestine (and is ongoing as I write this) – while dealing with plentiful personal challenges on top of all of that was even more difficult. Like many folks, I have been striving to leave this world better than how I found it. However, due to the current state of affairs, there were countless periods of disillusionment where I felt demoralized and demotivated, which further impacted my dissertation work. It was this very quote by Davis that offered me a glimmer of hope which kept me going. It was a reminder of how the ruling class aims to divide and isolate us to uphold the status quo. It is through acknowledging the interconnectedness of our personal struggles that we can achieve solidarity, further empowering each one of us to work together to forge a sustainable future – for all of us. I also felt that this

quote captured the very essence of my dissertation. Oftentimes we feel alone in our individual fight to live our truth, which especially applies to us aces struggling to have our asexuality recognized. The goal of my dissertation was to illustrate that we are not alone in this fight – our personal stories are vital in identifying the common struggles we aces face in healthcare. Our existence alone is a powerful driver for change, and together we have the potential to combat compulsory sexuality and create a world where being ace is universally recognized as just another way to be, like being heterosexual, for example.

I'm sure this is starting to feel like trying to look up a recipe online and getting hit with the blogger's generational story where you have to scroll like 20 pages to get to the ingredients and instructions (*"I don't care how your great-great-great grandmother twice removed came up with this recipe. I just want to make a soufflé!"*), so I will get to my acknowledgements. All of this was just to say this dissertation could not have been possible on my own – it was thanks to *my collective* that I was able to reach the finish line. I am incredibly grateful to many people who have influenced and supported me throughout this journey. And it was thanks to them I (hopefully) made a positive contribution to the world during my fleeting time in this universe as a mere mortal. I could even write a separate dissertation thanking each person, but I will spare everyone that torment. – and I'll try to keep this short (emphasis on *try*).

First, of course, I would like to thank **Angela Davis** for reminding me how each of us have the power to contribute to collective liberation. In similar vein, I want to acknowledge **all ace activists** (this includes widely known and unknown ace writers, influencers, scholars, etc.) who have helped to set the foundation for my research. Their efforts have allowed me to not only learn of my own asexuality and find a community where I feel I belong; they have inspired me to work towards achieving the goal of worldwide acceptance of asexuality.

Similarly, I would like to thank **Bhavya, Chandana, Shounima, Rachana, Rocky, and Vipasha** for being the vital starting block for my dissertation. Their continuous support helped motivate me to pursue my passion for ace research. Most importantly, it was their incredible thoughtfulness with helping me shape my dissertation idea that made this possible.

A TREMENDOUS thank you to my primary advisor, **Dr. Charles Basch**, for actualizing my passion. It has been an incredible honor to have his unwavering support throughout my dissertation journey. He is an incredibly humble individual – he often states he did very little to help me, but that is far from the truth (as you can already tell by the length of this paragraph). I had the great pleasure of meeting him by pure happenstance working as an Administrative Assistant for another faculty member in his department during my master's study. It was thanks to his insight into the field of public health education, and his encouragement, I applied to the Health Education Ed.D. program (little did I know that this is exactly where I wanted to land!). It was also thanks to him that I was even able to pursue a doctoral degree in the first place. I could not even fathom being accepted to any doctoral program, especially due to my countless pitiful performances on the GRE (I am sure you can tell I didn't do so hot on the reading and writing sections of the exam based on my writing style – don't even get me started on the math). Most importantly, it was thanks to him I was able do my dissertation focusing on ace experiences. We typically hear from other ace scholars of how their research pursuits exploring asexuality are often met with resistance from mentors, peer reviewers, and other scholars as it's deemed an "unworthy topic for academic pursuits" (Cerankowski & Milks, 2024). So, I was delightfully surprised and incredibly grateful that Dr. Basch candidly supported my idea. It was also thanks to his help that I was able to have 2 wonderfully supportive faculty members at Columbia, Drs. Matthew Zajic and Traci Schwinn, to be a part of my committee (who I will be thanking shortly).

And on top of all that, Dr. Basch has always provided me guidance at the drop-of-a-hat and provided me incredible grace and flexibility as I struggled to wrap up my dissertation dealing with comically endless personal challenges over the past couple of years (as my friends like to call it, *Mohima's Rock-Bottom Era*) (sidenote: even to this very moment, I have promised to have this version of my dissertation submitted to Dr. Basch about two weeks ago… sorry, Dr. Basch). Aside from these perpetual pestilent predicaments preventing my progression, my dissertation experience has been an absolute pleasure thanks to Dr. Basch. Had it not been for the typical financial barriers imposed by higher education institutions in the U.S., I would have loved to have extended my time working on my dissertation with him.

Subsequently, I would like to thank my equally marvelous committee members for whose support have been instrumental in this journey. I could not have asked for a better team of incredibly brilliant, kind, and thoughtful individuals to have guided me. To start, I would like to thank my second reader, **Dr. Matthew Zajic**. Dr. Zajic is well-known in our department to be the faculty member who is "never short on feedback." So, of course, I was incredibly thankful (albeit intimidated) that he agreed to be in my committee. Anytime I had submitted portions of my work for his review, I really appreciated how he always provided prompt and incredibly thoughtful constructive feedback – even though I am sure he was annoyed with me each time he had to review my work because it was never in TC's ODS required dissertation format (it was *always* the first critique he had). I also thank him for his invaluable suggestion of utilizing an existing theoretical framework to ground my analysis. As someone who is new to qualitative research, I initially felt lost and overwhelmed with trying to figure out how to even begin to make sense of my data. Thanks to Dr. Zajic's recommendation, selecting an existing conceptual

framework and adapting it to fit my study really helped me with developing codes for the analysis and presenting the findings in a structured way.

Next, I would like to thank my third reader, **Dr. KJ Cerankowski**, who I was honored to have on my committee. I consider KJ a veteran ace scholar whose work paved the way for novice ace researchers like me to even be able to pursue a study on asexuality. His research on asexuality and its intersection with trauma, feminist, and queer theory laid the vital foundation I needed to expand my scope to investigate ace experiences in healthcare spaces. I am incredibly grateful for his expert guidance on how to best conceptualize asexuality that is inclusive of all ace experiences (especially since there is ongoing discourse on how to best conceptualize asexuality within the ace community, I was struggling with how to effectively introduce and discuss asexuality within my study). On top of that, I appreciated KJ's warmth, compassion, flexibility, and support as I completed my dissertation among a myriad of challenges.

Lastly, I would like to thank my fourth reader, **Dr. Traci Schwinn**, for her generosity in agreeing to being my final committee member. I truly appreciated her patience, flexibility, understanding, and compassion as my dissertation plans abruptly and frequently changed soon after she joined my committee. I very much thank her for sticking around until the end, especially coming in with the expectation that my dissertation would be a short read, but only to her (and I'm sure to the rest of my committee's) horror my writing ending up being about 300 pages long. I am incredibly grateful for the fresh perspectives Traci brought in to help me further refine and communicate my thoughts.

As I expressed earlier, completing a doctoral program is not so easy. So, I am incredibly grateful for my fellow doctoral students' support as we all toiled through our theses troubles together. Thank you to **Emma Kaywin**, for allowing me to use their own dissertation as

inspiration to develop my qualitative study. I am grateful for their invaluable guidance with reflexive thematic analysis. Along with Emma, thank you to **Caitlin Larussa, Heather Nuskind, Lisa Brichacek,** and **Melissa Mendelson** for their thoughtful ideas and brilliant suggestions for interview questions – their insights and guidance have been instrumental for my study. And thank you to **Burcu Pekan, Pavita Singh,** and **Sabrina Dang** for their kindness and support as we all struggled completing our dissertation in solidarity. Overall, I am honored to have had opportunity to work with such talented individuals in my cohort. I am so very proud of us and I look forward to seeing us reach new heights.

Of course, the completion of my dissertation would not have been possible without the support of **all the participants** in this study. I am incredibly humbled and honored that they have trusted me to share their stories in hopes of making a difference – I hope I have represented everyone well. Every single person's contributions have been instrumental in putting a step forward towards universal recognition and understanding of asexuality. I hope that one day we get to experience universal acceptance of being ourselves.

A major shout out to my "motley crew" of kindred spirits for keeping me sane as we all live amidst the perils of environmental and societal collapse. Thank you to the following people for their unwavering support, for always checking on me, and for bringing joy in my life through our countless swapping of squalor stories, conspiracy theories, memes, TikToks, cute animal videos, and accompanying me on various video gaming adventures: **Kayla, Kristian, Stela, Kevin, Isaac, Kristine, Li, Lynn, Maggie, Tara, Taylor, Charisse,** and **Nadia**. I am truly blessed for our friendship. To answer the question my friends had for the longest time – *Yes, I guess I did finish writing my dissertation before Luffy found the "One Piece"* (a reference anime enthusiasts will understand).

Most importantly, thank you to my Dad and Mom, **Moasser** and **Neera**, for instilling their work ethic, determination, perseverance, humility, and empathy in me, which has allowed me to make it this far. I have been devastatingly heartbroken that my Dad had departed for greener pastures as I was very close to graduating. It has been incredibly difficult to complete my degree without my biggest cheerleader rooting me on. Although I will no longer be able to cross the finish-line with him by my side, I hope that he will accompany me in spirit. Dad, and Mom, *I hope I made you proud*.

My second to last acknowledgement goes to **myself** – *you did it, you aspirational fool*. Being forced to function "normally" in a world riddled with violence – living in an imperialist nation that would rather prioritize colonial pursuits than invest in the livelihood of their constituents, and similarly, completing my education at an institution that would rather punish their students for speaking up against ongoing genocides than divest from companies investing in these imperialist ventures – has been incredibly damaging to my spirit. And then on top of that, I had to navigate various personal challenges – with the biggest being losing my Dad. Despite these ongoing dispiriting circumstances, I have continued to persevere, holding onto my aspiration of leaving the world better than I have found it. I hope that with the completion of this dissertation, all thanks to the support of the many wonderful people I have mentioned above, I am not only able to help improve the healthcare experiences of my fellow aces, but to also help us to be unapologetically ourselves.

Last, but not least, my final acknowledgement goes to **you, reader**. Thank you for taking the time to learn more about us and our experiences. Maybe you are being made to read this dissertation for displeasure (because, truly, who would want to even read a dissertation? – "*ain't nobody got time for that!*"). Regardless, I encourage you to hone in on the participants'

narratives, because understanding their experiences is what really matters. I hope that after your engagement with these stories, we can garner your support in helping us gain universal recognition and acceptance of asexuality.

Dedication

This dissertation is dedicated to all my fellow aces. Navigating in an allonormative world can often be incredibly challenging. There may be times where you feel like no one seems to understand you and you begin to doubt yourself. Let this study serve as a reminder that you are valid and you are not alone. You are not broken – you are just the way you are meant to be. Live your truth. Don't try to change yourself for society – live so that society changes for you (as I always like to say, "just face it and *ace* it!"). May we all get to experience a world where being ace is universally acknowledged as just another way to be.

Chapter 1: Introduction

1.1 Background and Significance

Over the past few decades, public health care professionals and researchers have become increasingly aware of the range of health disparities and unique and challenging inequities in access to health care faced by Sexual and Gender Minority (SGM) communities (Mayer et al., 2008; Salcedo-Betancourt, Farouk, & Reddy, 2022). To define, health care encompasses services and delivery related to the health and well-being of individuals and communities, including preventive, diagnostic, therapeutic, rehabilitative, maintenance, monitoring, and counseling services (American Psychological Association [APA], 2025). A healthcare provider is a person or entity that provides medical care or treatment, such as doctors, nurse practitioners, labs, hospitals, urgent care clinics, and other professionals, facilities, and businesses that provide such services (Davis, 2024). SGM is an umbrella term used to describe individuals whose sexual orientation and gender identity or expression vary from traditional, societal, and cultural constructs of sexual orientation, gender, and/or sex (National Institutes of Health Sexual and Gender Minority Research Office [NIH SGMRO], n.d.; Salcedo-Betancourt et al., 2022). This definition includes but is not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex; individuals with same-sex or same-gender attractions or behaviors; those with a difference in sex development; and those who do not self-identify with one of these terms, but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender and/or sex (NIH SGMRO, n.d.).

Studies have consistently shown that SGM individuals are at increased risk of numerous health problems compared to heterosexual and cisgender individuals, including higher rates of

substance use disorders, violence victimization, HIV and other sexually transmitted infections, psychiatric disorders, and suicidality (Hsieh & Shuster, 2021; NIH Office of Disease Prevention, 2022). These disparate and poor health outcomes probably result from disproportionate exposure to inequitable and poorer-quality health care, marginalization and/or discrimination, and reduced access to health-promoting resources (Ayhan et al., 2020; Salcedo-Betancourt et al., 2022). In addition, until 1973, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) of the American Psychiatric Association designated "homosexuality" as a mental illness, which contributed to the stigmatization and pathologization of SGM individuals (Salcedo-Betancourt et al., 2022). Due to the history of healthcare services stigmatizing and pathologizing SGM identities, SGM individuals are more likely than non-SGM individuals to experience distrust of and dissatisfaction in healthcare settings and are less likely than heterosexual and cisgender individuals to seek or benefit from healthcare services (Mohottige & Lunn, 2019; Salcedo-Betancourt et al., 2022). Delayed or avoidance of healthcare can lead to increased risk and severity of negative health outcomes and can lead to increased treatment expenditures, hospitalization, and even mortality (Ng et al., 2020).

Despite political and social advances over the past decade, biased clinical interactions and suboptimal provider education with regard to SGM care persist, especially in regards to providing care to individuals who identify as asexual as their sexual orientation (Flanagan & Peters, 2020; Gupta, 2017; Salcedo-Betancourt et al., 2022). Asexuality can be best conceptualized as a spectrum or umbrella of identities that suggests multiple ways of experiencing an absence of sexual attraction, desire, or practice (see section on "Conceptualizing Asexuality" in **Chapter 1** for better understanding).

Throughout history, medical and psychological discourse often described the absence of sexual attraction, desire, or practice in pathologizing contexts (Cerankowski & Milks, 2010; Fedtke, 2014). In the 1980s, the DSM included the diagnosis of "Inhibited Sexual Desire," later changed to "Hypoactive Sexual Desire Disorder" (HSDD) was used to describe "persistently or recurrently deficient (or absent) sexual fantasies and desire for sexual activity" (APA, 1980; APA, 1987; Brotto, 2010; Hinderliter, 2015). It was only until the early 21st century that studies on human sexuality began separating asexuality from presumptive pathology, arguing that individuals who do identify as asexual are not characterized by 'marked distress' and 'interpersonal difficulty' as a result of an absence of sexual attraction or desire, both of which are necessary to obtain the diagnosis of HSDD (APA, 1994; Bogaert, 2006; Cerankowski & Milks, 2010; Przybylo, 2013). With advocacy from the asexual community for the exclusion of self-identifying asexual people from the diagnosis of HSDD, the APA (2013) included the following statement under the criteria for Female Sexual Interest/Arousal Disorder (FSAID) and Male Hypoactive Sexual Desire Disorder (MHSDD), which replaced HSDD, in the DSM-5: "If a lifelong lack of sexual desire is better explained by one's self-identification as 'asexual,' then a diagnosis of [FSAID or MHSDD] would not be made" (Ace Week, 2020; APA, 2013; Cerankowski & Milks, 2010). Although these changes have been implemented in 2013, asexual individuals have reported having felt that their mental health providers "did not seem to believe they were asexual," did not understand asexuality, or continued to attribute the absence of sexual attraction or desire to other clinical causes (Gupta, 2017b).

Although there has been a rise in research about asexuality within recent decades, the asexual community remains a largely unrecognized and understudied sexual minority group (MacInnis & Hodson, 2012). There is a dearth of information regarding health risks specific to

the asexual community. To begin filling this gap of knowledge, members of the asexual community formed The Ace Community Survey, and several questions within the survey inquired about the unique health needs of the community. The survey specifically inquired about rates of sexual violence, substance use, physical and mental health, and suicidality (Hermann et al., 2022). For a comprehensive discussion of the unique health risks of the asexual community identified by the Ace Community Survey, see **Chapter 2**. Highlighting some of the findings, of the 15,132 respondents from over 100 countries, 59.1% participants reported experiencing one type of contact sexual violence, which suggested that asexual respondents experienced generally higher levels of sexual violence compared to the National Intimate Partner and Sexual Violence Survey [NIPSVS] (Hermann et al., 2022). About 32.3% of respondents seriously thought about trying to kill themselves, 10.6% made plans to kill themselves, and 2.7% tried to kill themselves, which indicated that there is a higher rate of suicidal thoughts, plans, and attempts among asexual-identifying individuals compared to the general adult population in the United States (Hermann et al., 2022; Ivey-Stephenson et al., 2022). Although the Ace Community Survey cannot be considered to be representative of all asexual-identifying individuals in general, and taking into consideration that this survey included data from participants internationally which may have contributed confounding factors, there is reason to believe that the asexual community experience health disparities which are not being captured in healthcare (Hermann et al., 2022). This survey emphasized the need for more empirical studies to investigate the specific health risks of the asexual community.

1.2 Research Purpose and Goal

With the understanding of the asexual identity being historically pathologized and the preliminary insight into unique health risks of the community via the Ace Community Survey, there is a possibility that asexual-identifying individuals are less likely than other SGM individuals to seek healthcare due to distrust and dissatisfaction. To begin addressing this concern, a small number of studies have investigated asexual-identifying individuals' experiences in clinical settings. Specifically, studies have investigated 1) how relevant asexual individuals find their identity to be relevant to their well-being, 2) the attitudes and expectations asexual individuals have towards healthcare providers, and 3) elucidating specific interactions they have had with their healthcare practitioners. However, there has not been a study conducted investigating healthcare-seeking experiences of asexual-identifying individuals. This study aims to understand ace individuals' experiences receiving and seeking healthcare to help improve patient experience and health promotion.

1.3 Healthy People 2030

Healthy People 2030 is the fifth and current iteration of the Healthy People initiative, which sets data-driven national objectives to improve health and well-being over the next decade (U.S. Department of Health and Human Services [USDHHS], n.d.). Building upon knowledge over the last four decades, the current *Healthy People 2030* initiative has an increased focus on health equity, social determinants of health, and health literacy (Office of Disease Prevention and Health Promotion [ODPHP], 2021).

The goals of this study are in alignment with the mission of *Healthy People 2030* to promote health equity and evaluate the social determinants of health. This research aim to contribute to the achievement of the following *Healthy People 2030* objectives (USDHHS, n.d.):

> *Increase the proportion of adults who get recommended evidence-based preventive health care — AHS-08.* Access to preventive health care can prevent both disease and early death. The number of people getting preventive services has increased in recent years, but there are disparities by age and race/ethnicity. Strategies like providing team-based care and reducing copays can help people get recommended preventive care services (USDHHS, n.d.).

Although this objective does not explicitly mention disparities among SGM communities, as discussed, SGM individuals are less likely than non-SGM individuals to seek preventative healthcare due to distrust and dissatisfaction with healthcare services. By asking participants about their healthcare experiences, and for ideas about improvements in healthcare to make healthcare more accessible to ace identifying individuals, this study aims to bring insight into strategies healthcare services can implement to help improve healthcare-seeking behaviors of adults.

> *Increase the ability of primary care and behavioral health professionals to provide more high-quality care to patients who need it — AHS-R01.* This objective currently has research status, meaning it is a high-priority public health issue that doesn't yet have evidence-based interventions developed to address it. It may or may not have reliable baseline data available. If both baseline data and evidence-based interventions become available, this objective may become a core Healthy People 2030 objective (USDHHS, n.d.).

SGM individuals have unique health risks requiring competent care from healthcare providers. As discussed, asexual-identifying individuals reported that their healthcare providers were not knowledgeable of ace identities. By asking participants for ideas about improvements in healthcare to make healthcare more accessible to ace identifying individuals, this study aims to bring insight into ways providers can provide competent care to ace individuals.

> *Decrease the proportion of adults who report poor communication with their health care provider — HC/HIT-02.* Good communication between health care providers and patients is part of high-quality care, but many people have trouble talking with their health care providers. Poor patient and provider communication can involve listening, explanations, disrespect, and time. Strategies to improve communication between health care providers and patients can lead to better prevention, diagnosis, treatment, and self-management of diseases (USDHHS, n.d.).

Chapter 2 will discuss the various healthcare barriers SGM individuals face when seeking healthcare, including provider-level barriers which highlight communication barriers. By asking participants to share their healthcare and patient-provider experiences, and ideas for improvement, this study can bring insight into how to address this objective.

1.4 Conceptualizing Asexuality

Asexuality has traditionally been defined in academic literature as, "a sexual orientation described as individuals experiencing a lack of sexual attraction" (Bogaert, 2004; Bogaert, 2006; Brotto & Yule, 2017; Brown et al., 2021; Conley-Fonda & Leisher, 2018). However, this conceptualization is largely critiqued because, 1) "Lack" insinuates a negative connotation, as something missing or needs to be fixed. (Chen, 2020; Decker, 2015); 2) This definition restricts the asexual label to only describe attraction, and does not successfully capture the diversity of experiences of attraction, relationships, and arousal within the asexual community (Carrigan, 2011; Chasin, 2013; Conley-Fonda & Leisher, 2018; DeLuzio Chasin, 2011). Additionally, there is criticism of establishing a standardized definition, as 1) the multiplicity of aceness is difficult to capture within a singular definition (Chasin, 2019), 2) it may lead to folks feeling they need to have certain experiences to "qualify" as being ace, which is the antithesis of the mission of inclusivity the asexual community aims to achieve (Siggy, 2023). There has been ongoing discourse within the ace community regarding the best way to holistically conceptualize

asexuality, with the goal of effectively educating others about asexuality, especially to those who may be questioning their sexuality.

In essence, readers should understand that asexuality is experiencing sexuality that is different from the normative understanding – i.e. a spectrum of experiencing sexuality to not experiencing sexuality. For the purposes of guiding the discussion within this study, asexuality will be conceptualized as a spectrum or umbrella of identities that suggests multiple ways of experiencing not as much to not experiencing sexual attraction, desire, or practice. To further help with the conceptualization, the following four examples illustrate ways of experiencing asexuality (though this is not meant to be exhaustive):

- **Person 1:** An ace individual enjoys engaging in sexual behavior, but is not sexually attracted to others.
- **Person 2:** An ace individual does not enjoy engaging in sexual behavior, but is sexually attracted to others.
- **Person 3:** An ace person sometimes or rarely enjoys engaging in sexual behavior, and is sometimes attracted to others or feels sexual attraction to others.
- **Person 4:** An ace person who does not enjoy engaging in sexual behavior, nor experience sexual attraction.

Additionally, some folks may just use the label "asexual" to describe their experience. Other folks may like to use more specific labels (see **Appendix A** for a non-exhaustive list of identity labels ace folks often use). **Chapter 4** includes narratives of participants sharing "What being ace means to them," to further highlight the diversity of identification within the ace community. In essence, however an individual choses to describe their asexuality is valid.

Also, please note the term “asexual” and “ace” may be used interchangeably throughout this study, intending to be inclusive of all experiences within the asexual spectrum. Based on context, the term “asexual” may be used by participants to describe the identity of experiencing very little to not experiencing sexual attraction.

Chapter 2: Literature Review

2.1 Introduction

Little research exists in the literature specifically on the lived experience of self-identifying asexual individuals navigating healthcare. Although this review aims to be comprehensive, it is far from exhaustive in terms of discussed topics and findings. As such, what follows is a review of a breadth of adjacent literature relevant to the understanding of asexuality, in addition to covering the existing literature on asexuality in regard to healthcare.

This literature review will begin with an inquiry into asexuality, as this topic is necessary for understanding the experiences of individuals who identify as asexual (ace). This inquiry is not all-inclusive, as there is various literature regarding the conceptualization of asexuality than it is feasible to include here. Instead, the **Understanding Asexuality** section aims to provide an introduction to asexuality, which includes a historical overview of the conceptualization of asexuality and how to best describe the asexual community.

The next section, **Sexual and Gender Minority Healthcare,** will be an inquiry into the healthcare of sexual and gender minority communities. This section is delimited to the literature that is the most significant and relevant to the research topic. This section will include an introduction to Sexual and Gender Minorities (SGM), an overview of the medicalization and stigmatization of SGM identities, barriers to healthcare faced by SGM individuals, unique health outcomes of SGM individuals, and current efforts being made to address these barriers.

This chapter will conclude with an overview of the literature on asexuality in relation to healthcare. The **Asexuality and Healthcare** section will focus on existing literature related to the research topic. This section will include a discussion of existing healthcare literature in regard to the asexual community and the gaps in knowledge that this study aims to address.

Literature was identified primarily through the use of relevant keywords through Google Scholar, with follow-up based on the review of individual papers' bibliographies and works cited. The literature has not been delimited by time period, as much of the seminal work into asexuality violence is from the 1980s to 2000s. Whenever possible, both older, more foundational texts and more recent inquiries are included.

2.2 Understanding Asexuality

2.2.1 Introduction of Asexuality

Prior to 2004, asexuality was a term primarily used to describe the reproductive patterns of single-celled organisms (Brotto & Yule, 2017). With the rise of empirical research on human sexuality in recent decades, asexuality has grown to be used to describe one's sexual identity. Although there is not a singular definition of asexuality, various academic sources generally refer to it as a sexual orientation describing "a lack of sexual attraction" (Bogaert, 2004; Bogaert, 2006; Brotto & Yule, 2017; Brown et al., 2021; Conley-Fonda & Leisher, 2018). The Asexual Visibility and Education Network (AVEN), an organization aimed to create awareness and promote acceptance of asexuality, defines the asexual (ace) identity as:

> An asexual person is a person who does not experience sexual attraction. Unlike celibacy, which is a choice to abstain from sexual activity, asexuality is an intrinsic part of who we are, just like other sexual orientations. Asexual people have the same emotional needs as everybody else and are just as capable of forming intimate relationships. (AVEN, n.d.).

While is not within the scope of this project, it is important to note that there is contention among the ace community regarding this mainstream definition of asexuality, which is largely used in academic literature. For instance, the use of the language "lack" implies a slew of negative associations, such as broken or deficient, implying asexuality is a disorder needing to be

"fixed" (Chen, 2020; Decker, 2015). Additionally, this definition insinuates that asexuality solely refers to an absence of sexual attraction, and it does not successfully capture the diversity of experiences of attraction, relationships, and arousal within the asexual community (Carrigan, 2011; Chasin, 2013; Conley-Fonda & Leisher, 2018; DeLuzio Chasin, 2011).

To best conceptualize asexuality, this section will include a historical overview of asexual discourse in relation to healthcare, followed by a description of the asexual community, and conclude with an inclusive definition of asexuality that will be used as a reference throughout this study.

2.2.2 Historical Overview of Asexuality

Early conceptualizations of human asexuality can be found in nineteenth-century medical and psychological discourse, solely in pathologizing contexts (Cerankowski & Milks, 2010; Fedtke, 2014). During this time, there was a surge of interest in human sexuality in attempts to unveil the origins of mental illness in sexual behavior (Filipova, 2018; Foucault, 1978). In *Psychopathia Sexualis* (1886), German psychiatrist Richard von Krafft-Ebing described dozens of cases of sexual dysfunctions, including *anaesthesia sexualis* which is explained as "an absence of sexual instinct" or "an absence of sexual feeling" (Filipova, 2018, p. 108; Krafft-Ebing, 1886, pp. 36-42). Krafft-Ebing distinguished between both definitions: "absence of sexual instinct" was a 'congenital anomaly,' whereas "absence of sexual feeling" was acquired (Fedtke, 2014, p. 531; Krafft-Ebing, 1886, pp. 36-42). Krafft-Ebing referred to *anaesthesia sexualis* as an illness as a result of "cerebral disturbances, states of psychical degeneration, and anatomical signs of degeneration" (Filipova, 2018, p. 108; Krafft-Ebing, 1886, pp. 42-47). Similarly, in *Sappho und Sokrates* (1865) German sexologist Magnus Hirschfeld uses the term *anaesthesia*

sexualis to describe "individuals who are without any sexual desires" as a result of sexual dysfunction (AVEN, 2014; Hirschfeld, 1896, p. 6). Although these early mentions of individuals without sexual feelings or instinct were pathologized, and cannot be taken as the first scientific mentions of asexuality as a sexual orientation, both Krafft-Ebing and Hirschfeld's works are important in challenging the notion that all human beings are naturally sexual, and the definition of *anaesthesia sexualis* set the stage for the current understanding of asexuality (Filipova, 2018).

Modern conceptualizations of asexuality as an orientation can be attributed to American sexologist Alfred Kinsey (Filipova, 2018). Based on extensive interviews with heterosexual and sexual minority participants, and learning about their past and present behavior and attractions, Kinsey popularized the notion that human sexuality is fluid and does not fall neatly into the dichotomous categories of exclusively heterosexual or exclusively homosexual (Filipova, 2018; Galupo et al., 2014; Kinsey et al., 1948). To illustrate that one's sexual behavior and interests fall along a continuum between these two extremes and are subject to change over time, Kinsey developed the famous Heterosexual-Homosexual Rating Scale, more commonly referred to as the "Kinsey Scale" (Galupo et al., 2014). Human sexuality was measured on a seven-point scale, ranging from 0 being *exclusively heterosexual* to 6 being *exclusively homosexual* (Filipova, 2018; Kinsey et al., 1948). A separate category labeled "X" was added to the scale to represent individuals with "no socio-sexual contacts or response," which alludes to the modern definition of asexuality (Brotto & Yule, 2017; Kinsey et al., 1948; Stange, Oyster & Sloan, 2011). Although Kinsey described a category of individuals that did not experience sexual response, the category "X" did not incorporate such a designation on the scale itself (Galupo et al., 2014; Przybylo, 2013). It is important to note that Kinsey did not further investigate the absence of sexual response, nor employed the term 'asexuality,' due to his primary focus on disrupting

conservative views of human sexuality in regard to heterosexuality and homosexuality (Przybylo, 2013). In the study conducted by Galupo et al. (2014), which investigated how individuals of sexual and gender minority identities perceived the Kinsey Scale, a participant noted, "The fact that asexual is not really on the actual Kinsey scale would indicate a failure. I also feel that my asexual identity is more complicated than a simple checked box" (Galupo et al., 2014, p. 418). Additional limitations to Kinsey's Scale include its assumption that gender is binary, misrepresenting bisexuality as being a "halfway point" between heterosexuality and homosexuality, and not taking into account that sexual and romantic attraction can differ (Wang, 2022; Zietsch & Sidari, 2020).

To address the limitation of the 'unidimensionality' of the Kinsey Scale, which is limited to capturing the heterosexual and homosexual experience, American psychologist Michael Storms engaged in a remodeling of Kinsey's sexuality scale, producing the sexual orientation of asexuality as a byproduct (Przybylo, 2013). Storms created a "Map of Erotic Orientation" in a form of a four-quadrant axis, with categories of heteroerotic, homoerotic, ambierotic, and anerotic (Storms, 1980). Storms classified heterosexual individuals as being highly attracted to the other sex (i.e. high in heteroeroticism), homosexual individuals as being highly attracted to the same sex (i.e. high in homoeroticism), bisexual individuals as being highly attracted to both sex (i.e. high in both heteroeroticism and homoeroticism, being in the ambierotic quadrant), and asexual individuals who are not attracted to either sex (i.e. low in both heteroeroticism and homoeroticism, being in the anerotic quadrant) (Bogaert, 2004, p. 279; Storms, 1980, pp. 784-785). A significant limitation of Storms' model is the assertion that fantasies alone construct sexual orientations, which has not been shown to be valid (Swan, 2018). Although Storms' model can be attributed to being the first sexuality scale to incorporate a component for

asexuality, it is important to note that asexuality was still only a theoretical possibility and a small element of Storms' work which was not further investigated (Chasin, 2013).

Like Storms around this time, several researchers took up asexuality unconsciously, taking for granted its status as a sexual orientation (Przybylo, 2013). However, these researchers created proximity to pathology for asexuality (Przybylo, 2013). American psychologist Paula Nurius suggested that asexuality is associated with a greater risk for 'clinical dysfunctions' such as depression, lower self-esteem, and lower sexual satisfaction (Nurius, 1983). Similarly, American sexologists William Masters, Virginia Johnson, and Robert Kolodny linked asexuality with negative and pathological traits in their work (Przybylo, 2013). They employed asexuality as a typology of homosexuality, referring to it as 'asexual homosexuality.' They emphasized that homosexual individuals, like heterosexual individuals, have diverse sexualities, and asexual homosexual individuals are "those low in sexual interest and activity and not 'coupled'" (Masters, Johnson & Kolodny, 1988, p. 365; Przybylo, 2013, p. 229). Reviewing a study by Bell and Weinberg (1978), they linked asexual homosexuality with negative traits, such as being 'least happy of all homosexuals,' as 'worse off psychologically,' having 'considerable difficulty coping with life,' and 'generally loners' (Masters et al., 1988, p. 365; Przybylo, 2013, p. 229). These descriptors are affectively charged and imbued with a fear of singlehood, equating asexuality with asociality - an inability to network or bond with others through friendships, romantic partnerships, and sex (Przybylo, 2013).

With research interests in sex therapy booming in the 1980s, the American Psychiatric Association (APA) introduced dramatic changes to the Diagnostic and Statistical Manual of Mental Disorders - 3rd edition (DSM-III), which included the addition of a section on sexual dysfunctions (APA, 1980; Hinderliter, 2015). Prior to this inclusion, psychiatrists and

psychologists often used unofficial diagnostic systems, and the DSM-III provided a system of standardization (Hinderliter, 2015; Seagraves, Balon & Clayton, 2007). Of the sexual dysfunctions listed, "Inhibited Sexual Desire" was used to describe "persistently or recurrently deficient (or absent) sexual fantasies and desire for sexual activity" (APA, 1980, p. 278). In the DSM-III-R (1987) the name was changed to "Hypoactive Sexual Desire Disorder" (HSDD) because the former name suggested a psychoanalytic, and potentially ambiguous, etiology (APA, 1987, p. 292; Brotto, 2010; Hinderliter, 2015). The judgment of deficiency or absence is made by the clinician, who takes into account factors that affect sexual desire, such as age, health, and context of the person's life when making the diagnosis (APA, 1987, p. 292). The name and criteria for HSDD remained the same in the DSM-IV, except that the criterion of having "marked distressed or interpersonal difficulty" was added (APA, 1994; Brotto, 2010, p. 222). HSDD is considered to be the official link to pathologizing the disinterest in sex. Although there are diagnostic cases that demand psychiatric or medical attention, the presumption that all cases of disinterest in sex are pathological "contributes to the pejorative flavor of the word 'asexual'" (Cerankowski & Milks, 2010, p. 653).

It was only until the early 21st century that studies on human sexuality began separating asexuality from presumptive pathology (Cerankowski & Milks, 2010, p. 653). Canadian social psychologist Anthony Bogaert is often credited with being the first to argue against the pathologization of asexuality, and to view "a lack of sexual attraction" as a unique sexual orientation (Cerankowski & Milks, 2010; Pryzbylo, 2013). Bogaert distinguished asexuality from HSDD by arguing that asexual-identifying individuals are not characterized by 'marked distress' and 'interpersonal difficulty,' both of which are necessary to obtain the diagnosis of HSDD (APA, 1994; Bogaert, 2006; Przybylo, 2013). To further support Bogaert's claims, Prause

and Graham (2007) argued that the distress asexual identifying individuals may feel may be due to feeling the pressure to conform to the expectation of having sexual desire, and "then a psychiatric diagnosis implying abnormality may exacerbate concerns of an asexual individual" (Prause & Graham, 2007, p. 353).

In 2007, the APA formed the DSM-5 Task Force to begin revising the manual for publication in 2013 (APA, n.d.). At this time, members of the Asexuality Visibility Education Network (AVEN) formed a committee to advocate for the exclusion of self-identifying asexual people from the diagnosis of HSDD (Ace Week, 2020; Cerankowski & Milks, 2010). The DSM-5 ultimately replaced HSDD with two new disorders: Female Sexual Interest/Arousal Disorder (FSAID) and Male Hypoactive Sexual Desire Disorder (MHSDD). Under both diagnostic criteria, it is mentioned: "If a lifelong lack of sexual desire is better explained by one's self-identification as 'asexual,' then a diagnosis of [FSAID or MHSDD] would not be made" (APA, 2013). While this inclusion was thought to be a step in the right direction, there are criticisms raised by members of the asexual community, such as asexuality not being mentioned in the Desk Reference version of DSM-5 and having quotes around the term asexual under the FSAID criteria giving the unintended side effect of delegitimizing asexuality in the minds of the reader (Asexuality Archive, 2015). This indicates that more research and collaboration are needed with the asexual community to address these limitations and to better inform healthcare practice.

2.2.3 Describing the Asexual Community

In 2001, Asexuality activist David Jay founded The Asexual Visibility and Education Network (AVEN), a web community with the aims of creating public acceptance and discussion of asexuality and facilitating the growth of an asexual community (AVEN, n.d.). The flourishing

of the asexual community via the internet is attributed to technological revolution. Members of AVEN are located around the world coming from various backgrounds and identities (Cerankowski & Milks, 2010). Over the years, AVEN became the largest asexual community, amassing over 30,000 members by January 2006 (Cerankowski & Milks, 2010). AVEN is largely given credit for the conceptualization of asexuality.

In the influential article 'Asexuality: Prevalence and Associated Factors in a National Probability Sample,' Bogaert (2004) utilized data from the UK National Survey of Sexual Attitudes and Lifestyles published by Johnson et al. (1994) to investigate the prevalence of asexuality. Based on the data, Bogaert estimated that 1.05% of participants were asexual. However, several researchers argued that this estimation is not accurate or reliable (DeLuzio Chasin, 2011; Hinderliter, 2009; Prause & Graham, 2007; Przybylo, 2013). Initially, the estimate was based on data collected from the UK and for purposes unrelated to asexuality, not accurately reflecting the global prevalence of asexuality and not addressing self-identification of asexuality in any way (DeLuzio Chasin, 2011; Prause & Graham, 2007). Subsequently, since the data was collected prior to the existence of the asexual community, and did not allow individuals to self-identify as asexual, Bogaert's one percent is uncertain (DeLuzio Chasin, 2011; Przybylo, 2013). Lastly, Bogaert's determination of asexuality as individuals who "have never felt sexually attracted to anyone at all," restricts asexuality in regards to attraction and not sexual desire, which neglects the diversity of identities and experiences within the asexual community and assumes asexuality to be lifelong and absolute (Hinderliter, 2009, p. 620; Prause & Graham, 2007, p. 342). Despite these critiques, many studies continue to use Bogaert's (2004) one percent prevalence rate to describe the asexual community across the globe (Przybylo, 2013).

As discussed in **Chapter 1**, there has been ongoing discourse regarding reconceptualizing the mainstream understanding of asexuality, with a recent rise in asexuality research exploring ways to holistically conceptualize asexuality to effectively capture the diversity of identities and experiences within the ace community (Chasin, 2019). Cerankowski and Milks' (2024) call for "a pluralization of asexualities" to not only move beyond the singular conceptualization of asexuality – where early scholarly work defined it as an umbrella term for various iterations of sexuality that entails little to no experience of sexual desire or attraction – but to also "push asexual theorizing beyond identity and orientation together" (p. 1). Their ongoing work aims to expand upon the understanding of asexuality regarding how asexuality offers new ways of understanding sex, sexuality, romance, kinship, identity, selfhood, intimacy, friendship, and humanness through analysis within feminist and queer theoretical lens – the intersectionality of asexuality and gender, race, age, disability, nationhood, and more (Cerankowski & Milks, 2024, p.2). Similarly, writer Angela Chen calls for the conceptualization of "Ace" as a verb rather than a noun or adjective, where Chen argues that the emphasis of asexuality as a sexuality identity prevents from seeing "ace" within larger structures, such as challenging compulsory sexuality – the normative assumption that all individuals experience sexuality and engage in sexual behavior (Chen, 2020; Cerankowski & Milks, 2024; Gupta, 2015; Jacobs & Seymour, 2024). While there is ongoing discourse regarding an acceptable inclusive conceptualization of asexuality, the key-takeaway is there is diversity within asexuality that needs to be acknowledged. To best understand the heterogeneity that exists within the ace community, asexuality is best conceptualized on a spectrum, and self-identifying asexual individuals use certain identity labels within the ace spectrum to describe their experience (Bradshaw et al., 2021). For example, individuals may identify themselves as gray-asexual to describe experiencing occasional

attraction in isolation or with specific partners, to varying levels (p. 2). Individuals who identify themselves as demisexual use this label to describe only experiencing sexual attraction when an emotional bond is formed (Bradshaw et al., 2021). For a more comprehensive but non-exhaustive list of identities used in the asexual community, please refer to **Appendix A**. Similarly, please see **Chapter 4** section "What Does Being Asexual Mean to Participants?" to find how participants personally define their asexuality.

To gain a better insight into how many individuals identify with asexuality, along with capturing the diversity within the ace community, several members within the ace community developed the Ace Community Survey. Annually since 2014, the Ace Community Survey has collected data including, but not limited to, general demographics, identity navigation, discussion of discrimination, sexual violence, and health and ability (Hermann et al., 2022). In the 2020 report, approximately 15,000 individuals from 109 different countries participated in the survey. An advantage of this report compared to the estimation provided by Bogaert (2004) is this survey is more representative of global estimates of asexuality via self-identification. Similarly, responses demonstrated the co-occurrence of queer sexual identity across other sexual orientations – e.g. individuals identifying as pansexual and asexual – in addition to romantic identities, which captures the diversity of identities and experiences within the ace community (Hermann et al., 2022, p. 109-112). While this annual survey is well revered by the ace community, the findings from this survey have not been utilized in academic literature.

2.2.4 "Defining" Asexuality for the Purposes of This Study

The purpose of this study is to understand the lived experience of self-identifying ace individuals navigating healthcare. In order to accomplish this, as discussed in **Chapter 1**, it is

necessary to conceptualize asexuality in a way that successfully captures the diversity of individuals who do identify with asexuality. Thus, in this study, asexuality is conceptualized as an umbrella term inclusive of multiple ways of experiencing not as much to not experiencing sexual attraction, desire, or practice.

2.3 Sexual and Gender Minority Healthcare

2.3.1 Introduction of Sexual and Gender Minority Healthcare

Sexual and Gender Minority (SGM) is an umbrella term that encompasses populations whose sexual orientation and gender identity or expression vary from traditional, societal, and cultural constructs of sexual orientation, gender, and/or sex (National Institutes of Health Sexual and Gender Minority Research Office [NIH SGMRO], n.d.). Populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex (NIH SGMRO, n.d.). Individuals with same-sex or same-gender attractions or behaviors and those with a difference in sex development are also included (NIH SGMRO, n.d.). It is important to note that SGMs are not a monolithic group, and several decades of work documented the diverse range of identities, experiences, and structural forces that shape the experiences of SGM individuals (Hsieh & Shuster, 2021).

Due to the documented history of pathologization, stigmatization, and discrimination faced by SGM communities in healthcare, research on health and healthcare experiences of Sexual and Gender Minority (SGM) communities has grown rapidly in the last two decades (Hsieh & Shuster, 2021). This section will begin by providing an overview of the medicalization and stigmatization of SGM individuals, followed by a discussion of barriers faced by SGM

individuals and the resulting healthcare outcomes due to these barriers, and concluding with the discussion of current efforts being made to address the healthcare barriers experienced by SGM communities.

2.3.2 Medicalization of Sexual and Gender Minority Identities

Medicalization refers to the process by which human problems come under the control of medical authority and become classified as something to be diagnosed, treated, and potentially cured (Conrad, 1992; Johnson, 2019; Zola, 1972). In healthcare interactions, the use of diagnostic labels has allowed providers to make meaning of circumstances surrounding the etiology of unknown symptoms, illnesses, or diseases, and provides convenient means for communicating the expected course and prognosis of the condition to patients and healthcare professionals (Garand et al., 2009; Hsieh & Shuster, 2021). However, an ongoing concern for many SGM health scholars is how sexual and gender identity has been historically recognized and labeled as a medical problem in healthcare (Conrad & Schneider, 2010; Hsieh & Shuster, 2021). By conscribing the understanding of gender, sex, and sexuality within biomedical models, medicalization has been found to pathologize difference, rather than treating diversity as a part of a natural variation (Conrad & Schneider, 2010; Fausto-Sterling, 2000; Hsieh & Shuster, 2021).

While labels have been found to provide patients with a sense of community and a way to validate their experiences, several health scholarships have highlighted the disadvantages of using labels, especially for SGM individuals (Hsieh & Shuster, 2021). Negative consequences of labeling include social control and increased surveillance over normative behaviors or people (Conrad & Schneider, 2010). For example, providers pathologized intersex and trans people by pathologizing non-normative bodies, which in doing so, they maintained authority over intersex

and trans people while going to great efforts to align embodiment along binary and normative constructions of sex and gender (Davis, Dewey & Murphy, 2016; Hsieh & Shuster, 2021).

Additionally, scholars have highlighted the difficulty of changing or abandoning diagnoses once incorporated into medical diagnostic manuals (Hsieh & Shuster, 2021). Although "homosexuality" was removed from the DSM in the 1970s after robust activism by the gay community, several members of the gay community were suspicious that the new appearance of the diagnostic criteria "gender identity disorder" would continue to enable the medical community to treat lesbian, gay, bisexuality, and queer sexuality as a disease (Rottnek, 1999, p. 22). As of DSM-5, the diagnosis of "gender dysphoria" remains, and the diagnostic criteria remain contested by the SGM community and several SGM scholars because it symbolically conveys that being a gender minority is an illness (Dewey & Gesbeck, 2017; Hsieh & Shuster, 2021; Johnson, 2019). As a result of historical practices of labeling SGM individuals as "abnormal, perverted, or deviant," SGM communities have been disempowered and the medical establishment remains a key driver of the maintenance of medical authority over sexual and gender non-normativity (Hsieh & Shuster, 2021; Paine, 2018; Shuster, 2019).

2.3.3 Stigmatization of Sexual and Gender Minority Individuals

Another consequence of the medicalization of SGM identities is stigmatization associated with diagnostic labeling. According to Goffman (1963), stigma refers to "an attribute that is deeply discrediting within a social interaction" (p. 3). Individuals who are stigmatized are considered "undesired and shameful, and reduced from a whole and usual person to a tainted, and discounted one" (Goffman, 1963, p. 3). Stigma enables varieties of discrimination that ultimately deny individuals or groups full social acceptance, reduce individuals' opportunities,

and fuel social inequalities (Goffman, 1963; Parker & Aggleton, 2003; Stangl et al., 2019). As mentioned earlier, due to the medicalization of SGM identities, SGM individuals are often stigmatized as being abnormal or deviants.

In addition, people with certain diagnostic labels may also experience self-stigma, or internalization of the stereotypes held by the general public (Corrigan, 2007; Garand et al., 2009). Even when the opportunities are available, many individuals with internalized or self-stigma deter from seeking treatment and social services to avoid the stigma-associated labels (Garand et al., 2009). Individuals may choose not to seek healthcare as a means of protecting themselves from embarrassment and feelings of inferiority or incompetence (Garand et al., 2009; Nadler, 1987; Wills & DePaulo, 1991). Stigma is well-documented as being a global barrier to health-seeking behavior, engagement in care, and adherence to treatment across a range of health conditions (Corrigan, 2004; Link & Hatzenbuehler, 2016; Mahajan et al., 2008; Scott et al., 2015; Stangl et al., 2019).

2.3.4 Barriers to Care

The invisibility of SGM healthcare needs and experiences has significant implications in terms of the provision of evidence-based, culturally competent healthcare (Colpitts & Gahagan, 2016). SGM individuals consistently experience various barriers to optimal care, clustering around 3 main issues: (1) healthcare provider-related barriers, (2) reluctance by SGM patients to disclose sexual or gender identity when receiving care, and (3) structural barriers that impede access to health insurance and limiting visiting and medical decision-making rights for SGM individuals and their partners (Ayhan et al., 2020; Mayer et al., 2008; Hsieh & Shuster, 2021).

Provider-Level Barriers. Common provider-level barriers include lack of culturally competent training in medical education, prejudice, refusing treatment, and disrespectful behaviors (Davis et al., 2016; Dickey et al., 2016; Giffort and Underman, 2016; Hsieh & Shuster, 2021; Sabin, Riskind, & Nosek, 2015).

SGM individuals may first experience a healthcare provider-related barrier even before meeting face-to-face with healthcare providers. Patients may experience microaggression when asked to complete non-affirming intake forms (Holt et al., 2018; Hsieh & Shuster, 2021; Smith, Shin, & Officer, 2012). For example, forms that only allow for a selection of "male" or "female" when asking a patient for their gender or sex create a microaggression by reinforcing the sex/gender binary and may show little consideration for SGM identities (Holt et al., 2018; Smith et al., 2012). This may lead to felt stigma prior to face-to-face interaction with providers, which may keep SGM patients from disclosing their sexual or gender identity or fearing refusal of care (Goines & Pye, 2013; Holt et al., 2018).

Healthcare providers may unintentionally interact with SGM patients with bias as they draw on their hetero-normative understandings of "proper" gender and sexual behavior and expression when providing care to SGM patients, and this can have lasting negative consequences in the diagnosis and prognosis of illness and patterns of SGM individuals seeking healthcare (Hsieh & Shuster, 2021). For example, gender-nonconforming individuals reported experiencing "embodied disruptions" whenever healthcare providers referred to body parts using standard medical language that is explicitly gendered, such as referring to a trans man's chest area as "breasts" instead of using inclusive terminology such as "chest tissue" (Hsieh & Shuster, 2021; Paine, 2018; Van Boerum et al., 2019). Additionally, providers taking a "neutral" stance by avoiding conversation regarding gender and sexuality reinforces heteronormativity and

cisgenderism in medicine and contributes to sub-optimal care (Hsieh & Shuster, 2021). For example, healthcare providers may neglect essential screening, diagnostic, or preventative health measures for health concerns unique to SGM communities by assuming that patients are heterosexual (Petroll & Mosack, 2011). To receive appropriate care, 25 percent of SGM patients reported that they had to teach a doctor about SGM identities due to a lack of provider training in treating SGM patients (Mahowald, Gruberg, & Halpin, 2020).

Over 25 percent of SGM patients, which includes 49 percent of transgender patients, reported that their doctor or medical provider was visibly uncomfortable because of actual or perceived sexual orientation (Mahowald et al., 2020). Providers' sense of discomfort, fear, and lack of knowledge regarding SGM identities demonstrate implicit bias against SGM individuals and further reflect the lack of provider training necessary in providing competent care to SGM individuals (Hsieh & Shuster, 2021; Sabin et al., 2015).

Patient-Level Barriers. Medical professionals' lack of training to work specifically with SGM individuals further amplifies gender and sexuality-based barriers to care (Hsieh & Shuster, 2021). Stress, stigmatization, homophobia, transphobia, and lack of social support are thought to be the reasons why SGM individuals do not always receive equal treatment from healthcare providers (Ayhan et al., 2020; McNair, Anderson, & Mitchell, 2001). Due to the medicalization and stigmatization of SGM identities, SGM individuals are more reluctant to seek care, not see a regular healthcare provider, and skip medication or other needed treatment compared to their cisgender and heterosexual counterparts (Agenor et al., 2014; Dahlhamer et al., 2016; Hsieh & Ruther, 2017; Hsieh & Shuster, 2021). Many SGM individuals choose not to disclose their gender and/or sexual identities out of fear of judgment, discrimination and receiving poor medical treatment even though disclosure of such information may facilitate proper treatment

through revealing health risks and associated healthcare needs unique to SGM communities (Cruz, 2014; Everett & Mollborn, 2014; Hsieh & Shuster, 2021; McNair, Hegarty, & Taft, 2012; Petroll & Mosack, 2011).

According to the Center for American Progress: The State of the LGBTQ Community Survey (2020), 15 percent of respondents reported postponing or avoiding needed medical care when they were sick or injured due to disrespect or discrimination (Mahowald et al., 2020, p. 17). More than 1 in 10 SGM Americans faced mistreatment by a doctor or healthcare provider (p. 19). One-quarter of SGM Americans who faced discrimination in the past year postponed or avoided receiving medical care for fear of further discrimination (p. 18). Concerns for discrimination are even more prominent among transgender respondents. 28 percent reported that doctors or providers refused to see them because of their actual or perceived gender identity, and 34 percent of respondents reported providers were physically rough or abusive when treating them (Mahowald et al., 2020, p. 20).

Additionally, SGM patients not disclosing sexual or gender identity to providers due to fear providers would tell the patients' families about their identities, or that they would be referred to a mental health care provider for treatment due to their sexual orientation (Allen et al., 1998; Ayhan et al., 2020). SGM individuals often delay medical care and report dissatisfaction when receiving healthcare because providers are not knowledgeable about their identities, specific healthcare needs, or they are not able to make competent referrals to other providers (Agenor et al., 2015; Ayhan et al., 2020; Cruz, 2014; Hsieh & Shuster, 2021; Poteat, German, & Kerrigan, 2013).

Patient-Provider Relationships. Both provider and patient-level barriers can be best explained by ineffective patient-provider relationships. The patient-provider relationship is a

"complex psychosocial interplay of vulnerability, trust, and authority in a professional setting" in which a patient seeks assistance from a physician and the physician accepts the person as a patient (Honavar, 2018). The onus of an effective patient-provider relationship lies on the provider since patients approach providers from a place of vulnerability and providers are influential in deciding if, when, and how healthcare services are delivered (Honavar, 2018). Effective patient-provider relationship results in improved patient satisfaction of care, "the degree to which the individual regards the health care service or product or the manner in which it is delivered by the provider as useful, effective, or beneficial" (Chipidza, Wallwork, & Stern, 2015).

To summarize, existing research largely point to the following elements of a patient-provider relationship playing a role in patient satisfaction: 1) Trust, 2) Knowledge, 3) Regard, and 4) Loyalty (Bennett et al., 2011; Chipidza et al., 2015; Lerch et al., 2024; Mohiuddin, 2018; Razzaghi & Afshar, 2016). It is important to note that although the identified elements were divided as individual categories, they are intertwined in the overall patient-provider relationship dynamic. The element of trust in patient-provider relationships typically refer to the patients' expectation that the physician "will provide beneficial care and truthful information to the patient, regardless of their ability to monitor or control the physician" (Hall et al., 2002; Chaohui, 2019; Wu, Jin, & Wang, 2021). Patients' trust in their providers is built when providers demonstrate knowledge, regard, and loyalty (Chipidza et al., 2015). The element of knowledge can be best understood as providers' competency in providing culturally sensitive care, or care that is appropriate and relevant to patients' needs and expectations (Majumdar et al., 2004; Tucker et al., 2011). Providers' competency includes physician being up-to-date in their specialization (Lerch et al., 2024), having the knowledge and skills to appropriately respond to

the attitudes, feelings, or circumstances of groups of people that share a common distinctive racial, gender, national, religious, linguistic, or cultural heritage (DHHS US Office of Minority Health [OMH], 2001; Tucker et al., 2011), and having communication skills to deliver care in a compassionate and sensitive manner, (Hallstrom & Elander, 2001; Pascoe, 1983; Tucker et al., 2011). To elaborate, features of effective or quality communication include engaging in active listening, allowing patients to speak without interruptions, encouraging patients to ask questions and answering their questions, using language that is understandable to patients, and nonverbal behaviors such as maintaining good eye contact, open body language, and smiling (Canavera, 2021; Cook et al., 2004; Gopichandran & Chetlapall, 2015; Hendren & Kumagi, 2019; Lerch et al., 2024; Sharkiya, 2023; Świątoniowska-Lonc et al., 2020). The element of regard, in other literature may be described as "respect" or "valuing the patient", implies that patients feels as though "the doctor likes them as individuals and is 'on their side'" (Chipidza et al., 2015; Razzaghi & Afshar, 2016). Providers demonstrate regard through showing empathy, warmth, genuineness, support, and sharing balance of power by respecting patients' autonomy in making decision about their health (Beach, Saha, & Cooper, 2006; DiMatteo, Hays, & Prince, 1986; Razzaghi & Afshar, 2016; Sharkiya, 2023; Świątoniowska-Lonc et al., 2020; Tucker et al., 2011). Loyalty refers to providers' commitment to not abandon a patient, such as maintaining constant communication with patients and being present in critical situations (Chipidza et al., 2015; Razzaghi & Afshar, 2016).

While medical professionals have long subscribed to a body of ethical statements to ensure their approaches to care benefit patients, the American Medical Association (AMA; 2001) adopted standards of conduct to further guide providers in establishing an effective patient-provider relationship. The guiding principles include that physicians provide competent care with

compassion and respect, being professional during interactions, respecting patients' rights, and regard responsibility to the patient as paramount (AMA, 2001). Although the importance of establishing an effective patient-provider relationship has long been acknowledged, there has been little understanding of whether these principles are being effectively implemented into practice. Several measures have been developed to determine the quality of a patient-provider relationship, such as the Patient-Doctor Relationship Questionnaire (PDRQ-9) and The Health Care Relationship (HCR) Trust Scale, both self-report evaluations completed by patients (Bova et al., 2006; Van der Feltz-Cornelis et al., 2004). Although both measures were suggested to be promising from their initial internal consistency, test-retest reliability, and construct validity evaluations, these scales have not undergone further validity and reliability testing, nor there has been a tool to be universally accepted. To elaborate, the PDRQ-9 had a Cronbach's alpha of 0.94, Pearsons r = 0.61, and the Construct Validity comparing Primary Care Settings with Epilepsy Clinic was T = 3.94, significance one-tailed test = 0.000 (Van der Feltz-Cornelis et al., 2004). The HCR had a Cronbach's alpha of 0.92 at time one and 0.95 at time 2, test-retest reliability was .59 ($p < .01$), and The HCR Trust Scale did not correlate with the Marlowe-Crowne Social Desirability Scale ($r = .20$, $p = .07$) or the Rapid Estimate of Adult Literacy in Medicine scale ($r = -.21$, $p = .13$) (Bova et al., 2006). More testing is needed to be done to test its usefulness and applicability in various clinical settings and with diverse patient demographics.

Structural-Level Barriers. Formal policies in the United States present structural-level barriers to equitable care for SGM individuals (Hsieh & Shuster, 2021). The fractured insurance landscape in which each state has different insurance coverage policies can determine whether SGM-specific care is covered or denied based on categorical exclusions (Bakko & Kattari, 2021; Hsieh & Shuster, 2021). For example, some state insurance perceives gender-affirming

interventions as “cosmetic” whereas others perceive them as a medical necessity (Hsieh & Shuster, 2021). 52 percent of transgender patients reported that health insurance companies denied them affirmative care (Mahowald et al., 2020).

In addition, the lack of marriage rights for many SGM individuals and their partners further contributes to structural barriers to healthcare. For example, only some organizations and legal jurisdictions extend insurance coverage to domestic partners, in effect denying coverage to unmarried partners of employed SGM individuals (Mayer et al., 2008). Additionally, even partners in decades-old relationships may be denied medical decision-making rights and prevented from providing crucial support during a partner’s medical crisis (Mayer et al., 2008).

Although gaps in health coverage for SGM individuals have been closing since the implementation of the Affordable Care Act and the legalization of same-sex marriage, many SGM individuals report more delayed or unmet care compared to heterosexual-identified patients (Hsieh & Ruther, 2017; Hsieh & Shuster, 2021; Skopec & Long, 2015). It is important to note that constant changes in healthcare policy in the United States continue to affect healthcare accessibility for SGM communities.

2.3.5 Health Outcomes of Sexual and Gender Minority Individuals

Many studies have consistently shown a higher burden of disease among SGM individuals compared to heterosexual and cisgender individuals (Hsieh & Shuster, 2021). Specifically, SGM populations have higher rates of substance use disorders, violence victimization, HIV and other sexually transmitted infections, psychiatric disorders, and suicidality (NIH Office of Disease Prevention, 2022).

To best understand the health disparities of SGM communities, the Minority Stress Model can be employed. Minority stress refers to the additional stressors that individuals encounter as a direct result of their membership in a marginalized group (Lund & Burgess, 2021). SGM individuals face numerous physical and mental health disparities, which can be strongly linked to unique stressors, including chronic, high levels of interpersonal and systemic discrimination, prejudice, and oppression (Lund & Burgess, 2021). Individuals with more than one minority identity are especially vulnerable to poorer mental and physical health outcomes (Sarno et al., 2021). The Minority Stress Model posits 2 major categories of minority stress: Proximal and Distal stressors (Lund & Burgess, 2021; Michaels, Parent, & Torrey, 2016). In regards to sexual orientation, proximal stressors are stressors that individuals experience internally as a result of broader social attitudes held towards SGM individuals, such as internalized homophobia and stress related to self-concealment of sexual identity (Lund & Burgess, 2021). Distal stressors are external negative experiences related to sexual orientation, such as violent victimization, harassment, bullying, and discrimination (Ashley, 2019; Lund & Burgess, 2021). Utilizing the Minority Stress Model, both proximal and distal stressors contribute in tandem to increased risk for psychological and physical illnesses among SGM communities (Lund & Burgess, 2021; Meyer, 2013).

Regarding substance use, the National Survey on Drug Use and Health (NSDUH, 2019) reported 28 percent of Americans have a substance abuse disorder (Murphy, 2022; Substance Abuse and Mental Health Services Administration [SAMHSA], 2019). It is important to consider the historical importance of bars and clubs for SGM communities (Lund & Burgess, 2021). LGBTQ+ bars and clubs were frequently the only places where SGM individuals could safely express their true sexual orientation or gender identity, which resulted in alcohol and substance

use being prominent in SGM communities and made it difficult for individuals to reduce substance use in fear of being socially isolated or cut off from the community (Bux, 1996; Hughes & Eliason, 2002; Lund & Burgess, 2021). In addition, SGM individuals may use alcohol and other substances to cope with distress caused by the forced concealment of their sexual and/or gender identity, the discrimination they face as a result of expressing their identity, or both (Hughes & Eliason, 2002; Lund & Burgess, 2021).

SGM individuals are far more likely to be targets of harassment and violence than heterosexual, cisgender individuals due to their identity (Katz-Wise & Hyde, 2012; Lund & Burgess, 2021; Stotzer, 2009). The rate of violent victimization of SGM individuals is approximately 2.5 times more than the rate for heterosexual individuals (Truman & Morgan, 2022). Violence victimization can take on a variety of forms, including bullying, sexual assault and abuse, intimate partner and family violence, and harassment from strangers, up to and including homicide (Katz-Wise & Hyde, 2012; Lund & Burgess, 2021; Rodriguez-Roldan, 2020; Stotzer, 2009). This victimization has been consistently linked to a variety of negative physical and psychological health outcomes, including post-traumatic stress disorder, depression, gastrointestinal symptoms, musculoskeletal injuries, and chronic pain (Bonomi et al., 2009; Hughes et al., 2019; Lund & Burgess, 2021; Nicolaidis et al., 2004). These health effects may result from direct violence, such as physical assault, or may occur as a consequence of the acute and chronic stress of victimization experienced across the lifespan (Hughes et al., 2019; Lund & Burgess, 2021; Nicolaidis et al., 2004).

SGM individuals are disproportionately affected by homelessness, which is another health risk factor (Corliss et al., 2011; Lund & Burgess, 2021; Spicer, Schwartz, & Barber, 2010). 17% of SGM adults reported experiencing lifetime homelessness, which is more than

twice that of the general population (Wilson et al., 2020). SGM youth and young adults are at higher risk for homelessness because in order to preserve their well-being and to protect themselves from victimization at home, they often leave their non-affirming homes (Lund & Burgess, 2021). 28% of SGM youth reported experiencing homelessness or housing instability in their lifetime (The Trevor Project, 2022). Homelessness reduces access to consistent healthcare and creates a chronic source of physical and psychological stress, especially if individuals are unable to return home for reasons of personal safety or facing discrimination because of their sexual and gender identities (Fraser et al., 2019; Lund & Burgess, 2021; Maccio & Ferguson, 2016). Additionally, homelessness places individuals at higher risk of violence victimization from strangers, substance abuse, and high-risk sexual behaviors leading to increased risk for HIV, STIs, and blood-borne diseases (Keuroghlian, Shtasel, & Bassuk, 2014; Lund & Burgess, 2021).

With the challenges that SGM communities face which put their physical and mental health at risk, delayed or avoidance of healthcare can lead to increased risk and severity of negative health outcomes (Ng et al., 2020). For example, avoidance of preventative care can exacerbate negative health conditions and can lead to increased treatment expenditures, hospitalization, and even mortality (Ng et al., 2020).

2.3.6 Addressing Healthcare Barriers of Sexual and Gender Minority Patients

In efforts to reduce health disparities among SGM patients, researchers have been in the process of identifying, adapting, and developing SGM practice guidelines/recommendations and implementation strategies for healthcare providers in recent years (Willging et al., 2020, p. 1). Although current guidelines/recommendations contain critical information about SGM patient-

centered care in clinical environments and interactions, they are often fragmented (p. 2). Thus, McNair and Hegarty (2010) conducted a systemic review of available guidelines, and synthesized the following recommendations for primary care for SGM individuals (p. 539):

1. **Creating inclusive environments:** having overt signs acknowledging SGM identities, using sensitive language during treatment and on intake forms, having non-discrimination policies, and having procedures for addressing complaints.
2. **Standards for clinician-patient communication:** non-judgmental and affirming attitudes, assuring patient confidentiality, using gender-neutral language, using language preferred by the patient, having open and inclusive questioning; gathering complete sexual history, and responding to patient disclosure properly.
3. **Sensitive documentation of SGM identity/orientation:** documenting SGM identity/orientation in medical notes properly, informing SGM patients what is documented in the notes.
4. **Special knowledge for SGM awareness:** understanding the impact of discrimination on health, unique health needs and risks such as mental health and substance misuse, reproductive health, safer sex practices, and knowing SGM-specific support groups and healthcare providers for effective referrals.
5. **Staff training:** knowing proper procedures for maintaining confidentiality, using intake forms with affirmative language, how to identify and address SGM negativity, supporting the visibility of SGM employees, and inclusive hiring practices supporting SGM recruitment.

6. **Addressing population health issues:** marketing services to SGM communities, engaging in SGM-targeted health promotion, performing community outreach and forging relationships with SGM agencies, and advocating for SGM individuals.

These synthesized guidelines can be readily applied to any healthcare setting to provide culturally competent care (McNair & Hegarty, 2010). However, it is important to note some limitations. Initially, population-based intersectional attributes, such as race/ethnicity and culture, and input from both service providers and SGM patients were not taken during the development of these guidelines (Willging et al., 2020). Additionally, most of the guidelines reviewed made general statements pertaining to lesbian, gay, and bisexual communities as a whole, rather than highlighting specific healthcare needs according to sex, diverse expression of sexual orientation, socioeconomic status, age, and ethnicity of each individual (McNair & Hegarty, 2010). Also, these studies solely focused on lesbian, gay, and bisexual identities, and guidelines were not created taking all SGM identities into consideration, such as transgender, intersex, agender, asexual, or Two Spirit identities.

Although these recommendations were developed prior to and around 2010, there is still a lack of institutional policies, guidelines, and practices focused on patient-centered care for SGM populations in various healthcare settings, such as cancer centers (Wheldon et al., 2018). According to the National Academies of Sciences, Engineering, and Medicine (NASEM), a lack of clinically and culturally responsive healthcare providers remains a major concern for SGM patients (Committee on Understanding the Well-Being of Sexual and Gender Diverse Populations, 2020; Yu et al., 2023). Many health professionals also admit their lack of training regarding SGM care (Caceres et al., 2020; Yu et al., 2023). According to the 2022 Inaugural State of LGBTQ Health National Survey, over 80 percent of physicians expressed never

receiving training for transgender care although they have previously treated a transgender patient (Chisolm-Straker et al., 2018; Davidge-Pitts et al., 2017; Yu et al., 2023). Similarly, a 2011 survey found that medical students enrolled in 132 United States and Canadian medical schools only received about 5 hours of SGM-related training on average (Obedin-Maliver et al., 2011). Another study has found that nearly half of first-year medical school students in the U.S. expressed some explicit bias, and most implicit bias against SGM individuals (Burke et al., 2015; Taliaferro et al., 2021). As of 2022, only 4 medical schools in the U.S. have curriculum and concentrations on LGBTQ+ healthcare: University of Louisville, Brown University, University of Washington, and University of California San Francisco (Study International Staff, 2022). In addition, although the Accreditation Council for Graduate Medical Education (ACGME) implemented a major revision of their Common Program Requirements that requires residents to demonstrate, as a competence, respect and responsiveness to diverse populations, many resident training programs fail to train physicians to care for LGBTQ patients (ACGME, 2021; Pregnall, Churchwell, & Ehrenfeld, 2021).

To address this gap in training from medical schools, several national organizations have begun developing continuing education training programs for healthcare providers to provide SGM-affirming care (Yu et al., 2023). Despite such initiatives, there is a widespread scarcity of SGM-focused training to equip health professionals with clinical and cultural competence to address the frequently unmet and unique health needs of certain SGM patients, such as gender-affirming treatments for transgender patients (Yue et al., 2023). According to the 2015 U.S. Transgender Survey, about 24% of transgender patients reported having to have taught their providers about their unique health needs, which led to them feeling frustrated, unsafe, and/or burdened (Chong et al., 2021; James et al., 2016; Yue et al., 2023). Similarly, asexual-identified

individuals reported feeling uncomfortable discussing health issues related to sexuality with their providers because they felt their providers had no knowledge about asexuality (Flanagan & Peters, 2020). In addition, requirements for continuing education curriculum for licensure varies for physicians across the U.S. As of 2018, only the District of Columbia requires two hours of LGBTQ cultural competency as part of the LGBTQ Cultural Competency Continuing Education Amendment Act of 2015, which suggests that some providers across the U.S. may not have any basic level SGM healthcare competency, provided they did not receive specific curriculum during their time in medical school (AmeriHealth Caritas District of Columbia, 2016; Federation of State Medical Boards, 2024).

In addition, it is important to note that although there has been progress made in regard to the development of SGM affirmative care training, the majority of training protocols do not explicitly address how to care for patients who identify as asexual. For example, training materials from the following most commonly referred organizations do not mention asexuality: GLMA Health Professionals Advancing LGBTQ+ Equality (GLMA), The National LGBT Cancer Network, and the U.S. Department of Veteran Affairs (GLMA, 2023; The National LGBT Cancer Network, 2017; US Department of Veterans Affairs, Veterans Health Administration, n.d.). The SGM affirmative care training that does explicitly mention asexuality often only defines asexuality and asexual individuals' experiences are not discussed (Schneckenburger, Tam, & Ross, 2023).

Regarding ensuring inclusive care spaces are available to patients, the Human Rights Campaign (HRC) developed a Healthcare Equality Index (HEI) as an accreditation recognizing healthcare facilities and hospitals that promote LGBTQ+ inclusive policies and affirming practices (HRC, 2024). The HEI evaluates facilities based on four main objectives 1) ensuring

foundational non-discrimination protection are in place for patients, visitors, and staff via policy implementation and provision of cultural competency training on LGBTQ+ inclusion, 2) facility demonstrates progress toward inclusion on LGBTQ+ patient care services and support, 3) cultivates an inclusive workplace by providing LGBTQ+ inclusive employee policies and benefits, and 4) demonstrates engagement with and public commitment to the LGBTQ+ community (HRC, 2024). Items evaluated include effective collection of Sexual Orientation and Gender Identity (SOGI) data, establishment of advisory boards, and availability of support groups (HRC, 2024). Facilities obtain points by meeting requirements and receive a designation based on the number of best practices and policies in place. are ranked in 3 tiers: Builders (receiving full credit for staff receiving foundational non-discrimination and staff training), High Performers (along with staff training, receiving partial credit on benefits, patient services and support, and community engagement), or Leaders (receiving full credit in all criteria). In the 2024, 1065 facilities across the U.S. were evaluated. Of the participating facilities, 36% (n=384) were given the "Leaders" status and 43% (n=462) were given "High Performers" status (HRC, 2024). According to X Map (2024), there are approximately 238,759 healthcare establishments scattered across the country (Rafaqat, 2024). As the HEI performs accreditation for facilities seeking evaluation, this may suggest that an overwhelming number of healthcare practices may not meet the standards for inclusive SGM care as they were not interested in partaking in the accreditation process. Additionally, although the HEI aims to be inclusive of all LGBTQ+ identities, evaluations largely center around care for patients who identify as lesbian, gay, or transgender – which may have implications on evaluating inclusive practices for ace individuals. Researchers are continuing to address these limitations and are in the process of developing strategies to implement culturally competent practice at multiple delivery service levels (Bass &

Nagy, 2022; Willging et al., 2020). In addition, *Healthy People 2030* continues their mission to "improve the health, safety, and well-being of lesbian, gay, bisexual individuals" and to improve healthcare access and quality and health communication (Office of Disease Prevention and Health Promotion [ODPHP], n.d.). More details about how *Healthy People 2030* aligns with improving SGM healthcare can be found in **Chapter 1.**

2.4 Asexuality and Healthcare

2.4.1 Introduction to Asexuality and Healthcare

As mentioned, SGM individuals face various barriers to obtaining equitable healthcare. This section will specifically focus on the healthcare experiences in the asexual community. This section will begin with a discussion of what is known about asexuality and healthcare, followed by a discussion on the gaps in knowledge and how this study aims to close the gap, and will conclude with future areas of inquiry.

2.4.2 What is Known About Asexuality and Healthcare

Biases Against Asexual Individuals. Although biases against SGM individuals are well established, potential biases against asexual individuals, who are a largely unrecognized sexual minority group, have remained uninvestigated (MacInnis & Hodson, 2012, p. 725). MacInnis & Hodson (2012) attempted to fill this gap by examining the extent to which asexual-identifying individuals who do not desire sexual activity are viewed negatively by heterosexual and other sexual minority groups (p. 738). Conducting a questionnaire with a sample of undergraduate students and community sampling, they found that both heterosexual and other sexual minority

groups have evaluated asexual individuals more negatively, viewed them as less human, and less valued as contact partners (p. 725). Although this study did not exclusively investigate biases against asexual individuals in healthcare settings, this preliminary study suggested that negative attitudes, dehumanization, and discrimination intentions against asexual individuals do exist (p. 740). However, it is important to note methodological limitations of this study when considering the conclusions. This study claims that bias toward asexual individuals is "either equivalent to, or even more extreme, than bias towards homosexuals and bisexuals" (p. 738). To support this claim, they used sapiosexuality – individuals who are sexually attracted to human mind; they engage in sexual activity but find intelligence to be the most arousing quality of their sexual partners (p. 735) – to control for confounds of bias due to unfamiliarity. They argue that "asexuals were evaluated more negatively than a very unfamiliar sexual minority comparison group, sapiosexuals" (p. 738). However, their data illustrates that attitudes towards sapiosexuals (M = 6.81) (p. 738) was more negative than towards asexuals (M = 6.45) (p. 736). This suggests that lack of familiarity of may be a reason why there is negative bias towards asexuality and sapiosexuality. Despite this limitation, their data suggests attitudes towards asexual individuals are more negative compared to heterosexual (M = 6.45), bisexual, (M = 6.45), and homosexual (M = 6.45) individuals (MacInnis & Hodson, p. 732). This brings up the possibility of discrimination against asexual-identifying individuals occurring in healthcare settings due to negative attitudes held by providers due to lack of familiarity with asexuality and emphasizes the need for culturally competent provider practice to prevent discrimination experienced by asexual individuals when seeking healthcare. More research is needed in regard to how healthcare provider biases play a role in caring for asexual-identifying individuals, and how this ultimately impacts the health outcomes of asexual individuals.

Medical Issue or Sexual Variance. There has been a significant ongoing discussion about the proper definition and treatment of sexual desire disorders in the academic, medical, and mental health communities. As mentioned previously, low sexual desire has been medicalized until recent decades when individuals have begun to identify as asexual (Gupta, 2017a, p. 1). To understand when low sexual desire should be treated as a medical or mental health issue, specifically as Hypoactive Sexual Desire Disorder (HSDD), and when it should be treated as a benign sexual variation, Gupta (2017a) conducted semi-structured qualitative interviews with 30 asexual identifying individuals living in the United States (p. 1). Five main findings from the interview include (p. 6):

1. HSDD and asexuality is not clear-cut and individuals may pass back and forth across the line.
2. Asexual-identifying individuals may experience distress as a result of stigma or marginalization stemming from norms established by a sex-centered society.
3. Asexual-identifying individuals may face pressure from a partner as a result of the partner's sexual expectations.
4. Asexuality is not always distressing, rather it can be experienced as simply an alternative way of 'being in the world'.
5. Many asexual-identifying individuals believe in the usefulness of maintaining HSDD as a diagnostic category and support medical and mental health professionals in their efforts to develop treatments for HSDD.

Additionally, many interviewees who identified as asexual described themselves as experiencing little to no sexual desire or attraction, and/or not having a libido or sex drive, and expressed a positive preference for not engaging in sexual activity with other people, which supported the

notion of describing asexuality as an orientation rather than a disorder (p. 7). Evidence suggests that there is no clearly defined line between HSDD and asexuality, and it should be up to the individuals to decide to adopt the label of HSDD and seek treatment, to choose to use "asexuality" to describe their experience, to use both labels, or to use none, and this decision will ultimately contribute to the individual's flourishing (p. 11). Gupta (2017a) provided the four following recommendations for medical and mental health professionals to sensitively and productively work with people who experience low levels of sexual desire or attraction, whether or not they identify as asexual (p. 11):

1. Clinicians should work with clients who are distressed by low levels of sexual interest to determine whether the label of HSDD, asexual, both, or none is best for them. Clinicians are responsible for educating and providing resources to patients about HSDD and asexuality, and ultimately let clients decide what label they should use.
2. Clinicians should recognize that some individuals who identify as asexual may be interested in increasing their levels of sexual interest, and this does not need to undermine or contradict their identity as asexual.
3. When people in a relationship are experiencing problems due to a discrepancy in levels of sexual interest, the issue should be addressed as a relationship issue, not as the problem of one of the partners.
4. Health professionals should examine their own "pro-sex" biases and should also consider how these biases are impacting their clients.

This preliminary study helped with developing a more nuanced understanding of sexual disinterest, and provided insight into how healthcare providers can best support patients who

identify as asexual and individuals who do not identify as asexual but are experiencing temporary or permanent declines in levels of sexual desire or activity (Gupta, 2017a, p. 12).

Conley-Fonda and Leisher (2018) further asserted that the inclusion of asexuality in the definition of sexual health can provide numerous benefits and insights into how sexual health is defined for both asexual and sexual people (p. 10). They argued that the concept of "sexual health" implicitly assumes that sexual desire is a requirement of healthy sexuality, and a lack of sexual interest or desire is assumed to be a dysfunction (p. 6). This definition inherently pathologizes the experiences of asexual-identifying individuals, and the exclusion of asexuality from the conceptualization of sexual health furthers the experience of invisibility described by asexual individuals and contributes to the discrimination which they experience (p. 9). This exclusion can influence not only any positive and healthy sexual experiences but also any negative or clinically significant ones (Conley-Fonda & Leisher, 2018, p. 9).

Clinical Experience of Asexual-Identifying Individuals. The discussion of asexual-identified individuals' experience in clinical care began in the recent decade. Foster and Scherer (2014) aimed to explore the experiences of asexual-identified individuals with health and mental health practitioners to expand the literature on multicultural competent approaches to affirmative practice in counseling psychology and social work (p. 424). They conducted an online qualitative survey with 86 asexual-identified individuals to investigate the salience, prevalence, and relevance of asexual identities in interactions with health and mental health practitioners (p. 425). The findings revealed three central themes concerning multicultural competent care with asexual clients (pp. 425-427).

1. *Asexuality is healthy.* Contrasting the stereotypes that portray asexual people as needing health or mental health intervention to "repair" their lack of sexual desire or attraction,

most participants described themselves, and other asexual people, as healthy. Furthermore, participants described themselves as happier and healthier because they are at lesser risk of contracting STI compared to nonasexual individuals based on infrequent sexual activity.

2. *Expectation of practitioner bias about asexuality.* Most participants reported anticipating negative interactions with their health or mental health providers regarding their asexuality, expecting clinicians may have antiquated notions about issues of sexuality.
3. *Positive experiences with practitioners.* Some participants described positive interactions with practitioners that contributed positively to their long-term well-being, such as providers having an open and affirming attitude regarding issues of sexuality.

From the findings, Foster and Scherrer (2014) proposed three strategies for health practitioners to best support their asexual clients (p. 428). Initially, it is important for practitioners to gain knowledge about asexuality and the experiences of asexual-identifying individuals to be able to provide competent care (p. 428). Second, practitioners should seek out ways to signal to clients that they are accepting and affirming SGM and asexual identities, such as using gender-neutral and affirming language (p. 428). Lastly, given the history of pathologization of SGM identities, practitioners should take into account that experiencing a lack of sexual attraction in a sexualized culture can be an isolating and marginalizing experience to those that identify as asexual (p. 428). Thus, practitioners should take time to carefully evaluate the source of "distress" when working with asexual clients in regard to identity development, disclosure, and forming romantic relationships. (p. 428). This study is among the first to examine asexual individuals' experiences with health and mental health practitioners and begin to construct culturally competent approaches (Foster & Scherrer, 2014, p. 428).

Gupta (2017b) conducted an in-depth interview study with 30 participants to explore how self-identified asexuals understand their own experiences and engage with sexual norms (p. 993). For one of the questions which inquired about asexual-identifying individuals' experiences with medical professionals, around half of the interviewees described experiences of pathologization (p. 996). One-third of interviewees reported that they were led by social factors, such as relationship difficulties and pressure from friends and families, to consult a health professional in order to find an explanation for asexuality (p. 997). One interviewee decided to stop attending therapy because they did not think it would change their sexuality (p. 997). Four interviewees reported that their healthcare professionals did not find an explanation for their asexuality, and they stopped pursuing the issue (p. 997). Two interviewees reported negative experiences with mental health professionals, where they felt their provider did not seem to believe the interviewee was asexual, but rather a "repressed lesbian," or suggesting "just go have sex and you'll like it, you don't know it yet" (Gupta, 2017b, p. 997). Although investigating healthcare experiences of asexual-identifying individuals was not the focus of this study, it is evident from the inquiry that asexual-identifying individuals do experience pathologization of their identities, impacting their intent to seek healthcare.

To further explore the potential pathologization of the asexual identity, Flanagan and Peters (2020) were the first study to ask about specific interactions asexual-identifying individuals have had with their healthcare practitioners (p. 1632). They conducted an online survey that included questions asking asexual-identifying individuals about their experiences with mental and medical practitioners (p. 1631). From the responses of 136 participants, it was found that the majority of participants chose not to disclose their identity and felt uncomfortable discussing issues related to sexual identity with their healthcare providers in an attempt to avoid

anticipated negative interactions (p. 1639). Participants who had positive experiences after disclosing their identity shared that their practitioners' reaction was positive because they were accepting, supportive, and aware of asexuality (p. 1636). Participants who had negative experiences after disclosing their identity shared that their practitioners disbelieved the existence of asexuality, with about one-quarter to one-half of the participants reporting that practitioners attributed asexuality to a mental, physical, or sexual health disorder (p. 1640). Some participants reported that because practitioners pathologized lack of sexual desire, activity, or drive, they felt forced to disclose their asexual identity in an attempt to explain their feelings and behaviors (p. 1640). For example, health providers believe that not being sexually active is abnormal, and that explaining that one is asexual functions as an adequate explanation for why someone not to have sex (p. 1640). Evidence suggests that the majority of asexual-identifying individuals continue to face pathologization of their identity in healthcare settings. This study further highlights the need for the inclusion of information about asexual identities in health education and ongoing diversity training for providers in order to increase the cultural sensitivity of healthcare practitioners (Flanagan & Peters, 2020, p. 1631).

Health Outcomes of Asexual-Identified Individuals. As mentioned, many studies have consistently shown a higher burden of disease among SGM individuals compared to heterosexual and cisgender individuals, specifically in rates of substance use disorders, violence victimization, HIV and other sexually transmitted infections, psychiatric disorders, and suicidality (Hsieh & Shuster, 2021; NIH Office of Disease Prevention, 2022). However, there is no existing academic literature focusing on the prevalence of health outcomes of asexual-identifying individuals, and there is a need to understand in order to best serve members of the asexual community.

To address this, members of the asexual community spearheaded The Ace Community Survey to gain insight into the unique health needs of the community. This survey brought insight into rates of sexual violence, substance use, physical and mental health, and suicidality (Hermann et al., 2022). Of the 15,132 respondents from over 100 countries, 59.1% participants reported experiencing one type of contact sexual violence, with 53.6% reporting unwanted sexual contact, 26.2% experiencing sexual coercion, and 18.8% experiencing rape (Hermann et al., 2022). These findings suggested asexual respondents experienced generally higher levels of sexual violence compared to the National Intimate Partner and Sexual Violence Survey [NIPSVS], although it is important to note that the Ace Community Survey had respondents around the world whereas NIPSVS investigated within the United States (Basile et al., 2022; Hermann et al., 2022). As mentioned, sexual violence victimization can be linked to various negative health outcomes, such as chronic depression, anxiety, physical disabilities, and sexually transmitted illnesses (Basile et al., 2022).

Regarding substance use, 50.7% of respondents had consumed alcohol at least once in the previous twelve months, while 13.0% had used marijuana and 7.1% had used tobacco, and 3% of respondents said using prescription drugs for recreational purposes (Hermann et al., 2022, p. 78). Although not directly comparable, a 2020 study by the Substance Abuse and Mental Health Services Administration (SAMHSA) found that among the general population, 50% of people aged 12 or older had used alcohol, 18.7% had used tobacco, and 17.5% had used an illicit drug in the past month alone (Hermann et al., 2022, p. 78; SAMHSA, 2021).

Regarding physical health, 11.2% of asexual-identifying individuals considered themselves disabled or chronically ill, while smaller populations (5.1%) considered themselves physically disabled (Hermann et al., 2022, p. 79). Regarding mental health, 37% of respondents

considered themselves mentally ill, with 33.3% reporting being professionally diagnosed with anxiety and depression disorders (p. 80). 0.2% of respondents have been professionally diagnosed with HSSD or Sexual Interest/Arousal Disorder (SIAD) (Hermann et al., 2022, p. 80).

Regarding suicidality, about 32.3% of respondents seriously thought about trying to kill themselves, 10.6% made plans to kill themselves, and 2.7% tried to kill themselves (Hermann et al., 2022, p. 82). Compared to the 2015 and 2019 estimates of the National Survey on Drug Use and Health (NSDUH), there is a higher rate of suicidal thoughts, plans, and attempts among asexual-identifying individuals compared to the general adult population in the United States (Hermann et al., 2022, p. 82; Ivey-Stephenson et al., 2022, p. 1). The NSDUH reported that 4.3% of the adult population in the United States of America had thoughts about suicide, 1.3% planned suicide, and 0.6% attempted suicide (Hermann et al., 2022, p. 82; Ivey-Stephenson et al., 2022, p. 1). When compared with the suicidality of gay, lesbian, and bisexual men and women, ace respondents' suicidal thoughts and plans were higher (Hermann et al., 2022, p. 82).

Although the Ace Community Survey cannot be considered to be representative of all asexual-identifying individuals in general, the survey highlighted the unique health needs of the asexual community, which further emphasizes the need for more research into these unique health experiences (Hermann et al., 2022, p. 8).

2.4.2 Gaps in Knowledge and Closing the Gap

Although there has been growing research on the healthcare experiences of SGM individuals, there are still gaps in knowledge to consider. Initially, the breadth of existing literature on SGM individuals mainly focuses on the experiences of lesbian and gay communities. The original literature under **Sexual and Gender Minority Healthcare** on topics

such as barriers to healthcare faced by SGM communities did not consider asexual identities within their studies. The exclusion of ace experiences from research may be because of the misconception that ace individuals do not experience sexuality as greater LGBTQ+ community. As mentioned, even within the SGM community there are unique ranges of experiences among various sexual and gender identity groups, and it is important for healthcare professionals to have knowledge about each identity group to better serve their patients.

As mentioned, there is no existing academic literature focusing on the prevalence of health outcomes of asexual-identifying individuals. This creates a challenge in understanding the unique health needs of asexual individuals, and whether barriers to care further perpetuate negative health outcomes. Although The Ace Community Survey spearheaded by members in the ace Community aimed to close that gap by identifying the unique healthcare needs of asexual-identifying individuals, more research is needed to best understand the needs to better inform ways to address these unique health needs.

In recent years, there have been a small number of studies that have investigated asexual-identifying individuals' experiences in clinical settings, specifically about 1) how relevant asexual individuals find their identity to be relevant to their well-being, 2) their attitudes and expectations towards healthcare providers, and 3) specific interactions they have had with their healthcare practitioners, there has not been a study conducted investigating healthcare utilization of asexual-identifying individuals. This study aims to understand how healthcare experiences impact the healthcare-seeking behaviors of asexual-identifying individuals. As mentioned, delaying seeking care can exacerbate negative health conditions. The implications of this study include identifying barriers to healthcare faced by asexual-identifying individuals and informing ways to address these barriers to care.

Chapter 3: Methods

3.1 Introduction

This chapter describes the methods that were implemented in the study. The following topics will be discussed: *Rationale, Researcher Reflexivity and Positionality, Research Questions, Research Design, Data Collection, Data Analysis, Methods for Assuring the Protection of Human Subjects, and Untrustworthy Participants*. Please note that in this section the terms "Principal Investigator" and "Researcher" will be used interchangeably, but will refer to the same individual who will be conducting this study.

3.2 Rationale

Given the experiential focus of inquiry, this dissertation research was a descriptive exploratory qualitative study grounded in interpretive phenomenological theory that utilized semi-structured interviews. This section will provide a rationale for the study methods.

3.2.1 Building Upon Past Research

As mentioned in the literature review, there has been a small number of studies that have investigated asexual-identifying individuals' experiences in clinical settings. This study aims to build upon the research findings from Foster and Scherer (2014), Gupta (2017b), and Flanagan and Peters (2020).

Both Foster and Scherer (2014) and Flanagan and Peters (2020) utilized online surveys to gather data. Although online surveys have many benefits, such as being easy to conduct and distribute with global reach, there are limitations to the methodology (Andrade, 2020, p. 575). Initially, it is impossible to ask follow-up questions to clarify responses, which allowed some

questions to remain misconstrued (Foster & Scherer, 2014, p. 428). Additionally, the generalizability of findings is difficult when the population cannot be described (Andrade, 2020, p. 575). In order to protect the identity of SGM participants who experience marginalization, Flanagan and Peters did not collect demographic information on their participants (p. 1642). This may have also prevented the analysis of other potentially relevant variables that may have impacted the participants' experiences with their healthcare providers, such as race, gender identity, or age (Flanagan & Peters, 2020, p. 1642). Gupta (2017b) utilized semi-structured interviews and a demographics questionnaire, which addressed these methodological limitations, and this study design draws upon this methodology.

3.2.2 Qualitative Descriptive Studies

Qualitative research approaches are used to understand everyday human experience in all its complexity and in its natural settings (Wu & Volker, 2009, p. 2721). In regard to healthcare, qualitative research allows researchers to gain knowledge and insight into the realities of patients and providers via in-depth accounts to inform ways to improve the environment of care and enhance health outcomes in those receiving care (Malagon-Maldonado, 2014, p. 124). Because reality is relative and multiple and perceived through socially constructed and subjective interpretations, qualitative research allows for a deeper understanding of how the social world is interpreted, understood, experienced, or constructed (Carson et al., 2001, p. 10; Cleland, 2017, p. 62).

In order to understand the experiences of asexual-identifying individuals seeking healthcare, conducting qualitative research is justified.

3.2.3 Interpretive Phenomenology: Capturing Lived Experience

Phenomenology presents a unique opportunity for capturing the lived experience of participants (Frechette et al., 2020, p. 1). An interpretive phenomenological study aims to explore the lived experience of a phenomenon, representing an individual level of analysis with an understanding that social contexts are embedded within an individual's being (Frechette et al., 2020, p. 5). This methodology allows the elicitation of meanings and interpretations that people attribute to their experiences by exploring the "human condition" (Frechette et al., 2020, p. 6; Malagon-Maldonado, 2014, p. 129).

3.2.4 Semi-Structured Interview Model

The data collection for interpretive phenomenological studies is normally conducted through interviews (Malagon-Maldonado, 2014, p. 129). Individual interviews elicit a participant's narrative, which allows the storyteller to remember a past event and recount it in light of what is meaningful for them - with the meaning being an essential component of lived experience (Benner, 1994, p. 110; Frechette et al., 2020, p. 7).

Interviews usually begin with specific questions to gather concrete examples of everyday experience and then move into general questions (Malagon-Maldonado, 2014, p. 129). While the researchers ask the participants questions, they "bracket," or put aside their own assumptions, beliefs, and own interpretations to be as objective as possible, and focus on uncovering and producing a description of the participant's lived experience (Frechette et al., 2020, p. 7; Malagon-Maldonado, 2014, p. 129).

The structure of interviews allows participants to share what they feel is most important to them while allowing researchers to probe to clarify meaning and uncover the importance of

the experience attributed by the participant (Frechette et al., 2020, p. 7). In addition, this methodology aims to amplify the voices of groups who often are marginalized.

3.3 Researcher Reflexivity and Positionality

Reflexivity involves the critical reflection of one's own thoughts and actions in the study and helps locate the researcher in the research project (Malagon-Maldonado, 2014, p. 123). Self-reflexivity involves reflecting on how research projects are shaped by researchers' interests, values, experiences, and political commitments (Corlett & Mavin, 2018, p. 12; Willig, 2003, p. 9). Researchers have posed self-reflexivity questions, relating to the chosen research topic and personal motivations and interests for studying it as (Corlett & Mavin, 2018, p. 12): 1) Why am I undertaking the research topic I have selected? What are my personal motivations? What are my personal and political reasons for undertaking my research? What personal experiences do I have related to my research topic? (James & Vinnicombe, 2002, p. 97). 2) What (or who) has prompted the research and why? How is the research shaped by my own personal interest and, if applicable, the interests of a sponsoring organization? Has this influenced the framing of the research question and the context in which the research is carried out? (James & Vinnicombe, 2002, p. 97). 3) What is the motivation for undertaking this research? How am I connected to the research, theoretically, experientially, and emotionally? And what effect will this have on my approach? (Haynes, 2012, p. 78)

Scholars engaged in critical social science research should assess their positional-reflexivity, which is how their own positions and experiences might contribute to their interpretations of people's lived experiences (Corlett & Mavin, 2018, p. 14; Scharp & Thomas,

2019, p. 147). Positional reflexivity can be enabled by considering questions such as (Corlett & Mavin, 2018, p. 14):

- What is my (expected) role as the researcher? (Cassell et al., 2005; James & Vinnicombe, 2002, p. 98)
- What effects does my role have on how the research is conducted? (Cassell et al., 2005)

What are my relationships with research subjects/participants? (Cunliffe, 2003, p. 995)

3.3.1 The Principal Investigator's Positionality

The above-mentioned questions for self-reflexivity and positional-reflexivity will be used to guide the discussion of the positionality of the principal investigator (PI).

This research stems directly from the PI's passions and personal experiences. The PI has had a lifelong experience with seeking healthcare as a caregiver for family members with chronic illness. From their experience, the PI has learned firsthand that the healthcare system can be very overwhelming, especially regarding various systemic barriers in place making various vital care inaccessible. Thus, the PI is passionate about addressing systemic barriers to allow access to equitable healthcare for all.

As an aromantic asexual cisgender Desi woman, the PI had negative experiences seeking healthcare, such as having providers invalidate and pathologize their identity, which causes them to be hesitant to seek necessary preventative care, although they understand that it is crucial to maintain good health. As a sexual minority, the PI is able to participate in various Queer and asexual-focused support groups across various social media platforms. In these groups, the PI found many other members sharing similar healthcare experiences. The PI's passion, experience, and resonating with other members of ace community inspired the conceptualization of this

research. Through this research, the PI aims to amplify the voices of asexual-identifying individuals to inform future research in healthcare design and policy.

Although the PI is a member of the sexual minority community and shared many identities with participants in the study, the PI had to critically evaluate their own identity in relation to the research. As a doctoral student, the PI has the privilege to use their dissertation to amplify the voices of asexual-identifying and other SGM individuals. However, being a member of the sexual minority community does not qualify the PI to speak on behalf of all SGM individuals as each SGM individual has unique experiences. As such, the PI bracketed their own personal experiences, assumptions, and interpretations by engaging in reflexive journaling, asking participants clarifying questions during interviews and member-checking to ensure the participants experiences were accurately interpreted.

Although the PI exercised reflexivity and positionality when conducting this research, it is important to note that it is easier said than done. As mentioned, the PI's passion and experience drives this research. The PI is connected experientially and emotionally to the research, making it challenging to be strictly objective. However, as the PI's identity and experience were in alignment with a number of participants in the study, it allowed for them to connect with the participants in a more deeper level, allowing for an enriching conversation to flourish that informed this research. During data analysis and discussion of discussion of findings, the PI sought to always keep in mind their own experiences and biases, while acknowledging that much of their bias will always be unconscious.

3.4 Research Questions

The research questions are as follows:

1. What have been the experiences of ace individuals when receiving healthcare?
2. Does a person's ace identity influence healthcare seeking behavior?
3. How do ace individuals describe their patient-provider relationship?
4. Do ace individuals have ideas about improvements in healthcare to make healthcare more welcoming to ace identifying individuals?

3.5 Research Design

The researcher used an interpretive phenomenological approach to investigate the lived experience of asexual-identified individuals seeking healthcare. A one-on-one in-depth semi-structured interview was conducted via Zoom meetings with eligible participants.

3.5.1 Pilot Study

Four ace individuals were recruited from a private South Asian Queer Facebook group who met all eligibility requirements engaged in a full pilot of the study, which allowed the PI. To test feasibility of recruitment and data collection prior to the full study. The participants responded to an initial draft of an interview schedule, and were queried about if the questions asked were easy-to-understand, whether they felt any of the questions were offensive, and soliciting feedback for how to improve questioning in the interview schedule (see **Appendix L** for the pilot interview questions). In response to the pilot, the interview schedule was substantially modified for the main study to incorporate further probing about patients' healthcare experiences.

3.5.2 Eligibility Criteria

Individuals were determined eligible for the study if they: 1) Were aged 18 or older - the legal age for consent, 2) Use the asexual identity label to describe their sexual orientation or identify under the asexual umbrella (including categories such as individuals identifying as asexual, demisexual, or gray-a), 3) Were willing to speak about their healthcare experiences in the United States and have their responses audio recorded, 4) Fluent in English (as interviews were conducted in English).

3.5.3 Sampling and Recruitment Activities

A purposive sampling strategy was used in this study, which is commonly used in phenomenological research as it allows the selection of participants who have rich knowledge of the phenomenon (Frechette et al., 2020, p. 6). Participant were recruited from the following Queer and Asexual-focused social media platforms:

- *Reddit*: r/asexuality
- *Facebook:* Various public and private groups, such as The Asexual Visibility and Education Network and the South Asian Queer Community
- *Instagram:* Various public accounts such as Columbia Aces and AceyDesi
- *Discord:* Various private asexual and aromantic centered servers

Recruitment from private sites occurred following approval from respective group administrators to post the digital recruitment flyer (see **Appendix B** for the recruitment flyer and **Appendix C** for both the message that were sent requesting permission from the group administrators and the message that were posted along with the digital recruitment flyer once admin approval was obtained). For *Instagram* pages, the owner(s) of respective accounts shared the recruitment flyer

via post or story. For public forums, the PI posted the recruitment flyer along with the "To Group" message (see **Appendix C**) as a public post. The flyer consisted of all of the required information about the study, inclusive but not limited to the eligibility criteria, the PI's contact information, and the IRB protocol number. The recruitment flyer also included a link to a brief eligibility survey that was delivered via Google Forms (see **Appendix E** for the Pre-Eligibility Survey and **Appendix D** for associated IRB approved consent form). The order of recruitment occurred with the researcher advertising the study in the more private asexual-focused groups, in consideration of the time it may take to receive permission to recruit from the administrator. Based on the response rates of the pre-eligibility screening and enrollment of participants, the researcher waited two weeks after posting in one group before posting in another.

3.5.4 Incentives

Participants who complete the interview for both the Pilot and Main study were compensated with a $50 incentive, paid through a payment method of their choosing: MasterCard Gift card, PayPal, Venmo, or Zelle. The standardized message associated with incentive was, "Thank you!" Incentives were funded by the PI. Member checking was optional and was not incentivized financially.

3.6 Data Collection

3.6.1 Pre-Interview Eligibility Survey

All those interested in taking part in the study were asked to complete a brief survey to assess eligibility via Google Forms (see **Appendix E** for the eligibility survey). Prior to the

eligibility questions, participants were required to consent to the screening on Google Forms (see **Appendix D** for a copy of the Pre-Interview Eligibility Survey Consent Form). Participants were informed at the end of the Google Forms that the PI will reach out to them with more information if they qualify for the study.

A total of 110 individuals completed the eligibility screening survey. 10 individuals were deemed ineligible because they were not living in the United States. Of the 100 individuals initially deemed eligible, due to unusual circumstances (see **Chapter 5** section on "Limitations" for discussion of "Unusual Circumstances" for details), 22 individuals who were deemed eligible through *Reddit* were not considered for recruitment. 78 individuals deemed eligible to recruit were all invited via email to participate in the interview.

3.6.2 Informed Consent

Once the individual was qualified, they were sent an email with a link to the Informed Consent form outlining the study (see **Appendix M** for the email template that was sent to participants and **Appendix F** for the consent form). The Informed Consent was housed in a Google Drive folder created specifically for everyone. Folks were asked to review the consent form prior to the scheduled interview session. The PI reviewed the contents of the form with each participant verbally at the start of the interview. Participants provided verbal consent at the start of the interview once they have consented to be audio recorded.

3.6.3 Interview Scheduling

Individuals who were eligible based on their responses to the eligibility survey were invited via email to schedule an online interview via Zoom. The email contained a link to

Calendly, where individuals scheduled an 1-hour interview session with the PI. Once they reserved a time, they were sent a unique Zoom link with instructions on how to join the meeting (see **Appendix M** for the messages sent).

Of the 78 individuals invited to the interview, 54 people scheduled an interview. 2 individuals did not show up for their scheduled interview time, and the PI followed up with the "No-Show" email message (see **Appendix M**) – however, these individuals did not respond. Due to the unusual circumstances detailed in **Chapter 5** (see section on "Limitations" for discussion of "Unusual Circumstances"), 5 individuals recruited from *Reddit* who had scheduled an interview with the researcher prior to the action taken to address the circumstance had their interviews cancelled. The 5 individuals affected were sent the following standardized message:

> Dear Participant, Unfortunately, study recruitment for this research has been suspended until further notice. For that reason, I have to regretfully cancel our scheduled interview session. I truly apologize for any inconvenience this may have caused. I thank you once again for expressing your interest in this study.

Ultimately, 47 individuals participated in the interview with the PI.

3.6.4 Semi-Structured Interview and Demographics Survey

In the one-to-one interview via Zoom, participants were asked open-ended, verbal survey and demographics questions (see **Appendix G** for the interview schedule). Audio recording was required for participating, but video recording was optional. Interview length ranged greatly in time, from 37 minutes to 2 hours 15 minutes long. On average, interviews lasted 52 minutes.

The interview questions were designed to address the research questions mentioned previously. Demographic questions were verbally asked toward the beginning of the interview session. These demographic questions were used to describe the sample and helped the PI identify any trends for analysis. Details on participant demographics can be found in **Chapter 4.**

The interview session began with the researcher reviewing the informed consent form with the participants and answering any questions participants may have about the study. After obtaining verbal consent for the audio recording of the interview session, the researcher began with asking participants a couple grounding questions and demographic questions. Then the researcher asked questions relevant to the study aims. This included asking about a healthcare experience that has impacted the participant, whether it is positive or negative. The researcher probed follow up questions asking patients to describe details of the patient-provider relationship from the experience, their experience seeking the respective provider, details inquiring about the time and place of their experience, and details describing the facility which the experience took place. Then the researcher asked the participant to describe a healthcare experience of the opposite in nature, i.e. if the first experience was negative, participants would. then share a positive experience, and vice versa. The researcher asked the same probing questions as described previously. Afterwards, participants will be asked questions about how their identity influences their experiences seeking and receiving care. The interview concluded with asking participants for ideas for how healthcare can improve the patient experience for ace individuals.

In total, all 47 participants who consented to conducting the interview completed the full interview. However, 4 interviews were excluded from member-checking, transcription, and data analysis. 3 interviews were deemed "untrustworthy" by the researcher (see **Chapter 5** section on "Limitations" for discussion of "Unusual Circumstances" for details). 1 interview was excluded as the participant largely described their experiences navigating healthcare in Canada.

3.6.5 Member-Checking

Once interviews were transcribed, participants were sent a brief summary of their interview to review for member-checking. The transcript summary was housed a Google Drive folder that is specific to each participant. Participants were sent a link to the Google Document and asked not to share the link with anyone to maintain confidentiality. Participants were given 1 month to make edits to their document, after which their permission to access the document was removed. If participants needed access after their permission was removed, they were welcome to reach out to the investigator. On the document, participants were asked to make edits to identify and clarify any areas of confusion, or share thoughts they were not able to share during the interview. See **Appendix H** for the template of the member-checking document.

Of the 43 participants' whose data is included in the study, 5 participants provided feedback. Feedback was in all cases that the summary looked correct.

3.7 Data Analysis

3.7.1 Transcription

The PI hand transcribed all interviews in Microsoft Word using the audio files recorded by Zoom. All de-identified transcripts were housed in TC protected Google Drive folder.

3.7.2 Coding and Analysis

A reflexive thematic analysis (RTA) method was performed for data coding and analysis, informed Braun and Clarke's (2022) best practices. RTA is described as an "theoretically flexible - accessible and robust method for developing, analyzing, and interpreting patterns

across a qualitative dataset" (Braun & Clarke, 2022, p. 4). This method for qualitative data analysis is often used in lived-experience studies which are focused on "understanding situated or life-embedded truth or multiple truths" as it aims to "generate contextualized and situated knowledge" through meaning-making (Braun & Clarke, 2022, p. 6). A central component of RTA is that the researcher's position and contribution is "necessary, unavoidable, and an integral ingredient of the process" as they are the "situated interpreter of meaning, subjective storyteller - subjectivity valued" (Braun & Clarke, 2022, p. 6; Devine, 2021). The researcher and their subjectivity are "tools to actively utilize" (Devine, 2021) and are "not just unproblematic, but an asset, especially if reflexivity is engaged with" (Braun & Clarke, 2022, p. 6). Researcher reflexivity involves critically interrogating how the researcher's experiences, pre-existing knowledge, and social position (e.g. sexuality, ethnicity, gender, class, etc.) influence and contribute to the research process and potential insights into qualitative data (Devine, 2021). The RTA embraces the researcher's own interpretation and engagement in the research, allowing for a nuanced exploration of the data that "acknowledges and utilizes the complexity of human perspective" (Delve, Ho, & Limpaecher, 2024). As such, RTA positions as a non-positivist approach that argues that a researcher's role is "not to reveal universal objective facts, but to apply their theoretical expertise to interpret and communicate the diversity of perspectives of a given topic" (O'Connor & Joffe, 2020). The quality of RTA is established through, "1) Deep questioning data engagement and a systematic, rigorous analytical process, 2) Analysis moving beyond summary or paraphrasing, and 3) Researcher reflexivity and explication of choices" (Braun & Clarke, 2022, p. 236). To demonstrate deep engagement with the data and active reflexivity, the researcher maintained a reflexive journal to "reflect on and interrogate expectations, assumptions, and researcher practices, and how these, alongside design choices,

shape the research" (Braun and Clarke, 2022, pp. 293-294). Keeping a reflexive journal, the researcher was able to engage in critical self-reflection of how their positionality contributed to the interpretation of the data and the presentation of findings of this study, which is necessary in establishing "trustworthiness" in a qualitative study (Braun & Clarke, 2013; O'Connor & Joffe, 2020).

Braun and Clarke's (2022) six phases of RTA were used to guide the coding and analysis: 1) familiarizing with the data set, 2) coding, 3) generating initial themes, 4) developing and reviewing themes, 5) refining, defining, and naming themes, and 6) writing up (Braun & Clarke, 2022, pp. 35-36). Although the six-phase guideline appears to be linear, the coding and analysis was a "progressive but recursive process" (Braun & Clarke, 2022, p. 36). Braun and Clarke (2022) highlighted that "doing RTA *well* often involves going sideways, backwards, and sometimes even around in circles" along the trajectory from dataset to developed analysis (p. 36). They further assert that "rigidly following the phases of RTA as a series of 'steps' will not guarantee a good analysis," as it prevents researchers from engaging more deeply with data, as the researcher's understanding "might be quite different from what is noticed during data collection, familiarization, or even early coding" (Braun & Clarke, 2022, p. 36). As such, data analysis and coding were largely done concurrently – details of which will be discussed further in this section.

To guide with the familiarization with the dataset, the researcher noted potential codes and themes as they emerged during the interview session. The researcher took notes of significant moments, such as interesting quotes or times in which the participant paused, and reviewed these moments during the reviewing of the audio recordings post-interview. As soon as the interview session with a participant was completed, the researcher took notes of the initial

impressions of the interview, such as the participants' demeanor, to retain a holistic view of the participant.

To begin familiarizing themselves with the data, the researcher initially reviewed the audio recording of each interview session to take note of significant moments. To facilitate this process, the researcher reflected some of the following questions proposed by Braun and Clarke (2022) to "engage critically and reflexively" with the dataset: "1) How does the person make sense of whatever it is they are discussing? 2) What kind of world is 'revealed' through their account? 3) What ideas does my interpretation rely on?" (p. 44). The researcher then compared the notes taken during the audio recording review with the notes taken during the interview. The researcher then transcribed the audio recording in Microsoft Word. Following transcription, the researcher generated a written summary for themselves for each interview, which was organized by participants' response to each stem semi-structured interview questions. In this summary document, the researcher highlighted quotes and incorporated the notes taken from the initial familiarization phase done prior to the transcription to inform thematic coding. Additionally, from the summary document, the researcher outlined a brief synopsis of the interview, which was sent to participants for member-checking.

As RTA is a "process of interpretation – or meaning-making – and research subjectivity fuels that process," Braun and Clarke (2022) argue that having a single coder, usually the researcher, is "normal practice, and indeed good practice, for RTA" (p. 55). As such, the recursive process of RTA resulted in an iterative process of concurrent code development and analysis.

During the early stages of RTA, the goal is to engage with the data, develop workable codes, and generate multiple plausible themes that have potential, pertaining to the research

question (Devine, 2021). For initial code and theme development, the researcher utilized a "batch-review" process. Once the first ten interviews, transcripts, and summaries were completed, this first set of data was reviewed to develop a preliminary codebook. Given the lack of existing theoretical frameworks related to understanding healthcare experiences of SGM individuals, initial codes developed were largely inductive - codes that are "developed following data familiarization" (Braun & Clarke, 2022, p. 237). The summary document was used to identify inductive codes. To help with grounding analysis of findings, the researcher considered the following 3 conceptual frameworks: 1) Johnson and Nemeth's (2014) Conceptual framework explaining the health care experience of lesbian and bisexual women, 2) Rossman, Salamanca, and Macapagal's (2017) Young-adult's disclosure and non-disclosure of LGBTQ identity to healthcare providers, and 3) Razzaghi and Afshar's (2016) conceptual model of physician-patient relationships. Ultimately, Johnson and Nemeth's (2014) model was selected as the foundation for analysis and discussion, as this conceptual framework best fit with the aim of illustrating the lived experiences of ace individuals navigating healthcare (see **Figure 3.1** for the model). However, all 3 models were used to generate deductive codes – codes that are "developed deductively from pre-existing theory or research" (Braun & Clarke, 2022). Once the preliminary codebook was developed with initial inductive and deductive codes, the first ten interview transcripts were coded in Microsoft Word with the utilization of the comments feature. This initial round of coding was used to generate initial themes, or "patterns of meaning (e.g. concepts, ideas, experiences-sense making)" (Braun & Clarke, 2022, p. 229).

For the second batch of ten interviews, a similar process was performed. The transcripts and summaries for the respective batch of interviews were reviewed, and both inductive and deductive codes were developed independently from the initial codes. Then, both initial and new

sets of codes were compared - with initial codes being reevaluated for its applicability, codes that were not initially considered were added to the codebook, and duplicates were removed or incorporated into an existing code. The second batch of ten interviews were then coded with the updated codebook. Themes from the second batch were also independently generated, then compared with the initially generated themes – with similar patterns grouped into one "preliminary" theme, and new patterns added as "possible themes to consider." This process was iterated 3 additional times to account for all 43 conducted interviews, where each batch was independently reviewed and then codes and themes were compared with the former batches. Because "earlier codes may lack nuance, subtlety, or depth," this iterative approach was taken to allow codes to "evolve" as the researcher "engages closely and systematically with the dataset" (p. 72) – i.e. codes shifting as the researcher's understanding of meaning in relation to the dataset develops through coding and analytical engagement – which reflects good practice in RTA (Braun & Clarke, 2022, p. 54). Previous batches were not coded along with each consequent batch to help the researcher "remain freshly engaged with the data and prevent glazing over which can easily happen when looking at data repeatedly" (Devine, 2021).

Once all interviews were reviewed in this "batch" process, all codes and themes generated were compared and consolidated. Then, the researcher engaged in a "refining" process. To ensure the updated codebook was applicable to all interviews, especially for the first few batches, the researcher re-coded all interviews. Prior to this initial re-coding of all interviews using the updated codebook, the researcher re-familiarized themselves with the data by re-reading all transcripts and summaries. Once all interviews were coded, the output informed further review and development of themes. It is important to note that during this "refining" process, there were multiple "back-and-forth" between phases of familiarizing with dataset and

development and review of codes and themes. Once the researcher felt the codebook was effectively refined for further definition and naming of themes, the researcher re-coded all interviews one more time. The output from this final round of coding were used to ultimately name and define themes. In total, all interviews were coded 2 times, aside from the preliminary "batch-review" coding that was used to develop the codebook. The final version of the codebook can be found in **Appendix K**.

The process of developing themes in RTA involved organizing codes "around a central concept – defined by meaning-unity and conceptual coherence" (Braun & Clarke, 2022, p. 77). To evaluate the viability of generated themes, the following guiding questions by Braun and Clarke (2022) were reflected upon to ensure that "a pattern has an identifiable central concept, as well as different manifestations of that idea" (pp. 98-99):

1)) Can I identify boundaries of this theme?

2) Are there enough meaningful data to evidence this theme?

3) Are the data contained within each theme too diverse and wide-ranging?

4) Does this theme convey something important?

Chapter 4 identified the themes developed in relation to the aims – i.e. as the research aims centered around ace patients' healthcare experiences, the themes developed centered around patient-provider relationships during the "Healthcare Interaction" phase. In alignment with RTA

best practices, the final analysis in **Chapter 5** tells a story that meaningfully responds to the research aims using the meaning collectively created from participants' interviews.

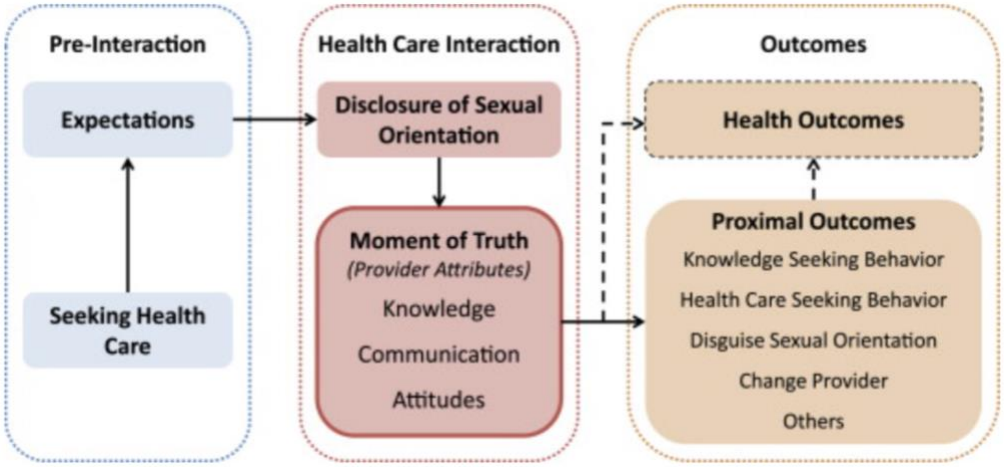

Figure 3.1: Johnson & Nemeth (2014). Conceptual framework explaining the health care experience of lesbian and bisexual women.

3.8 Methods for Assuring Protection of Human Subjects

3.8.1 Voluntary Participation

Participation was completely voluntary for individuals who wanted to take part in the study. Eligible participants were informed of what constitutes their participation via the informed consent form prior to the interview session, and the PI reviewed the consent form with the participant at the beginning of the interview session and answered any questions the participant had. Participants were made aware that the Zoom interview sessions would be audio recorded, but video recording was optional. In addition, the PI allowed participants an opportunity to change their Zoom screen name should they wish prior to the start of the record. Although it did not occur, the PI planned to inform those who do not consent to the audio recording that they would not receive any negative consequences for not participating in the study. Participants were

informed that they would be able to pause or stop the interview at any time and can revoke their participation at any point during the data collection until they have received their interview summary.

Participants were provided with a $50 incentive for their completion of the interview. Although it did not occur, participants who do not complete their interviews would not be provided with this incentive. Although it did not occur, in the event a participant completed a majority of the interview questions and then did not wish to conclude the study but allowed the PI to include partial data, the $50 incentive would have still been provided.

3.8.2 Benefits and Risks

There were no direct benefit to the participants regarding participation in the study. This was a minimal-risk study. Participants were told beforehand that if they feel uncomfortable with any questions asked, they can choose not to answer. Participants were notified of this in the Informed Consent form which they reviewed prior to the interview session, and the PI verbally informed them during the meeting session prior to the conducting of the interview.

Although no participants expressed being in distress as a result of the study, the PI had a plan to refer participants to online mental health resources and hotline numbers respective to the participants' location, if needed. See **Appendix I** for the list of resources, which has been collected from the Ace Community Survey (Hermann et al., 2022).

3.8.3 Confidentiality and Data Protection

All data was deidentified when collected. No files were saved that include participant information.

All research data is saved in TC Google Drive cloud services. An excel document connecting participants' names to an ID number and email information for the incentive was placed in an encrypted folder on the PI's password-protected computer that has updated virus protection. This excel document will NOT be placed on Google Drive to ensure participant information is not connected with the research data.

Documents that was shared with the participants, such as the Informed Consent Form and Member-Checking Document, were housed in a Google Drive folder created specifically for each participant. Participants were asked not to share this folder in order to maintain their confidentiality. In addition, participants were given a private Calendly link to schedule an interview session with the PI, and participants were also asked to not share the link with others.

Regarding the pre-interview eligibility form and post-interview survey, participants' email addresses and names were collected on Google Forms. This Google Form was created and stored on the TC Google Drive. This Google Form was placed in a folder that is separate from the research data that was collected from the interview.

During the interview, the PI worked with all participants to make sure they felt secured engaging in the interview. Initially, participants were given a unique Zoom link with a waiting room enabled to ensure that only the participant was able to enter the meeting. After obtaining participants' consent and prior to recording, participants were given the opportunity to turn off their cameras (if they had their cameras on prior) and change their Zoom name should they choose to do so. Cameras were not required to be on for the interview to allow patients feel comfortable, although it presented some methodological challenges (see **Chapter 3** section "Untrustworthy Participants" for further discussion).

After the interview, to deidentify participants, each participant were assigned an ID number for the purposes of analysis. Participant were later given pseudonyms for the purposes of discussion. A document matching the participant to their ID was be placed on the PI's local computer and the document will be encrypted. It will not be housed anywhere near the research data. Zoom Audio recordings will be kept on TC Google Cloud Services and were deleted once the PI transcribed the data. Only the part of the audio recording that was kept is the part where participants consent to participate in the research and consent to the recording. Each audio recording was saved using the participant ID number.

Regarding the post-interview member checking, participants were given a private Google Document link that had bullet-point items summarizing the interview. This document did not have any identifiers. Participants were also asked to not share this Google Doc link to ensure confidentiality.

When participants disclosed potentially sensitive information during the interview while sharing their healthcare experiences, such as quasi-identifiers like a medical condition or healthcare facility they were treated, the PI de-identified the information by redacting the data from the study. In the transcript which was saved, the PI will removed the quasi-identifier and wrote [omitted] in its place.

3.8.4 Trustworthiness

Trustworthiness in this study was ensured through the development of credibility and confirmability (Malagon-Maldonado, 2014, p. 132). Credibility, which is checking with participants to ensure interpretations are accurate, was ensured via follow-up questions during the qualitative interview session as well as member-checking post-interview. In addition, to

ensure confirmability, in which its findings of the research study could be confirmed by other researchers, the PI will be transparent by sharing all steps taken and materials used in the study when requested.

3.9 Untrustworthy Participants

Due to the logistical challenges of social distancing and lockdowns during the COVID-19 pandemic, many qualitative research had to shift recruitment and data collection to fully online methods (Jones et al., 2021; Newman et al., 2021; Roehl & Harland, 2022; Salinas, 2022; Schlegel et al., 2021; Sha et al., 2020). Since then, many studies have continued to conduct studies online as researchers found that methods like video conferencing for interviews was financially feasible and it allowed for recruiting geographically diverse participants (Jenner & Myers, 2019; Krouwel et al., 2019; Roehl & Harland, 2022). However with using these online methods, there is an increased risk for data contamination as participants can more easily misrepresent their identities and volunteer for studies even if they do not meet inclusion criteria "for the chance of financial gain" (Chandler & Paolacci, 2017; Hydock, 2017; Roehl & Harland, 2022; Salinas, 2022). Roehl and Harland (2022) utilizes the term "imposter participant" to describe participants who "completely fake their identities or exaggerate their experiences in order to participate in qualitative studies." As this is a recent phenomenon, little has been published on how qualitative researchers can prevent and handle this unique methodological challenge (Roelh & Harland, 2022).

As discussed, this qualitative study was conducted fully online, where participants were recruited from social media and online forums and were invited to participate in a Zoom interview once meeting eligibility. One of the methodological assumptions was that participants

would be honest when completing their eligibility screening survey and interviews. In an attempt to protect the identity of SGM participants who experience marginalization, participants were not required to join the Zoom call with their cameras on. As there were no steps established in the study design to verify participants' identities, this allowed for the inclusion of imposter participants who threatened data quality. The investigator first suspected an individual posing as two different participants when two consecutive interview sessions were similar in nature. Based on the investigator's judgment, "both interviewees" had the same vocal mannerisms and the responses from both interview sessions were similar, becoming clear that the experiences shared during both times were exaggerated or perhaps even fabricated. The investigator further suspected the interviews in question being disingenuous when reviewing the interview transcripts for all participants. For example, for the questions related to location of healthcare facilities and finding providers through health insurance networks, the suspected untrustworthy participants did not provide a response, which varied greatly from all other interviews where participants specifically noted the region in the U.S. where they sought care and received health coverage. Furthermore, following the completion of the interviews, although the suspected imposter participants were compensated for their time, they followed up with the researcher claiming they did not receive their electronic gift card incentive. The investigator verified with the electronic gift card vendor that the gift card was successfully delivered to the participant, which further added suspicion that the participants were faking their identity and experiences to earn $50. In total, the investigator suspected 3 interviews to be questionable.

The investigator consulted with both their dissertation advisor and the Internal Review Board to address these concerns. Between the inconsistencies identified in the transcripts, the participants' inability to share details about certain phenomena being discussed, and the

circumstances surrounding incentives, it was decided that some imposter participants had been interviewed. As such, cynical approaches to address these concerns were warranted. All 3 questionable interviewers were recruited from *Reddit*. To prevent further inclusion of imposter participants affecting data quality, it was decided that future recruitment from *Reddit* would be suspended, and any scheduled interviews with participants recruited from the forum were canceled. Additionally, the researcher had decided to completely eliminate data from the 3 untrustworthy participants from analysis to prevent data contamination. It is important to note that more substantive approaches to address this methodological challenge were explored - e.g. modifying the protocol to require participants to join the Zoom call with their cameras on to verify their identity, but allowing for cameras to be off for the recording of the interview. However, since the investigator was close to their goal of recruiting over 30 participants from other sources, it was decided that suspending recruitment from *Reddit* would suffice. Once these actions were taken, the investigator did not suspect any other instances of potential imposter participants taking part in the study.

Chapter 4: Results

Chapter 4 will present the key findings in relation to the aims of the study. This chapter will be divided into the following sections: *Alignment with Johnson and Nemeth's (2014) Conceptual Model, Describing the Participants, and Healthcare Experience Narratives.*

4.1 Alignment with Johnson and Nemeth's (2014) Conceptual Model

The presentation and analysis of ace individuals' healthcare experiences will be guided by Johnson and Nemeth's (2014) explanatory conceptual framework on "Young Lesbian and Bisexual Women's Experiences of Identity Disclosure in the Healthcare Setting," as seen in Figure 3.1. However, it is important to note that not all aspects of Johnson and Nemeth's model were used for analysis, thus an adaptation of the conceptual framework was developed to describe the findings, which can be found in Figure 4.1.

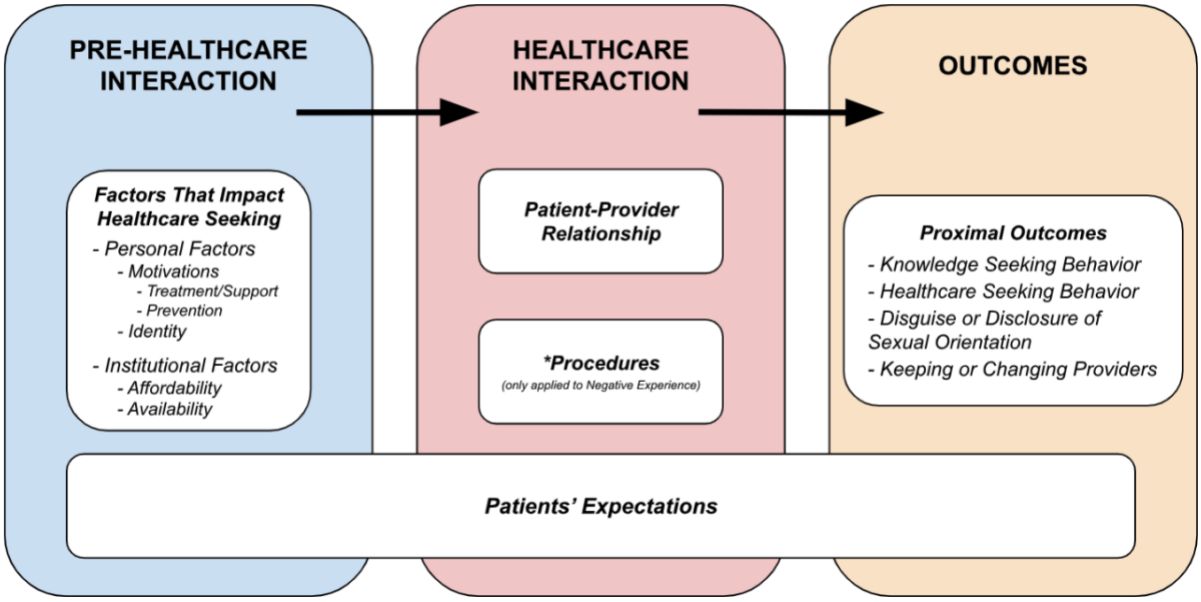

Figure 4.1: Adaptation of Johnson & Nemeth's (2014) conceptual framework to describe healthcare experiences of ace individuals.

To describe participants' healthcare experiences, the three phases of healthcare interactions from the conceptual model were used: Pre-Interaction, which included factors that impacted seeking healthcare; Healthcare Interaction, which included factors impacting patients' healthcare visits; and Outcome, which is used to describe how the healthcare visit impacted patients' experience navigating healthcare. This section will elaborate upon the adapted framework, setting the groundwork to help understand the narratives of participants' healthcare experiences and for analysis.

4.1.1 Pre-Interaction

Johnson and Nemeth's (2014) model proposed that during the "Pre-Interaction" stage, individuals engage in the process of 1) "Seeking Healthcare," and 2) "Setting Expectations" for their healthcare visit prior to their "Disclosure of Sexual Orientation" to providers. To describe the healthcare experiences of ace individuals, findings from the study confirm and expand upon Johnson and Nemeth's (2014) "Seeking Health Care" component to incorporate other "Factors That Impact Healthcare Seeking" behaviors in participants.

Factors that impacted participants' decision to seek healthcare include "Personal Factors" and "Institutional Factors." It is important to note that the interplay of both Personal and Institutional factors played a role in participants' healthcare-seeking experiences. Further exploration of this component will be made within the "Healthcare Experience Narratives" and "Discussion" sections.

Personal Factors. Personal factors impacting healthcare-seeking behavior can be conceptualized into two categories: Motivations and Identity.

Motivation. Participants were not explicitly asked about the reasons why they sought healthcare due to maintaining their confidentiality. However, through patients' narratives, the reasons individuals sought healthcare can be conceptualized into two categories: Treatment/Support and Prevention.

Aurora shares, "You don't go to the doctor when you're feeling all hunky-dory and amazing." This was a sentiment shared by the majority of participants. Participants largely sought healthcare to address health concerns, which included seeking treatment for illnesses, managing disabilities and preexisting health conditions, seeking gender-affirming care, and mental health support. Participants largely sought support from General Care, Primary Care, Gynecology, Urgent Care, Mental Health Care, and Specialty Care. Few participants shared seeking preventative services from Primary Care Physicians. Younger participants from the age group of 18 to 22 shared their experiences with the Pediatricians largely attributed to their guardians' motivation to seek care for the participant.

Identity. Several participants shared that in addition to their motivation to seek healthcare, their identities played a role in the types of services they sought. It is important to note that although participants were inquired about how their intersecting identities (e.g. race, ethnicity, sexual, gender, ethnic, cultural, religious, and disability) played a role in their healthcare experiences, participants largely emphasized that their gender, sex, sexuality, religious, and disability identities had an impact on their past experiences and were important to their healthcare.

Participants seeking care for their disability often visited Primary Care Providers and Specialists. Participants who identified as a cisgender Woman or Assigned Female At Birth (AFAB) highlighted that their sex and ace identity played a role when seeking reproductive

healthcare at a Gynecologist, Primary Care, Urgent Care, and/or Planned Parenthood facilities. Sexuality was relevant to participants when exploring how their identities played a role in relationships, in which they sought care from a Mental Healthcare Provider. Few participants sought gender-affirming care, in which they sought services from Primary Care, Specialists, and Planned Parenthood facilities.

An interesting finding was that three participants shared how their religious identity played a role when navigating local healthcare facilities that were strictly faith-based practices. Participants were concerned about the quality of care they would receive due to the facilities' religious background. Star's sentiment was shared by others:

> I don't know how feasible this would be, to move away from religious based clinics. Not because religion itself is bad, but because the clinic itself might have religious doctrine that they have to uphold that can affect what the doctors themselves can provide or even recommend because of it. So, I think it would be a lot better for my healthcare journey if I didn't have to worry about, like say, the second best option because the doctor couldn't recommend something else because that goes against the clinic's religious background.

Institutional Factors. Institutional factors impacting healthcare-seeking behavior can be conceptualized into two categories: Affordability and Availability.

Affordability. The majority of participants shared they had health insurance during the time of their healthcare experience, and the services they sought were covered. Patients were primarily insured by their place of employment, universities, state-based insurance, or were covered by their guardian's insurance. The few participants who did not have any health insurance shared that they had to pay out-of-pocket for Mental Health or Urgent Care services, but the services were affordable and they were offered discounts.

Availability. The majority of participants reported health services they were seeking were accessible to them. Most participants reported receiving care largely from suburban and urban

locations. Some participants reported having to travel long distances for care. For example, Aspen shared that she lived in a rural area and she had to travel approximately 40 minutes to seek preventative care from a Primary Care Provider. Three participants reported having to travel over 2 hours to seek care from a Gynecologic Surgeon for a hysterectomy because they were seeking a provider who would affirm their decision for the procedure. Some participants had to travel over state lines to obtain gender-affirming care. Coral shared their frustration with the challenges they had to face when having to plan for their gender-affirming care for months in advance because of policies in their home state having restrictions for gender-affirming care:

> It's really frustrating. And it makes me really angry to have to think, to plan my care around where I'm living at the time. So it's like, if I get a prescription for [gender affirming care], I won't have access to that over the summer, and having to manage that around absolutely atrocious policies like that… I wanted to be not just legalized, but specifically protected because it's my body, my choice, full stop. It's an inherent right, it shouldn't be ignored.

4.1.2 Healthcare Interaction

Johnson and Nemeth (2014) proposed that the "Healthcare Interaction" phase within the healthcare experience consists of 1) "Disclosure of Sexual Orientation," where patients disclose their identity to providers, and 2) "Moment of Truth," where providers' quality of care is revealed through their Knowledge, Communication, and Attitudes. To describe the experiences of ace individuals in the healthcare setting, the model was adapted to incorporate the factors that impacted the healthcare experience 1) Patient-Provider Relationship and 2) Procedures.

Patient-Provider Relationship. The core of the healthcare experience can be attributed to the patient-provider relationship participants have with their providers. As such, to describe the findings of this study, the "Patient-Provider Relationship" component will incorporate the "Provider Attributes" of Knowledge, Communication, and Attitudes from Johnson and Nemeth's

(2014) model. Knowledge refers to providers' understanding of asexuality and other sexual and gender minority identities. Although Johnson and Nemeth proposed that Communication and Attitudes were separate attributes, findings revealed that Communication and Attitudes were interconnected because providers' attitudes and comfort or discomfort with sexual and gender minority topics were conveyed through their communication (Johnson & Nemeth, 2014). A deeper insight into the patient-provider relationships from the study will be explored in the "Healthcare Experience Narratives" section.

Procedures. A unique finding in this study was certain healthcare procedures were not ace-affirming, which contributed to the negative healthcare experiences of participants. These procedures will be further explored in the "Healthcare Experience Narratives" section.

4.1.3 Outcomes

"Outcomes" refers to what happens after the healthcare interaction. Proximal outcomes are the participants' behavior or reactions that occur after the patient-provider interaction (Johnson & Nemeth, 2014). Proximal outcomes include: Knowledge Seeking Behavior, Health Care Seeking Behavior, Disguise Sexual Orientation, and Change Provider (Johnson & Nemeth, 2014). These proximal outcomes ultimately impact the Health Outcomes of the participants. Findings from the study aligned with the Proximal Outcomes proposed by Johnson and Nemeth. However, the "Healthcare Outcome" component was removed from the adapted model because patients were not asked to reveal sensitive health information to maintain patient confidentiality. Proximal Outcomes will be further explored in the "Healthcare Experience Narratives" and "Discussion" sections.

4.1.4 Patients' Expectations

Johnson and Nemeth (2014) proposed that "Patients' Expectations" for providers and healthcare occurred during the "Pre-Interaction" stage. However, findings from this study suggest that patients' expectations for healthcare span throughout the three phases of the healthcare journey. In the Pre-Interaction phase, participants' expectations for care align with their motivation for seeking care, such as seeking treatment/support or preventative care. Patient Expectations in the Healthcare Interaction phase align with how participants expect providers to react if and when they disclose their asexual identity. Patient Expectations during the Outcome phase align with whether participants' expectations for care were met. Further exploration of Patient Expectations will be made in the "Healthcare Experience Narratives" and "Discussion" sections.

4.2 Describing the Participants

A total of 43 participants were included in the analysis for the study (see **Appendix J** for "Participant Identity Data"). Table 4.1 presents the descriptive statistics of the demographic characteristics of the participants. Demographic information was collected from both the pre-eligibility survey and the semi-structured interview. All collected demographic data were de-identified by the PI before analysis.

The participants' ages were collected from the Pre-Eligibility Survey (found in **Appendix E**). One of the eligibility requirements for participation was that the participant had to be 18 years of age or older, which is the age of consent in the United States. Participants in this study ranged from 18 to 47 years old. The majority of participants were between the ages of 18 to 27 (n = 37, 86%). Information about participants' racial/ethnic identity, gender identity, sexuality

identity, completed level of schooling, and employment status was collected from the participants during the interview session (found in **Appendix G**). Majority of the participants identified as follows: White, Non-Hispanic/Latine (n = 28, 65%), Cisgender Woman (n = 27, 63%), and Asexual (n = 34, 79%). Participants were also highly educated, with all participants having at least a High School degree, and the majority of participants having at least a Bachelor's degree (n = 28, 65%). The majority of participants report being employed at the time of the interview (n = 34, 79%).

Table 4.1: Descriptive Statistics of Participant Demographics

Measure	***N***	***%***
Age		
18 to 22	12	27.91%
23 to 27	16	37.21%
28 to 32	9	20.93%
33 to 37	3	6.98%
38 to 42	2	4.65%
43 to 47	1	2.33%
Racial/Ethnic		
White, Non-Hispanic/Latine	28	65.12%
White, Hispanic/Latine	1	2.33%
Black	2	4.65%
Asian	7	16.28%
Biracial & Mixed	5	11.63%
Gender		
Cisgender Woman	27	62.79%
Cisgender Man	3	6.98%
Transgender, Nonbinary/Genderqueer	2	4.65%
Agender	3	6.98%
Nonbinary/Genderqueer/Genderfluid	8	18.60%

Sexuality		
Asexual	34	79.07%
Demisexual	3	6.98%
Gray-Asexual	6	13.95%
Highest Level of Schooling		
High School	10	23.26%
Some Undergraduate	3	6.98%
Associates	2	4.65%
Bachelors	17	39.53%
Some Graduate (Masters & Doctorate)	2	4.65%
Graduate Degree (Masters & Doctorate)	9	20.93%
Employment		
Employed	34	79.07%
Not Employed	9	20.93%

4.2.1 What Does Being Asexual Mean to Participants?

To help ground the discussion of their healthcare experiences, participants were explicitly asked to define "What does being ace mean to you?" This section will provide several definitions of how people defined their ace identity to help with capturing the diversity of experiences within the asexual community. In addition, the provided definitions will help with understanding participant narratives and guiding the discussion within this chapter.

Clover, a cisgender woman who identifies as aromantic asexual: "It means that I'm not romantically interested in anyone and, you know, I don't particularly experience sexual attraction to anyone."

Delta, a genderqueer individual who identifies as asexual: "Not really desire any type of, like, sexual contact or sexual interaction. I've never really experienced sexual attraction. It's a

pretty foreign concept to me… And for me, I'm sex-repulsed, so I don't, I'm not interested in sexual relationships either."

Diamond, a cisgender man who identifies as asexual: "[Being ace] is definitely validating, being able to say that like, my lack of sexual desire is not a problem that needs to be solved, but an aspect of who I am."

Emerald, a cisgender woman who identifies as grey-ace: "It was kind of a label that I, kind of, when I found it, I didn't feel broken, and that was important to me… It was kind of a way to identify where there was a community of people who felt like me, who didn't have this kind of attraction towards others… People always talk about how, like, when you feel a crush, like, you feel like almost a physical sensation. I've never felt that, and it always kind of made me feel a bit of broken."

Ivy, a cisgender man who identifies as heteroromantic asexual: "Well, there's always the just straight dictionary definition of asexuality being the lack of sexual attraction, which does not, I always like to point out, necessarily mean the lack of romantic attraction. That I feel is an important distinction to make, as it's what kept me from realizing I was asexual until I was 28."

Juniper, a cisgender woman who identifies as asexual: "To me, it means I don't have to worry about the extra or the extraness of dealing with having to look for a partner, be interested in any of that sort of thing. I can focus on my goals in life and I'm not distracted. I don't have those wants and needs at all. So it's not something that really ever crosses my radar in life."

Lotus, a cisgender woman who identifies as asexual: "I think, for me, it's just not having the desire to engage in sexual activities and intimacy. Like, I don't identify it as aromantic, so I still experience romantic feelings, and to some degree I enjoy intimacy. But I will never engage

in sexual activity. It's more like I will respond to it, maybe, but most of the time I am not interested."

Mist, a cisgender woman who identifies as queer asexual: "I have personally never experienced sexual attraction to anyone before. I've never looked at that person and wanted to have sex with them… I feel like a lot of people, in their head, just have kind of like the idea of sex-repulsion. But in reality, it's a lot more of a spectrum than that. So I would say that I'm probably more sex indifferent with like everything except sex itself, which is something that, as of right now, I don't ever see myself participating in. But then, as far as other sexual activities that are not sex itself, I'm more, like, indifferent to them. Or, if I have an emotional connection to someone, I might even be in favor of them. So it really depends, like on circumstances. But the label brings me comfort because I know that I don't experience sexual attraction in the same way that an allosexual individual would."

Onyx, a cisgender man who identifies as gray-ace: "It's something that I've always, kind of, knew, but I wasn't sure how to put it into words because there weren't words that, they didn't have the words back then when I was growing up. So I wasn't sure if there's something wrong with me, you know, broken, or something like that… Living in a society where it's like you have to have sex, you gotta experience it at least once. It's like they make it a big deal. It's hard, then if you're not feeling that you feel left out… I felt like I had to have sex just so people get off my back about being a virgin."

Opal, a non-binary individual who identifies as asexual and gray-ace: "It's a weirdly broad spectrum. So I identify, like ace and gray-ace, that kind of, like, fluctuates between the two. But mostly it just means, like, I desire, like, emotional relationships, but physical intimacy is really, like, for the most part, like, super off the table for me."

As seen above with how participants described what being ace meant to them, there are numerous ways of experiencing not as much to not experiencing sexual attraction, practice, and desire. This further illustrates the need for understanding the nuances of asexuality – a singular standardize definition is not enough to successfully capture the diversity of experiences – which has implications on providing ace affirmative care, which will be discussed in **Chapter 5**.

4.3 Healthcare Experience Narratives

This section aims to describe the healthcare experiences of ace individuals by highlighting participants' narratives. Through the reflexive thematic analysis of findings, participants' experiences can be conceptualized in two overarching themes: *Negative Healthcare Experiences and Positive Healthcare Experiences*.

4.3.1 Negative Healthcare Experiences

The majority of participants shared having a negative healthcare experience regarding their asexuality. The negative healthcare experiences can be attributed to two factors: *Inadequate Patient-Provider Relationships and Non-Asexual Affirmative Procedures*.

Inadequate Patient-Provider Relationships. A central experience shared by many participants is that providers' lack of understanding of the asexual and asexual ppectrum identities, interplaying with the providers' implicit biases, communication styles, and attitudes, contributed to the participants' negative healthcare experiences. To describe this phenomenon, the following subthemes were generated through reflexive thematic analysis: *Providers Viewing Asexuality as Needing to be Fixed, Providers Making Assumptions About Why People Identify With Asexuality, Providers Making Assumptions About Lifestyles and Identities of Ace and*

*Acespec Individuals, Providers' Unprofessional Attitudes When Discussing Asexuality, and Patient's Expectations for Healthcare Not Being Met***.**

Providers Viewing Asexuality as Needing to be Fixed. Several participants shared that once disclosing to providers that they identified as ace or on the ace spectrum, their providers attempted to establish a cause for asexuality, rather than acknowledging it as an identity or sexual orientation.

Ruby recounted the experience she had with a mental healthcare provider within the past year when she was seeking mental healthcare support from a therapist for an undisclosed reason. During one of the initial intake sessions with the provider, Ruby disclosed in passing that she identifies as ace, which the provider tried to make her ace identity the focal point of the mental healthcare, making Ruby feel pathologized:

> [W]hile talking about some of the other things, I brought up sort of as a side thing, "Oh, yeah, by the way, I'm ace. It's only partially relevant to the story. But like, that's that's not what I want to talk about here." And immediately she went, "Oh, wait! Why do you hate sex and intimacy?" And was like, "Can we talk about that?" I was like, "that's not… No." I had to, like, persistently be like, "that's not, that's not a problem for me. That's not what I'm talking about. And no, it doesn't mean those things, like excuse me?" I ended up not continuing to work with them, primarily for that reason… It came out of left field, like that was like definitely an immediate assumption that [asexuality] must be somehow pathological or related to mental health.

Ruby shared that this experience her felt awful. She further added that she was angry that her provider made their own inaccurate assumption about being ace without asking Ruby what it meant to her.

> It makes me angry, I guess, because it's kind of, like, she heard nothing but that one word. And it's like, "you don't know anything about my internal experience, or even what this label means to me. Why are you jumping too assumptions about this?" And also, like, "if you think you know what this word means to the point where you're immediately starting to talk about it, like, how dare you assume that it's a pathology? If you've researched anything about this, there are plenty of people who are ace, who do not believe it is a pathology. And, like, who are the hell are you listening to? If you weren't

> listening to them, like, where were you getting your information that you feel so confident about speaking over me about what you think is wrong with me?"

Gale shared a similar experience she had with a mental health provider she visited a year ago. Gale disclosed that she identified as ace on an initial intake form. When reviewing the intake form, the provider asked if it is something that Gale wanted to work on, which made Gale feel uncomfortable:

> I could just tell she just didn't quite understand what [asexuality] meant by that, and she asked if it was something that I wanted to work on. And that verbiage just kind of struck me as off, because I guess, when you go to a therapist, you want them to understand the kind of person that you are. So having her on the intake form when she was reading through it asked if I wanted to work on asexuality was a little off-putting. So, I mean, I did not end up seeing her for too long.

Gale added that because of the provider's response, they did not appear to knowledgeable about asexuality, which Gale felt that this provider "might not be a good fit" for her care. Gale ultimately did not continue her care with this provider.

Ivy shared seeking a mental health therapist approximately two years ago to help with navigating romantic relationships as someone who is ace. Ivy shared that although the provider presented themselves as being queer-affirming, the provider made the suggestion that Ivy's ace identity was related to a trauma that needed to be addressed.

> I mentioned something about being pretty sure I was asexual to that therapist who actually had a pride flag hanging in her office, like one of the standard current design pride flag with a trans pride stripe on it too. And then she said "alright, we'll unpack if you want to unpack the trauma that led to that." And I was like 'No, no." And she kind of backed off on that pretty quickly… It's the assumption of normality, right? It's the assumption of what is considered normal. And if you deviate from that norm there must be something wrong with you. There must be something broken about you. And, well, I feel like the fact that, that's the comment I always think of when I think of what got me seeking another therapist… I think that might have been one of the last times I saw her. I think I started looking for someone new not long after that.

Laurel shared seeking multiple healthcare providers for a diagnosis of a chronic condition. The most recent experience they shared was from 3 years ago with a Primary Care

Physician where they felt as though the provider was trying to connect their asexuality with a hormone imbalance issue tied to their chronic condition:

> There's a general survey that my doctor uses for all patients, just simple ethnicity, gender, sexuality. And I was lucky enough to it actually included asexuality… But even then, when I marked it, there's still a question of like, "is there some hormone imbalance? Is this like, is there some medical reason why this patient? It feels this way?... Is this like some sort of disease, that's where asexuality is a symptom?"... [The doctors] were going to look at every single thing possible, and see if it had any connection. And on the medical side, I completely understand that they're trying to figure out what's wrong and help me. But at the same time, like, it was a very specific program that I was in too for my condition. And there were other people that were of other different sexual identities, people that weren't straight, and I was the only one singled out with thinking about how my sexual identity could have played out in my condition.

Laurel shared that although this was a frustrating experience, they ultimately received the medical treatment they needed and is continuing to receive care from this provider. Because their priority was to find a doctor who was an expert for their specific health need and they "didn't really have any options to, like, search around," they felt as though they had settled with this provider.

Providers Making Assumptions About Why People Identify With Asexuality. Some participants shared their providers made anti-ace microaggressive assumptions, such as assuming that little to no sexuality is a byproduct of a disability or preexisting condition.

Clover expressed their frustration that several general practitioners they have visited in the past made the assumption that the reason they identify as ace is because they are not sexually active due to their disability:

> They were like 'oh, yeah, no, that makes sense for you.' And so it's, it's weird because they're like. And this happened several times… They're always just like 'Oh, well, no, of course you wouldn't," because they assume that because I am disabled, you know, I'm not. That's why I don't have sex, or why I'm not interested in any of that.

Clover shared that although they were upset by this encounter, they did not push back against the provider's comments, nor explicitly share that they identify as ace, because they were not sure if the provider was Queer affirming:

> I live in the South. And so where I live, you're lucky if people know what the, you know, the LGBT part of the acronym is, let alone, like Q or anything else. And so I really had to pick my, you know. I had to ask myself like, "Is this something that doctors should know about? Is this particular doctor gonna know about it or gonna care about it?" And I decided that ultimately the risk that she would just be dismissive about it, or the risk that she would see it as like a healthcare problem that I wanted to fix outlay the potential benefits of trying to explain it to them.

Coral shared a story about how they visited a new OBGYN provider approximately 3 years ago for a medical diagnosis. Coral shared that they identified as ace with the provider during the initial intake session, and the provider tied Coral's ace identity to their weight:

> [T]hen she asked me 'is there any chance that you could be pregnant?' I laughed a little too hard when I said 'no,' and so she kind of leaned in and she kind of lowered her voice and she was like 'is this because you're gay?' And I was like 'no.' And I explained that I was ace, that I didn't feel sexual attraction, and that I only felt romantic attraction so there would be no chance I could be pregnant just because that's not who I am as a person. And then she leaned in even further, she got quieter like she was trying to be considerate, she was trying to be thoughtful, but she asked 'is it because of your weight?' And that kind of hit a nerve because I'm fat. I've always been fat… I am not ace because of my weight. I am ace because I am ace. So yeah, that wasn't a great day.

Coral shared that they pushed back a little bit by explaining to the provider that their ace identity was a separate facet of who they are and not tied to their weight. Coral does not remember the provider's reaction after the pushback because they were still trying to process what the provider said. Coral described they felt as if the provider was overstepping boundaries between a doctor and patient by tying their weight to their sexuality. Coral added:

> [The OBYGN provider] kind of putting the implication that I was queer because my weight was holding me back when my weight shouldn't hold me back in terms of, like, romantic or sexual attraction. It's not connected to my romantic and sexual attraction. And so, those connections should never be made.

Coral mentioned that this interaction was one of the reasons they did not go back to the provider, and they do not plan to go back in the future.

Providers Making Assumptions About Lifestyles and Identities of Ace and Acespec Individuals. Participants shared that due to providers' lack of understanding of asexuality and the diversity within the ace community, providers make assumptions that do not align with each individual's experiences, impacting the healthcare experience. Several participants shared how the initial intake session with providers can be an odd, uncomfortable, and/or invalidating experience when providers ask patients to share their sexual history. Oftentimes when recounting their sexual history, participants feel as though their providers do not believe them.

Emerald, an undergraduate student, recounted feeling uncomfortable during the intake session with providers at an urgent care visit 2 years ago regarding a health concern. She felt providers made an assumption that college students her age engage in sexual behavior, and were trying to push her to give them an answer:

> And I told them that…'I, I'm not really comfortable… like answering those kinds of questions, because I don't really have a history like, sexually and stuff.' And they just didn't get it… I felt like they weren't believing me, which I feel like is normal. But it's just like, I was being truthful… I could tell they were trying to kinda get me to open up. They're like 'oh you can be totally honest with us, like your age, you know, things can get a little crazy.' And I'm like, they're trying to have me, you know, I don't know, like identify all these past experiences that I don't have, as an ace individual… This would not fly with other professions or whatever. It's just, they feel like they get so used to identifying certain archetypes within, like, college-age individuals and all that stuff. So I feel like they were looking for something that could help them identify the issue. But it just was not fun…

Hazel shared her experience with a Primary Care Provider approximately 3 years ago where she felt delegitimized when it seemed that her provider made the assumption that asexuality was synonymous with celibacy:

> I told her I was ace and in a relationship with an ace person. And she was confused, and like, asked me again like, "well, but you've had sex acts, right? Like you told me that in

> the past?" And I was like, "yeah." And she just, kind of didn't get it. She didn't say anything, like, bad. But it was also like, sort of not the understanding I hoped for… It felt kind of like… it delegitimized me in the provider's eyes, like 'oh this person is using some fancy labels that don't really exist. And, I'm just a doctor and I don't need to know all about that… I wish that they had… an understanding that, like sexuality and sexual behavior, is not prescriptive and don't assume anything."

Hazel further noted that the provider was "making weird comments about polyamory that I thought were not very informed" about SGM identities which made her feel "uncomfortable" and "put-off" by providers' demeanor. At that point she decided "okay, I need somebody," prompting her to switch providers.

Diamond, a man who recently identified as ace, pointed out how there is a placed assumption that men regularly experience sexual desire, thoughts, and behaviors, which has implications in care. He shared an experience with a Nurse Practitioner he had approximately a year ago, prior to identifying his asexuality, where he felt the provider wasted time discussing practicing safe sex with him when it was not applicable to his personal experience:

> I feel like an ace man, it's automatically assumed that you are a sexual being. And when they're like "so like, are you practicing safe sex?" And I'm like "well, no, but not for the reason you think." And it's, it's just sort of like the assumption that sexual activity is something that needs to be talked about is just kind of funny to me, because like "of course they do," there are some that actually need to be told to, you know, put a condom on. But like, also, the fact that [the provider] is like, "make sure." I'm like, "Okay, yeah buddy, say your 10-minute script" … Typically sex is seen like a reward, you know. But for me, it's yeah I'm willing to have sex. But it's, it's like a chore.

Diamond noted that this assumption affects him more when it comes to interpersonal relationships – e.g. "Being assumed to be the sexual in a relationship has definitely been a problem… I never talked about any being sexual with my friends, you know, engaged in that sort of like, locker room banter at work." He shares that the only time he feels that his ace identity comes into play in his healthcare is "when they ask if I'm sexually active, I laugh, and then we move on."

Providers' Unprofessional Attitudes When Discussing Asexuality. Participants shared that once disclosing they identified as ace or on the ace spectrum to providers, they were shocked by the providers' unprofessional response. Participants indicated that the providers' response made them uncomfortable, which motivated them to seek other providers for their care.

Nova recounted an experience she had with a General Practitioner approximately a year ago during an annual check-up appointment. After sharing with the provider that she identifies as ace, they explicitly prayed for a cure:

> When explaining what being asexual is… I had one doctor who, he hovered his hand over my head. And I thought "oh, that's, this is strange! What is he doing?" And he was praying that I would be cured, and that I would find a husband. And I was mortified. I had to explain to them that this is not something that could be cured, and that is, you know, this has nothing to do with me being nervous or being socially anxious… I think he just heard it and was like "you just haven't found the right one," kind of thing.

Nova added that this was a provider she was able to see for free through her community healthcare plan. However this experience was uncomfortable for her, which caused her to seek a different General Practitioner, and even impacted her future healthcare-seeking behavior:

> I actually ended up dropping him to see another GP who wasn't free. I'll have to pay $100 to visit for that. And so I've actually been avoiding seeing a general practitioner whenever I can. And I don't feel comfortable going back to him, unless I absolutely have to.

Holly shared an experience at a Gynecologist's office from 6 years ago where they felt othered by the way the Nurse Practitioner responded to Holly's response about their past sexual history:

> [She] was asking about my sexual activity. And I was like, "well, no, I used to, but I'm ace. I don't have sex now." And she looked at me and she went, "not even oral?" And I was like… it was almost felt like a zoo-animal type question sort of because it was like this person didn't know how to interact with anyone who was of varying, you know, sexual identity… I laughed inside, but I was also like a little horrified.

Topaz shared an experience they had 5 years ago during an intake session for a psychiatry visit where they felt dismissed by the provider. The provider inquired about Topaz's sexual orientation, which Topaz revealed they identified as demipanromantic asexual. After disclosing their identity, the provider's demeanor and response gave Topaz the impression that the provider found their identity complicated and was not willing to learn more about it:

> I think both, like her, in her body language, like, I think, she was almost like kind of like, maybe nervous laughing or something. But also like saying specifically that she thought that was really complicated. And I think that just like the wording made me feel like, "Okay, like, you don't seem very interested in getting to understand it." You just kind of are dismissing it already as something that's like, "oh, this is not like just, you know, gay or lesbian, or something that I find simple enough to grasp." So I think it was just more evident, like just that, rather than either asking questions or just being like "okay" and moving on. Like it, it felt like she was communicating that one, not only was she not familiar, but that she wasn't really interested in trying to understand it.

Galena recounted an experience she had with a Mental Health Therapist approximately 5 years ago when the provider tried to discourage her from identifying as ace, indicating Galena is too young to have a sexuality identity, as she was still a minor at the time.

> When I told her I was ace, she was basically like 'you may be a little too young to know what you're identifying, as you're still in high school, there are plenty of women' because at that point in time I thought was a woman, not nonbinary, 'there's plenty of women who mature and gain sexual attraction, and sexual attraction that grows in their 20s.' It was like 'you don't want to identify as this.' And I think another time that same therapist I let her know that I was feeling kind of lonely and ostracized at school because I was bullied at school for being ace. I had friends who were telling me that being ace didn't mean I was in the LGBTQ Community. So I had said that when I first joined the Asexual subreddit, and and I had let my therapist know, and I was like, 'this is making me so happy. I'm feeling a lot more comfortable. I can talk to people who can relate to my experiences,' and she was like, 'I don't think you should be making this much of a deal of it.'

Galena expressed feeling constantly invalidated and unsupported by this therapist. Unfortunately, due to the challenges of finding therapists covered by her insurance, Galena had to settle with this therapist for an extended period of time.

Patient's Expectations for Healthcare Not Being Met. Several participants shared they specifically sought care to explore how their asexual identity had an influence in various aspects of their lives. However, providers' lack of knowledge surrounding asexuality created a disconnect in an effective patient-provider relationship. Participants also reported not being satisfied with the quality of care from the experience.

Ray shared how she has constantly struggled with finding a Mental Health Therapist who was knowledgeable about asexuality to help her navigate her sexuality around a past trauma.

> The therapists that were better didn't have the competency to help me navigate my sexuality and my issues, like I experienced assault when I was like, I think 14… I didn't really have anyone to, like, help me navigate my sexuality around trauma except like the internet, and like, my friends, not professionals. And I have coped in very unhealthy ways, you know, like this idea of being 'broken' and not having anyone to like, really talk through my sexuality. And talk with my, like, talk about my insecurities with my sexuality. Just because no therapist is competent in understanding asexuality… I've never had a therapist who had such knowledge of the ace community and had such ability to help me navigate… I always had to be the one to educate them. And it's kind of just exhausting… So just someone who understands the totality of experiences, understands how it can impact mental health, understands how we can bring about insecurities, especially in a world that's so centered around sex and relationships.

Maple was seeking a Mental Health Provider who was well-versed in asexuality and other Queer identities to help her navigate her ace identity in regards to her past relationship. She visited her university's clinic about a year ago asking specifically for referral to a mental healthcare provider who is familiar with asexuality. However, Maple later found out the Primary Care Provider wrote her a referral to seek care for Gender Dysphoria, which delayed her process of seeking appropriate mental healthcare:

> So the next day I get this call from her office, saying that, asking me like "oh, like, your doctor said that you were looking for a therapist that treated gender dysphoria?" And that was not, that was not a term that I ever used. That was not a term that my doctor had ever used in our conversation, so I don't know if she just assumed that is what I was talking about and put it in her notes. But that was just like a weird thing… It was confusing… And the person who was calling me, like, it sounded like they didn't even know what gender dysphoria was. It was just, it was bizarre.

Ruby shared an incident where they felt like they had an "out-of-body experience," and they sought help from a mental health therapist who could help them process this experience. However, the provider was unable to effectively help guide Ruby since they did not understand how the experience Ruby had was dysphoric to them as a sex-averse ace individual, and kept insinuating that it was normal.

> Most of my life I have not had libido. I got one seemingly overnight out of nowhere. And it was intensely just fucking awful. And I felt like being addicted to drugs, or under some kind of compulsion. And I had a really difficult time talking about it with any sort of mental health provider… it was just so ego-dystonic and so dissonant with my sense of self… People use the word 'masturbation' and I'm like 'that feels like the wrong word, because it actually felt more like compulsive self-harm' And there was definitely at least several therapists who are like who I talked to about it… But this was a particular thing where she would keep calling it that. And I was like, 'can you not call it that?' But she just like, "that was just a word." And I'm like, I like, explain this multiple times, but why it didn't feel accurate. It didn't feel accurate to my experiences, and it just sort of was this like. 'well, I don't understand.'... There's a lot of weirdness about people who are sex adverse, or have like fluctuating levels of sex… So there was this sense of like I was trying to describe something that for some other people might be a healthy or neutral coping mechanism, being like inherently kind of traumatic, and very like problematic and more hurtful for me in ways that kind of seem like they would go over people's heads.

Non-Asexual Affirmative Procedures. A number of participants highlighted certain healthcare procedures which were not affirmative to their experiences as ace individuals. This section will highlight specific examples pointed out by participants.

Depression Screening Tools: Beck's Depression Inventory. Lotus recounts having complete the Beck's Depression Inventory during a visit to a mental healthcare provider where she felt the question about sexual interest was invalidating to her ace experience. She expressed her concerns that this will have implications on the care she receives:

> I was given a depression, it was like the Beck's or some kind of depression survey. And one of the questions was like, you know, "Do you agree or disagree? Having little or no sexual interests?" And I'm like, "how is that gonna be a measure of depression of somebody who is at that state naturally?" Like, that's gonna be a score down, because I said "No" like "Agree, no interest," whereas like, maybe somebody else, like someone

> who is allo, like, is gonna say, you know, not having that is a sign of depression. But for me, definitely isn't. I'm just naturally at that stage. So I feel like that question needs to be revised, or you know, changed. It have an impact on how it screens you for depression.

A unique experience for several participants who identify as a cisgender woman or Assigned Female at Birth (AFAB) is that although they do not have a sexual history, or had a history far in the past, and do not plan to engage in sexual activity in the future, they had to advocate for their decision for certain sexual healthcare procedures which caused them distress. Participants indicated that certain Pregnancy Tests Prior to Treatment, Cervical Screening, and the Process of Obtaining Accutane were non-ace affirmative.

Pregnancy Tests Prior to Treatment. A number of participants shared having invalidating experiences being forced to take pregnancy tests prior to receiving certain treatment. Brook expressed her annoyance of being required to take a pregnancy test prior to surgery she had earlier this year as she has no intention or opportunity to become pregnant, and felt it was "unnecessary" for her to test:

> I had to restate over and over and over that I had no intention of having children, and that I had no intention of being in a relationship. I've had to repeat to my general practitioner that I'm not sexually active, and they still don't believe me. Yeah, I'm required to take pregnancy tests pretty much for, like everything. And I'm like "unless I'm the Virgin Mary, you're not gonna find anything especially since I'm also on birth control." So, like, extra protection, I guess?

Similarly, Orchid expressed her frustration with having to constantly take pregnancy tests to obtain Depo-Provera injections to manage her pain related to a chronic condition, and feeling defeated having to take a test or she will not get the care she needs. She disclosed that she identified as asexual in hopes providers stop their insistence to no avail:

> I was just like, I just want you to understand that I never had sex, I am not having sex. I do not plan to have sex, you know, like it's actually not as complicated as you're making it... I say "I'm asexual," you know, like "we can stop the conversation… I will sign anything, I will tell you anything, I guarantee I am not pregnant." And, you know, they

> say like, “Oh well, this is the rule. You have to go pee in the cup and make sure you’re not pregnant.”

Cervical Screening. Participants described the Cervical Screening Procedure, commonly referred to as the Pap Smear Test, as, “the most uncomfortable experience. I think, as someone with a uterus, it’s probably one of the worst annual things to happen.” The procedure is described to be invasive, painful, cold, and violating.

Participants commonly expressed distress for not having their decision for the cervical screening procedure respected by providers. Galena shared that because she does not have a sexual history, doctors delay the procedure even though she wishes to have the screening done, especially since she has a family history of cervical cancer. She expressed how this experience makes her feel unheard, and she feel as though she is missing out on crucial preventative care:

> When doctors find out that you’re not sexually active after you get to a certain age, there’s kind of a concern. I also know that they delayed my pap smear by a year because they learned that I have never been sexually active. And they were like “oh you’ve never been sexually active… you don’t need a pap smear yet.”... From what I remember, I’m not fully knowledgeable about, but they can also help kind of recognize if you have a potential of developing cancer down there. And my family, there has been cancer on like both sides of my family… It’s kind of like “hey maybe like I should get checked out.

Many other participants wished they had the option to opt-out, and expressed their frustrations surrounding the exemption process. Nova shared how she felt annoyed with having to constantly inform her provider that she is are interested and that she was educated on the risks and benefits of the procedure:

> Anytime I transfer to a GP they always mention, “hey, we don't have any pap smears on record.” And so I usually mentioned to them, “you know, I've done enough research. I experience an incredible amount of discomfort and pain when it comes to my genitals and stuff like that. And I've determined that [I don’t need it] since I don't have a history of ovarian cancer, since I don't and have will never have sex or become pregnant.”

Autumn mentioned that to avoid constant questioning about the procedure, they changed their gender to "male" on the intake form: "I actually put that I was male because they kept bothering me to get a pap smear. I didn't want to. So it's like, 'all right, this is way to fix this is, tell them that I'm male.'"

Some participants shared they tried to skip the procedure, but they felt forced by the providers to go through with it. Lotus shared how it was a traumatic experience for her, and she does not plan on having future screenings due to this experience:

> The last time I got a pap smear at like, you know the gynecologist… it was very traumatizing. Like, first of all, as an ace person like I don't want anything touching down there and having some, you know, cold and like, just like up it, almost felt like violating.... I wasn't given the patience like it was such an impatient, rushed, I felt rushed. I wasn't comfortable at all with the whole procedure. And this is somebody who was recommended to me, too, as someone who dealt with teens, and like first timers to the, you know, screening… and oh my god it was the worst! I was crying, I was like shaking… and the only thing the doctor was saying like "oh well next time, we can sedate you so you can go through the procedure more comfortably," and that sounded absolutely awful for me, to like, be drugged out and have this procedure happen to me.

Accutane. Accutane (Isotretinoin) is a potent oral retinoid medication often prescribed to treat severe cystic acne (Cleveland Clinic, 2024). Due to the large amount of Vitamin A the medication produces, which can lead to severe birth defects, Accutane is only prescribed as a last resort (American Osteopathic College of Dermatology, n.d.). In addition, patients who have the potential of becoming pregnant have to go through a stringent iPLEDGE Risk Evaluation and Mitigation Strategy (REMS) program, which involves completing an educational course about the risks and benefits of the medication, taking required periodic pregnancy tests, and electing two forms of contraception prior to obtaining the medication (iPLEDGE, 2021).

Three participants mentioned how the process of obtaining Accutane can be an invalidating experience for ace individuals who do not have a sexual history and do not have

plans of becoming pregnant. Marine recounted how the administrative challenges faced during the COVID-19 pandemic lockdowns, coupled with the long iPLEDGE REMS process of obtaining Accutane was frustrating, invalidating, and also resulted in a delay in obtaining the medication which affected her health:

> [For the iPLEDGE program] There's like a list with 2 columns with 2 kinds of birth control… So you have to choose one form of birth control from each of the columns, and commit to employing such techniques for the entire like 6 months, or whatever that you are on the prescription. So, for instance, like in column 1 it would be more hefty stuff like you get an IUD or implant, and in column 2, it would have like condoms… So you're supposed to pick one from each column and sign a form saying that you would use 2 form of birth control throughout the entirety of your prescription, or you could choose abstinence throughout the entire prescription, which is what I did… Some providers don't allow you to choose abstinence as an option like they just don't trust you enough… which is frustrating… it is invalidating as an ace person… I think I said [to the nurse practitioner] I'm choosing abstinence and she just, like the look on her face was like "yeah right."…. As a part of the iPledge program, you have to get one month's prescription at a time, and you have to answer questions on the portal to get your next month's released to you… The questions were not remotely geared towards if you have chosen abstinence as your birth control… It also gave you a scenario to answer like 'I forgot to take my pill today, should I be having sex within the next 12 hours?' or whatever like 'I was having sex and the condom broke, what do I do' sort of thing. Which is just so very, it was like totally unnecessary, and just like hoops to jump through that I didn't feel like I needed to because I obviously wasn't having sex in the first place.

Participants also expressed how having to elect a form of birth control method and having to take periodic pregnancy tests were unnecessary, a waste-of-time, and costly. They wished they were able to exempt themselves from having to follow through with these procedures since they were not relevant to their care or lifestyles.

4.3.2 Positive Healthcare Experiences

Although the majority shared negative experiences, several participants shared having positive healthcare experiences with providers. Positive experiences can be attributed to two

factors: *Providers Exercised Competency in Affirmative Care and Providers' Professional Communication and Attitude*.

Providers Exercised Competency in Affirmative Care. Participants shared how providers having the training to provide culturally competent and affirmative care contributed to a positive healthcare experience. To describe this phenomenon, the following subthemes were generated: *Knowledgeable About Navigating Sexual and Gender Minority Identities and Patient-Centered Care.*

Knowledgeable About Navigating Sexual and Gender Minority Identities. The majority of the positive experiences shared by participants were attributed to the provider having previous knowledge and training in working with Sexual and Gender Minority patients. It is important to note that the majority of the participants indicated that they were not sure if their provider was knowledgeable about asexuality, however, the provider exhibited open-mindedness through their communication and attitudes. Several participants recounted that they appreciated that their provider exercised humility by admitting they were not knowledgeable about asexuality and expressed a genuine interest in learning.

Summer recounted an interaction she had with a mental health therapist she visited two years ago where she disclosed her ace identity. The therapist acknowledged that they were not familiar with asexuality and made the effort to learn more, which had a positive impact on Summer's care:

> She was okay with it. She didn't, like, doubt me or anything. And I think what really helped is I sent her a website that had, like a lot of the common like myths and stuff. And like, explained, like, what asexuality is and what it isn't, and she actually read it. And so, that was good… She'll acknowledge that she doesn't know everything, which is nice. And, like, I have been able to talk about [asexuality] since then, when it is applicable, like, [discussion about mental healthcare].

Willow shared how about two and a half years ago she was questioning her sexuality and was seeking a mental health therapist to help navigate her identity. That is when she met her current therapist, who shared they had some prior knowledge about asexuality. Willow shared how her therapist was able to guide her through her identity development process. She felt validated throughout the working relationship with her therapist:

> When I was working through [navigating identity], she's like "Oh, yeah, maybe you might be [asexual]." And then she like, had all these resources and other stuff… I think she's the only healthcare provider I've had that has known about asexuality prior me telling them… It felt validating. And because I was questioning myself, and I was like "is this, like, a real thing? And Am I like even [asexual]?" She was like, "Oh yeah, that's a real thing."

Patient-Centered Care. Several participants shared that they appreciated when providers were cognizant of patients' preferences, needs, values, and intersections of identities, and used that understanding to tailor their care.

Coral shared an experience from a month ago when they had visited their University Clinic seeking gender-affirming care. Coral expressed how much they appreciated the Nurse Practitioners' sensitivity and consideration for how Coral's identities interrelated with their healthcare:

> [S]he said that she saw in my record that I identified as ace… she was really considerate, and she wanted to make sure that she know, kind of, the facet of my identity, and how it played into my [health conditions] and gender care, and all that stuff. And so she really made sure that her care was multifaceted and helped address all of these other issues with my healthcare that tied into my identity, but respected them as separate parts of who I am.

Providers' Professional Communication and Attitude. Participants shared that a significant aspect of their positive health experience attributed to the providers' attitudes and how they communicated with them. To describe this phenomenon, the following subthemes were generated: *Accepted My Identity as Fact, Well-Informing and Transparent Communication, Patient-Provider Partnership in Care, and Respecting Patient Autonomy*.

Accepted My Identity as Fact. Participants shared that an affirmative part of their experience was that when disclosing their identity, providers were nonjudgemental and supportive by accepting their identity as facts and moving on to address the health concern in question.

Delta recounted an experience they had with a mental health therapist they started working with 2 months prior. Delta shared feeling validated by their therapist after sharing that they identified as aromantic and the therapist accepted their identity as a fact:

> He asked me about, like, "what about my relations or, like, love life?"... I said, "Well, I don't. I also identify as aromantic, and I have never really felt romantic attraction or sexual attraction." But he was really understanding and didn't try to say like, "Oh, you'll find the right person." So I'd say it was just very nice that he listened to me, and just was very supportive, and just said, "Thank you for sharing, and I completely understand." It was just nice to hear someone say "I understand" instead of trying to explain things for me like I don't know who I am. And I was really glad that it wasn't like, something we should work on, like it wasn't a goal that we needed to fix. It was just "okay, thank you for sharing that information." And then, like, actually focusing on what I had really been coming to see him about.

Similarly, Amber adds, "I think that would be a bit odd if medical providers were like, "Yeah! I'm an ally!" you know. I don't need a soccer mom as a healthcare provider." Amber shares having a positive experience at her local Planned Parenthood where providers deliver care in a Sexual and Gender Minority-Affirming approach.

> They strictly ask you about your health, and if they ask you about your lifestyle, like "Oh, do you drink? Do you smoke? How often do you exercise? Have you, you know, been tested for this? Have you ever had sex?" It's very straightforward, slightly clinical, but not heartless. Like that… they're like still a bit of warmth in their voice like "oh they, they care." But they're trying to make this not a big deal… They didn't outright say that [they're queer-friendly], you know? It was just obviously implied that "yeah this is a safe space. You're good here."

Well-informing and Transparent Communication. Participants shared they appreciated when providers were transparent about their care and took time to educate them about each step

of the care process. Participants shared that they could trust the provider and felt more at ease being well-informed about their care.

Emerald recounted her experience getting a full-body screening procedure at a research clinic approximately six months ago. She appreciated the providers' way of delicately progressing throughout the procedure, and appreciated their step-by-step narration of what was happening:

> They kind of really talked me through the [procedure]... "Okay this is what we're gonna do… this is what it looks like…" And it was very educational. I very rarely walk away from a visit actually feeling informed on what could be or what has happened and all that stuff. So I felt very educated, it was very comforting.

Patient-Provider Partnership in Care. Participants shared that they appreciated when providers encouraged a collaborative partnership by inviting them to participate in the decision-making process of their care.

Diamond described appreciating a partnership relationship he had with his former Primary Care Provider where they worked together to come together with a solution that best addressed his health needs.

> He was attentive, he was. he listened. He, like, was like he was interpreting, and he was definitely applying his clinical checklist, but he was doing it in a way that made me feel like it was we were working together to try to solve this problem, and that I wasn't just like, you know, a 'rat in a jar'.

Respecting Patient Autonomy. Participants felt validated and empowered when providers gave them options for their healthcare and ultimately let patients make the decision they thought was best for their needs.

Umbra described how she has been happy with her current Primary Care Physician whom she has been seeing for the past two years. Umbra shares how she appreciates her physician and respects her healthcare decisions:

I'm not sexually active. I have no intention to be sexually active, and I do not want a pap [smear], like, that was something I was like I don't want. And I was super uncomfortable about going into the conversation about that. And I will say my physician, again, I think I'm extremely lucky in that he's really understanding and informed. And, you know, make sure to know that I know that I don't have to do any tests that I don't want to do… The biggest thing that he has said in a past appointment is something along lines of it, you know, it doesn't really matter what he says in the moment. It really matters, like, how I feel.

Chapter 5: Discussion

Chapter 5 will synthesize findings from the generated themes in Chapter 4 and provide analysis in relation to the aims. This chapter will be divided into the following sections: *Summary of Results in Relation to Literature, Key Takeaways, Participants' Ideas of Making Healthcare More Welcoming for Asexual Individuals: Implications for Practice and Policy, Researcher's Recommendations for Practice and Policy, Limitations, and Recommendations for Future Research*.

5.1 Summary of Results in Relation to Literature

The purpose of this qualitative phenomenological study was to understand the lived experience of asexual individuals navigating healthcare in the United States. Participants recounting their personal experiences navigating healthcare provided valuable insights on how improvements can be made to make healthcare more welcoming for ace individuals. Findings suggest that a large proportion of participants have had negative healthcare experiences as a result of a continued lack of understanding of asexuality in healthcare settings. This lack of understanding of asexuality can be seen affecting patient-provider interactions and through the administration of certain procedures. However, participants reported having positive healthcare experiences when providers exhibited competency in Sexual and Gender Minority (SGM) healthcare, exercised humility, and provided care from a Trauma Informed Care (TIC) approach. The experiences participants had during their visits with healthcare providers ultimately influenced their future healthcare-seeking behaviors. This section will address the first three aims of this study through the synthesis of findings in relation to existing literature.

5.1.1 Compulsory Sexuality in Healthcare

"We're in such a hypersexualized world that like, well, there's, ads everywhere saying that 'this will up your sex drive." And so, I feel that's just in the subconscious in the medical world. They view that if anyone doesn't have sex, there's some problem." – Laurel

Compulsory sexuality, "the societal belief that sexuality is something people are obligated to participate in, that everyone desires sex and that it is normal and healthy and required to have sex," plays a significant role in healthcare in which experiencing a range of not as much to no sexual attraction or desire is perceived as adverse to well-being rather than an identity and/or sexual orientation (Bogaert, 2006; Brown, 2022; Foster & Scherrer, 2014; Gupta, 2015; Herbitter, Vaughan, & Pantalone, 2021; Schneckenburger et al., 2023). As such, compulsory sexuality influences how patients engage with the healthcare system and how providers deliver care, as demonstrated through participants' narratives. The goal of this discussion is to highlight the impact of compulsory sexuality in healthcare through the analysis of participants' healthcare journey via the adaptation of Johnson & Nemeth's (2014) theoretical model, seen in Figure 3.1.

5.1.2 Pre-Interaction

During the initial "Pre-Interaction" phase of the healthcare journey, some participants reported that their ace identity played a role when seeking Mental Healthcare Providers for support in identity development and navigating interpersonal relationships, aligning with findings from past literature (Flanagan & Peters, 2020; Foster & Scherrer, 2014). A unique finding from this study is that a large proportion of individuals who identify as a cisgender Woman and/or Assigned Female at Birth (AFAB) report that their experiences as an ace individual affect whether or not they seek sexual health services at the gynecologist. Autumn

shares a sentiment held by many participants, "[Being ace] is why I do not go to the gynecologist… I don't feel the need for a pelvic exam since I am not sexually active." Some participants reported that they had the cervical procedure done due to providers' insistence, and expressed that it was a vulnerable, invalidating, invasive, and painful experience, which contributed to their decision to delay seeking future sexual healthcare at the gynecologist. A participants' narrative in Flanagan and Peters (2020) alluded to how one's ace experience impacts seeking sexual healthcare when they recalled an experience with a Nurse Practitioner who "was trying to pressure a pap smear," and they felt forced to disclose that they were ace to have their sexual healthcare choices validated (Flanagan & Peters, 2020, p. 1634). Further exploration of how participants' intersecting identities impact their care will be made later in this discussion.

5.1.3 Healthcare Interaction

A pivotal point in the participants' healthcare experience is the healthcare interaction they have with providers (Johnson & Nemeth, 2014). As can be seen through the patients' narratives, compulsory sexuality has an impact on patient-provider relationships and the delivery of certain healthcare procedures during the "Healthcare Interaction" phase. This influences the "Outcome" of the patient's healthcare journey.

Disclosure of Asexual Identity. An important element within the "Healthcare Interaction" phase which shapes patients' overall healthcare experience is their decision to disclose sexual orientation and/or gender identity (SOGI) to providers. Patients' decision to disclose SOGI to providers via intake forms and/or to providers directly during an intake session is interrelated with patient-provider relationships (Flanagan & Peters, 2020; Foster & Scherrer,

2014; Rossman, Salamanca, & Macapagal, 2017). This conceptualization differs from Johnson and Nemeth's (2014) model where there is an assumption that all participants explicitly disclosed their SOGI to providers, and the focus was on providers' ability to care for patients post-disclosure (Johnson & Nemeth, 2014).

It is important to note that a unique experience shared by several participants, especially among those who are 30 years of age and older, is that their healthcare experiences related to their ace identity occurred before they learned about asexuality and identified as ace. This highlights how knowledge of asexuality even plays a role in the patients' ability to disclose their SOGI to providers. Many folks like Ivy shared that "I could always tell that there was something different about me, I could always recognize that." However, like Sky, they struggled to seek support for interpersonal relationships for many years because they "didn't have access to that kind of terminology" to communicate their experiences with providers. Like Onyx, folks shared that they began identifying as ace in the last 1-2 years after they "learned a couple of years ago about the asexuality community, learned about AVEN and Yasmin Benoit [Asexuality Activist]," via online platforms, where they realized their experiences are valid, and expressed, "I gained a better understanding of myself. I am not messed up, I am not broken. [Asexual] is a sexual orientation." This suggests that a unique experience shared by many ace individuals is that they were not able to engage in the process of identity disclosure during their healthcare interaction with providers because they did not have the language to describe their experiences, which ultimately impacted their healthcare experience. Healthcare providers may assume ace patients are heterosexual or address health from a heteronormative perspective, leading to patients receiving non-affirmative care, creating an unwelcoming environment, and decreasing their likelihood of seeking care in the future (Beehler, 2001; Eliason & Schope, 2001; Johnson &

Nemeth, 2014; Rossman et al., 2017; Utamsingh et al., 2016). It is only through online searches about their experiences that many folks were able to learn about asexuality. The rise of online discourse about asexuality in recent years has allowed many people to gain access to that knowledge, and more people are now able to identify with asexuality at an earlier age. This phenomenon can be seen in the demographics of the participants in this study, where approximately 86 percent of participants are between the ages of 18-27. As such, the act of disclosure was not always relevant in the healthcare interaction, which is why the element of "Disclosure of Sexual Orientation" from Johnson and Nemeth's (2014) model was not included in the adapted model.

Participants who identified as ace prior to the healthcare interaction, and did not specifically seek a provider to help with navigating their asexuality shared that they engaged in an involved decision-making process in the disclosure of their ace identity when asked about their sexual history and/or SOGI. They had to determine if their identity was relevant to their health, if they felt safe in disclosing their identity to providers, and had to contemplate the benefits and harm post-disclosure (Chaudoir & Fischer, 2010; Foster & Scherrer, 2014). Aligning with past research, many participants who revealed their identities to providers did so because "none of their personal history makes any sense without understanding they are an asexual person" (Flanagan & Peters, 2020). Some participants like Galena added, "I don't like lying, I like being truthful," to providers, emphasizing that building trust is necessary for an effective patient-provider relationship and a satisfactory healthcare experience (Razzaghi & Afshar, 2016). The majority of participants, however, shared they disclosed their identity to explain why they were not sexually active because their providers did not believe them, aligning with previous findings of patients feeling forced to disclose their ace identity in an attempt to

challenge their providers' assumptions that every adult experience "sexual desire, activity, or drive" (Flanagan & Peters, 2020).

Aligning with past research, the most common reason participants did not share their ace identity with providers was that they "were not asked about it," verbally by providers or via intake forms (Rossman et al., 2017). Many participants like Storm noted that providers with conservative viewpoints tended to be less understanding of queer identities, which translated into whether providers explicitly inquired about SOGI:

> Honestly, I'm just, kind of used to it like… I live in Central California, and I feel like some places here are kind of conservative… So I guess, like, I am not really surprised when there's stuff like [not asking about SOGI on intake forms]. You know, it's kind of like disappointing.

However, several participants noted that they did not explicitly disclose their ace identity to providers because they expected negative attitudes toward their identity (Flanagan & Peters, 2020; Foster & Scherrer, 2014). Participants living in rural areas, in particular, noted that they expect their providers to have a negative bias about ace identities due to the generalized social stigma about SGM identities in the region (Rosenkrantz et al., 2017). Camellia indicated that "rural spaces tend to be less liberal, less queer-friendly." Aligning with past research, many folks like Clover mentioned that they did not share their SOGI and even avoided discussing queer identities in anticipation of being stigmatized (Petroll & Mosack, 2011; Rozenkrantz et al., 2017; Tiemann, Kennedy, & Haga, 1998; Whitehead, Shaver, & Stephenson, 2016):

> I never had a conversation with [provider] about queer identity. This is always a minefield in my part of the country, you know. I've met healthcare professionals in this part of the country are wonderfully informed and wonderfully understanding. And I've met very many who are extremely Conservative Christian. And so it's like, you can't tell [if the provider is queer-friendly] unless you're gonna look them up on Facebook. You can't make that call. And I've always thought it's safer not to ask.

When explicitly asked about their SOGI or sexual history, many participants lied about their identity or described their behaviors, like "I am not sexually active" (Flanagan & Peters, 2020; Foster & Scherrer, 2014; Lund & Johnson, 2015; Schneckenburger et al., 2023). Many participants like Summer shared that the reason behind the non-disclosure of their identity is that they "don't want to be discriminated for it." Ivy shares that he "dances around" the question of sexual history because he "[doesn't] know how the average physician is going to react to it." Several participants like Brook shared that they let their providers presume they are straight because of the concern that, "is my level of care going to be the same as someone who is, like, straight, or presumed straight because I have said something now?" Other participants like Diamond added that they were never explicitly asked to share their SOGI on the intake forms nor during intake interviews, and they express hesitancy in being proactive about sharing their ace identity with providers because they "feel like [it's] a way to invite discrimination in."

Several participants also noted that allosexual people from within the greater Sexual and Gender Minority community often shut out ace folks from queer spaces due to the erroneous notion of asexuality being "anti-sex," and this leads to ace folks not feeling welcomed in healthcare spaces that claim to be queer-friendly (Gupta, 2017a; Rothblum, Heimann, & Carpenter, 2018; Schneckenburger et al., 2023; Steelman & Hertlein, 2016). Participants note that they expect providers who are not knowledgeable about asexuality to have their practices guided by the concept of compulsory sexuality, and this impacts the participant's decision to disclose that they identify as ace to providers even if providers claim to be queer-friendly (Flanagan & Peters, 2020; Foster & Scherrer, 2014; Jones, Hayter, & Jomeen, 2017). Ivy's sentiments were shared by many others:

> Sometimes in LGBT spaces in general, there is a sense of exclusion where it's like, they feel like you're, what's the word? Co-opting something. Or being ace and feel like you're

> trying to invade a space where you don't belong. So there is always this sense of anxiety about it… 'Okay, you say you're LGBT friendly. Do you think I count?' And that is something that hasn't entered my mind in an aggressive way. But it is something that, you know. I don't necessarily always think about it top of mind, when I'm looking for these [providers], but I don't ever forget it either."

The narratives suggest that participants' decision to disclose their ace identity is attributed to their attempt to avoid anticipated negative interactions with their healthcare providers. This aligns with past research that found that ace individuals anticipated negative responses from their providers about their asexuality (Foster & Scherrer, 2014). The factor of identity disclosure impacted patient-provider relationships and the type of healthcare experience participants had, which will be further discussed in the following sections.

Negative Healthcare Experiences. The majority of ace participants reported having negative experiences when visiting providers for care. As discussed in Chapter 4, factors contributing to participants' negative healthcare experiences include *Providers Viewing Asexuality as Needing to be Fixed, Providers Making Assumptions About Why People Identify With Asexuality, Providers Making Assumptions About Lifestyles and Identities of Ace and Acespec Individuals, Providers' Unprofessional Attitudes When Discussing Asexuality, and Patient's Expectations for Healthcare Not Being Met.* Participants' narratives suggest that clinical practices guided by compulsory sexuality and lack of knowledge about asexuality led to inadequate patient-provider interactions and non-affirmative approaches to care.

It is important to note that although the subthemes generated from participants' narratives distinctly highlight a factor contributing to negative experiences, they are also interconnected. A notable connection between these subthemes is that compulsory sexuality and the lack of knowledge about asexuality lead to providers having pathologizing attitudes and assumptions about asexuality, which impacts how they interact with and provide care to patients. As seen

through participants' narratives, providers operating from a medical model guided by compulsory sexuality often search for a "cause" for asexuality with the goal of "restoring" sexual attraction and/or desire (Kim, 2011). Aligning with past research, participants shared that most providers viewed the absence of sexual attraction as a physiological issue, (i.e., hormonal imbalance, disability, or higher weight), or a psychological issue as a result of trauma, further locating asexuality as an undesirable abnormality (Brotto et al., 2015; Cerankowski, 2012; Chasin, 2017; Foster & Scherrer, 2014, Prause & Graham, 2007; Schneckenburger et al., 2023). Providers' attitudes toward asexuality can be seen reflected in their communication with patients. As seen in the narratives, providers perpetuated anti-asexual microaggressions by "praying for a cure," not acknowledging participants' ace identity, discouraging participants from identifying as ace because they "will gain sexual attraction once they mature," or making unsolicited remarks about the participants' sexual history. The participants' experiences align with past findings where ace individuals reported being dehumanized by having their asexual identity dismissed and denied by providers (Chasin, 2015; Flanagan & Peters, 2020; Gupta, 2017b; Jones et al., 2017, Woodruff, 2020). In addition, the provider's lack of understanding of asexuality and other Sexual and Gender Minority identities may lead to medical negligence, a unique finding in this study. As seen in Maple's case, the clinic provider had written a referral for seeking support for gender dysphoria when she was seeking a mental health provider who was familiar with asexuality, illustrating that the clinic provider did not have the training or knowledge to work with Sexual and Gender Minority individuals. This negligence led to a delay in Maple receiving the support she sought. This suggests most providers, even those who are said to be "queer-friendly," are not informed on asexuality and may inadvertently pathologize and discriminate

against ace individuals, negatively impacting ace individuals' healthcare (Chasin, 2015; Flanagan & Peters, 2020; Foster & Scherrer, 2014, Schneckenburger et al., 2023).

Additionally, several participants noted that they did not expect their providers to have prior knowledge of asexuality and they anticipated having a negative interaction when discussing their identity because of such. Similar to the findings by Foster and Scherrer (2014), participants anticipated having their ace identity pathologized, dismissed, or invalidated, which also influenced their decision to disclose their identity to providers. As seen in the narratives, for many participants who shared with providers that they identify on the ace-spectrum, these concerns were validated because their providers made attempts to "fix" their asexuality or they did not acknowledge asexuality as an identity through their communication. Having first-hand experience working with healthcare providers, Autumn shared the unique perspective that they have come to accept the fact that most providers do not know about asexuality because they are aware that providers are not trained to work with queer populations in medical school:

> Unfortunately, I've kind of come to expect it. Especially, like, working in the healthcare field, and I work with a lot of providers as well, even like younger providers, like a lot of the doctors. I work with our residents. So they're kind of like, freshly out of medical school. Even they just really kind of fit into, like, the cis-het world. And not very many people in general know about queer topics, like, unless they are queer. So I don't know, I've kind of come to expect it from health care providers that like not very many of them get that training or know a lot about that queer space. So it's not really like, I'm let down or anything. But it's just, kind of like, I know, and expect an unfortunate reality that I've come to accept.

Autumn's perspective and the narratives from the other participants noted that most providers do not receive adequate cultural competency training working with Sexual and Gender Minority populations from professional schools. This suggests that most providers have not acquired applicable knowledge and skills to work with ace patients, as evident in the participants' narratives where their providers had unprofessional attitudes when the participants disclosed

their ace identity.

Compulsory sexuality not only influences how providers interact with ace patients, but it also has an impact on how certain clinical procedures are administered. A unique finding in this study is that several participants noted that in particular, cervical screening exams and the procedures for obtaining birth control medication and Accutane are non-affirmative to asexual patients. According to the Centers for Disease Control and Prevention (CDC) National Health Statistics Reports (2017), the age when individuals first become sexually active in the U.S. is at 17 years. As such, sexual and reproductive healthcare approaches have been standardized with the notion that all patients are sexually active by that age. As seen in the narratives, these standardized procedures can be non-affirmative for ace individuals, for example, providers insisting that patients take a pregnancy test prior to obtaining Depo-Provera shots even though patients had expressed multiple times that they are "very confident" they are not pregnant and had no chance of becoming pregnant.

It is important to note that ace participants who identified these non-affirmative clinical procedures were cisgender women or Assigned Female at Birth (AFAB). This alludes to how patients' intersecting sexuality and gender identities may have influenced the providers' approach to administering these procedures. Historically, cisgender women and AFAB patients have experienced medical misogyny where providers often dismissed their concerns as overdramatic or psychosomatic (O'Donnell, 2021; Plaza, 2020). This discrimination in medical practice has been attributed to the medical field using male biology as the standard medical model, due to the lack of research on female anatomy, coupled with deeply ingrained sexism (O'Donnell, 2021). Adding heteronormativity and compulsory sexuality to the mix, ace individuals further experienced having their concerns ignored, invalidated, or dismissed, as seen

in the narratives. It is important to note that several participants like Nova emphasized that her identities of being a cisgender woman and ace "intersects a lot. Especially, you know, with the fact that I can or cannot become pregnant. I feel like as a guy, it wouldn't be as big of an issue." Star also noted that their decision to be child-free is intricately linked to their ace identity. However, with clinical practices operating on the heteronormative notion that individuals of child-bearing potential have the desire to have children, many ace individuals report being further marginalized when it comes to making healthcare decisions surrounding reproductive health. For example, Brook's experience of being forced to take pregnancy tests illustrated how not only are ace patients' concerns ignored which negatively impacts patient-provider relationships, but can create further barriers to obtaining care, with procedures being time consuming and costly. Although Brook and several women and AFAB participants noted that they pushed-back and advocated for themselves regarding their sexual healthcare, providers ultimately overridden their decisions claiming that it was "medically necessary," which further illustrates the influence of medical misogyny on patients' level of autonomy in healthcare.

In addition, several participants noted that the intersection of their sexuality, disability, health status, and/or past history of trauma influenced their healthcare interactions with providers. As discussed previously, compulsory sexuality and the lack of understanding of asexuality lead to providers associating participants' ace identities as pathological. It is important to note that even if ace individuals do have physical or mental illnesses, are disabled, or have histories of abuse, asexuality itself is not a pathology (Brotto & Yule, 2017; Lund & Johnson, 2015; Parent & Ferriter, 2018; Schneckenburger et al., 2023). Individuals' ace identities should be met with validation rather than treatment, regardless of how participants came to adopt their

asexual identity (Bogaert, 2015; Flanagan & Peters, 2020; Kim, 2011; Schneckenburger et al., 2023).

The discussion of intersectionality of asexuality illustrates how the complexity of a patients' background and providers' cultural competency influences healthcare encounters. Aligning with existing literature, patients' with multiple intersecting identities face more barriers to equitable care and poorer healthcare experiences (Semlyen, Ali, & Flowers, 2018). The following narrative by Winter summarizes how several ace participants had to take their identities and experiences into account when interacting with their providers:

> I tend to look, in general like a normal white woman, you know. And, and there's all the misogyny and healthcare. So that's obviously a thing. And that was the other thing with the, with the emergency room visit. I felt like if I was in too much pain they would write me off as hysterical, and if I was not enough pain they wouldn't treat me. And so there's always like navigating that. And I feel like the other parts of my identity are more invisible, and I can choose to reveal them or not… There's like part of me that always wonders like it, for instance, on my insurance website, there's, there's a space there for religion. And for the longest time I had, like, agnostic or something in there. And I decided just a year ago to put "wicca." And part of me always wonders when I go into the doctor's office, "are they pulling up my profile and getting weirded out by that? Am I like, am I gonna offend? Even if it's not offending the doctor? Am I gonna offend the staff?" You know. "Is somebody gonna like, decide, I'm demonic," you know. So, so there's just always a worry that, like, if I don't conform to the doctor's expectations or to the medical staff's expectations that that's gonna throw off how they're treating me in some way.

Winter's narrative and the discussion of intersectionality of asexuality suggests that provider approaches and clinical practices need to use an intersectional approach to patient care, rather than operating on generalizations which may lead to the further marginalization of patients.

It is important to note that the majority of the negative healthcare encounters participants described happened 1 month to 6 years ago. This suggests that despite growing literature indicating that little to no sexual desire is not strictly problematic, the medical community continues to pathologize it as such (Bogaert, 2006; Foster & Scherrer, 2014; Hinderliter, 2013).

In addition, although more providers are receiving training on working with SGM patients over the recent years, providers' non-affirming interactions and approaches to care with ace participants suggests that these trainings continue to not adequately include education on working with patients from the asexual community.

Positive Healthcare Experiences. As described in Chapter 4, the themes generated from the narratives of several participants illustrate that providers' competency in delivering care in an affirmative manner was the primary factor in contributing to participants' positive experiences. It is important to note that only a couple of participants shared that their providers, at most, had some prior knowledge of asexuality. Most participants shared that although their providers were not knowledgeable about asexuality, the providers' sensitivity and open-mindedness contributed to a positive healthcare encounter. This suggests that ace participants have positive healthcare experiences with providers who exercised cultural competency in SGM healthcare and cultural humility.

To elaborate, according to the National LGBTQIA+ Health Education Center [LGBTQIA+ HEC] (2020), healthcare providers are expected to exercise both cultural competency and cultural humility. Cultural competence refers to having the knowledge to attend to the culturally diverse backgrounds of patients, providing person-centered care, and reducing health disparities (Lekas, Pahl, & Lewis, 2020). Provider's cultural competency is primarily determined by their knowledge of the communities they serve and the way they communicate with their patients. As seen in patient narratives, providers exercised competency working with SGM patients through appropriate inquiry about patients' sexual history, affirming their identity and experiences, all while having a matter-of-fact demeanor. This aligned with findings from Flanagan and Peters (2020) where ace individuals reported having positive experiences with

providers who accepted asexuality as a sexual orientation and provided support and validation. Notably, this contrasts from the negative experiences ace participants shared, as discussed previously, where they reported that providers made assumptions about participants' ace identity and experiences and approached the conversation in an unprofessional manner.

However, it is not expected for providers to have all the necessary knowledge to effectively attend to all patients, thus exercising cultural humility is needed. Cultural humility means admitting that one does not know and is willing to learn from patients about their experiences, while being aware of one's own embeddedness in culture(s) (Lekas et al., 2020). As noted earlier, the majority of providers were reported to not be familiar with asexuality. Participants like Maple shared they appreciated when providers admit that they are not knowledgeable and express their willingness to learn more because it shows "openness and honesty into where they are, but also showing respect for the patient." However, it is important to note that participants had differing viewpoints on the role of educating providers once providers share that they are not familiar with asexuality. Some participants shared Coral's sentiments that should providers express genuine interest in learning about ace identities, they are willing to take on the role of educating providers in effort to close the knowledge gap of asexuality in general:

> I am happy for people to ask questions, if they genuinely want to learn more about it. Because the more the people know about it, the harder it is to be ignorant or hateful, and more easy to be loving and considerate to other people. So I was happy to talk about [asexuality] with [provider] if she had questions.

However, several participants shared that once providers acknowledge that they are not knowledgeable about asexuality, they should actively learn about it on their own without relying on patients. This aligns with the finding from Flanagan and Peters (2020) where participants reported having positive healthcare encounters with practitioners who educated themselves about

asexuality. Summer shared, “in an ideal world, I wouldn’t have to educate people about [asexuality],” indicating that she did not wish to have the burden of educating her providers, a sentiment shared by many others. As seen in her narrative in Chapter 4, Summer appreciated that her therapist learned more about ace identities from the website she shared, and she felt that her therapist was better equipped to support her once they familiarize themselves with asexuality. Ocean noted that individuals from marginalized communities already face challenges in accessing equitable healthcare, and having the burden of educating providers may create additional barriers:

> The barriers, you know. How is the healthcare provider going to treat me? Am I going to have to educate the provider about x, y, z issue or identity? Am I going to be taken seriously? And this doesn’t even count, like, all of the barriers surrounding insurance and actually paying for healthcare in this country.

As noted in previous literature, a power-imbalance exists within a patient-provider relationship. Healthcare physicians and practitioners hold expert power associated with their professional status by virtue of their knowledge, skills, abilities, and for some, referent power which is based on providers’ character, relationships, and reputation (Saxena et al., 2019). As patients approach providers from a place of vulnerability when seeking care, healthcare providers are expected to demonstrate an appropriate and responsible use of power and influence (Honavar, 2018; Saxena et al., 2019). Supporting Ocean’s perspective, Umbra’s experience highlighted how the apparent difference in power-dynamics between a patient and a provider can make it uncomfortable for patients to educate providers about asexuality in order to advocate for themselves:

> I am only now in a space where I feel like I might decide to advocate for myself. Yeah, I did, I definitely struggle with the power dynamic in a healthcare scenario. And I don’t always feel comfortable pushing back on it. And sometimes, to be honest, it’s not really worth the fight in any scenario where I’m like, do I? It’s not my job to educate you.

While consensus among participants is that they expect providers to actively learn about asexuality on their own through resources created by the ace community like AVEN, many participants like Ivy emphasize the importance of providers still asking patients how they define asexuality. Because the asexual community is not a monolith, asking patients to define what being ace means to them allows the provider to capture the individuals' unique experience without making assumptions:

> Educate themselves. That is the simplest, easiest answer. Know what asexuality is. Know the diversity that exists under the spectrum of asexuality. Know that, you know, most of your stereotypes are probably wrong. Know that just because someone is asexual that doesn't mean you know anything about their history, and that you can't comfortably make assumptions… One of the questions that you opened with actually is a good one for health providers who are unfamiliar, don't know how to ask, and generally a good response to anything that you're unfamiliar with is "What does that mean to you?" That alone is not inherently judgmental, but does open the door for conversation. It opens the door for, you know, me to explain in my own words how it affects my life, what in general I feel it changes about me and how I interact with the world. It is a good starting point to start the conversation without making someone feel invalidated.

The participants' perspectives align with existing literature regarding proper practice of cultural competency and humility when working with SGM patients. To give affirmative care to patients, providers are expected to engage in life-long learning, such as obtaining continuing education and asking patients any questions without making assumptions about the patient (LGBTQIA+ HEC, 2020).

In addition to exercising cultural competency and humility, the generated themes and subthemes from participants' narratives suggest that ace participants have positive experiences with physicians and practitioners who provide care using a Trauma Informed Care (TIC) approach. As seen in existing literature, people with diverse sexual orientations, gender identities, and gender expression are at greater risk for trauma, discrimination, and victimization compared to heterosexual and cisgender populations, which makes it imperative for healthcare

professionals in an trauma-informed manner (Levenson, Craig, & Austin, 2023). TIC is a form of patient-centered care where the provider understands and considers the pervasive nature of trauma and promotes environments of healing and recovery for the patient rather than practices and services that may inadvertently re-traumatize them (University of Buffalo-Buffalo Center for Social Research, n.d). The University of Buffalo-Buffalo Center for Social Research outlines the following five guiding principles of TIC: 1) ensuring physical and emotional safety, 2) ensuring that the patient has an understanding of their rights and responsibilities, 3) patients are provided a significant role and decision-making power in their healthcare, 4) respectful and professional boundaries are maintained between provider and patient, and 5) patients are provided an atmosphere where they feel they have autonomy, they are validated, and affirmed (Simpson & Green, 2014). As seen in the narratives, participants appreciated when providers created a collaborative space that involved transparency, validation, and patient empowerment. This suggests that a TIC approach can improve patient-provider relationship by helping balance the power dynamic, and it is an approach that can be affirmative for ace patients.

Aside from provider attributes and healthcare approaches, participants like Winter noted that clinical spaces showing visible signs of being a queer-friendly space contributed to a positive healthcare encounter, sharing the sentiment, “the more queer-friendly the office-space feels, the more comfortable I feel coming out.” Given the historic marginalization of the SGM community in medical spaces, SGM patients often search clinics for signs that the provider is queer-friendly (GLMA: Health Professionals Advancing LGBTQ Equality, 2006; Sheedy, 2016; Wilkerson, Rybicki, & Barber, 2009). Participants shared that they appreciated when offices signaled they were queer-friendly through inclusive signage and intake forms, and having staff from diverse backgrounds. Participants like Hazel shared they felt welcomed at clinics that:

> [H]ave a gay pride flag and a Black Lives Matter flag hanging outside right at the entrance. So that feels like, better, like they're kind of telling me 'okay, you know, we accept, like, a diversity of experiences.' And that they have like staff is like different genders and sexualities and races.

The general consensus among many participants is that they appreciate when intake forms allow patients to share their sexual orientation, should they feel comfortable doing so. However, there were different perspectives on how an ideal intake form looks like to participants. Many participants expressed that having asexuality listed as an option for sexual orientation was validating, with Ray adding that "never seeing my sexuality, always having it to fill it in, like, [felt] very literally being 'othered'." Umbra shared that she was surprised that when filling out paperwork for her current physician, she noticed that "they actually had asexuality as an option, which never happens, so that just made me really happy right off of the bat," which contributed to a positive encounter she had with her provider. Other participants like Hazel stated that they prefer when intake forms have a fill-in-the-blank field for patients to self-describe their identity because providers "never end up putting the right options" for gender and sexuality. Holly noted that although providers may signal they are queer-friendly through inclusive signs and intake forms, they may not have the competency to be queer-affirming, suggesting that without providers demonstrating cultural competency working with SGM patients, the physical signaling becomes performative:

> I live in, like, a major metropolitan area on the East coast in a very liberal city. But it's, like, shockingly hard to find actually queer-friendly providers. I think, you know, everyone has the flag. It's very different to, like, practice what you preach, you know. Another example is, I went to, like, a queer-friendly therapy center, and, like, I had to explain to my therapist what agender was. And I was like, why am I having to do this?

Supporting existing literature, the participants' narratives suggest providers who signal that they are accepting and affirmative of asexual and other SGM identities through effective patient-provider interactions and physical signaling help contribute to patients having a positive

healthcare experience (Foster & Scherrer, 2014). Participants' narratives further suggest improvements can be made regarding provider cultural competency training to include knowledge about asexuality so providers are better able to serve asexual patients.

Patient-Provider Relationships. As discussed, a major contributing factor to patients' healthcare interaction experience is the effectiveness of patient-provider relationships. This study attempted to evaluate the implications of the patient-provider relationship on the quality of care participants felt they received by asking them to report each of the following elements on a scale from low to high: Level of empathy they felt their providers demonstrated, the level of respect they felt as patients, and the level of trust they had in their providers.

Many participants like Amethyst expressed that aside from cultural competency, "empathy is probably one of the most important [qualities]" for providers to have to effectively serve patients. Aligning with existing literature, a provider's empathy for patients is considered an essential element in establishing an effective patient-provider relationship consisting of mutual respect and trust (Mercer & Reynolds, 2002; Razzaghi & Afshar, 2016, VetSet2Go, n.d.). It is important to note that although empathy is an important construct of care delivery, it is not defined nor measured well in both research in practice (Sanders et al., 2021). According to Sanders et al. (2021), suggested definitions of empathy in healthcare practice include "general sympathy or prosocial concern for others, a vicarious or shared emotional experience, an ability to recognize or respond to another's emotions or perspective, or some combination of these." Providers are expected to demonstrate empathy through compassion, nonverbal communication, expressing genuine interest, engaging in active listening and perspective-taking (Hojat, DeSantis, & Gonnella, 2017; Rakel et al., 2011; Sanders et al., 2021). When providers effectively demonstrate empathy, patients report feeling "listened to, understood, and valued" (Sanders et

al., 2021). Additionally, respect is considered to be essential in providing high quality care, particularly for patients who are historically marginalized and stigmatized (Fernandez et al., 2024). Providers are expected to demonstrate respect by treating patients as a person, as equal, without blame and prejudice, and with concern and emotional support (Fernandez et al., 2024). Ultimately, trust is built in a patient-provider relationship when providers effectively exercise empathy and respect (Greene & Ramos, 2021). Foster and Scherrer (2014) noted that ace patients are often distrustful of health services due to concerns about provider competence on issues of asexuality, indicating that it is imperative for providers to be culturally competent as well to better serve patients. Existing literature suggests that patient trust in healthcare providers is associated with better health behaviors and healthcare utilization (Green & Ramos, 2021).

Aligning with existing literature, participants' narratives illustrate that providers conveyed competency, empathy, and respect through their interpersonal behaviors and interactions with patients. Participants' narratives also suggest that these elements were interrelated and contributed to the quality of care participants received. For example, as seen in Umbra's narrative, her primary care physician demonstrated empathy via active listening and perspective-taking by expressing that he understood Umbra's discomfort in proceeding with a cervical screening procedure, and emphasized that she did not have to proceed with the screening should she not wish to. Umbra felt she could trust her provider because he validated her concerns, and she expressed having a "really great experience" with them. On the contrary, as seen Topaz's narrative, their psychiatrists' demeanor and disinterest in learning about Topaz's demipanromantic asexual identity demonstrated a lack of empathy and competency working with SGM patients. Topaz expressed that they did not feel respected as a patient and their "trust in [provider] definitely deteriorated." These narratives suggest that providers' level of empathy and

competency working with SGM patients are associated with patients' level of satisfaction of care during the healthcare encounter. Participants report experiencing a higher quality of care with providers who effectively demonstrate competency and empathy, whereas patients report lower quality of care with providers who do not demonstrate competency and empathy effectively.

5.1.4 Outcomes

Participants' narratives suggest that satisfaction during the healthcare interaction is associated with subsequent healthcare practices, referred to as proximal outcomes (Johnson & Nemeth, 2014; Rossman et al., 2017). Aligning with existing literature, depending upon the type of healthcare interaction experience they had, participants had four types of behavior patterns: Healthcare seeking behavior, keeping or changing providers, disclosing or disguising sexual orientation, and knowledge seeking behavior (Johnson & Nemeth, 2014; Rossman et al., 2017). Although findings from Johnson and Nemeth (2014) suggest participants demonstrated a singular proximal outcome from their healthcare interaction, this study found participants demonstrating one or more proximal behaviors post-healthcare encounter.

An important proximal outcome to consider post-healthcare interaction is how encounters influence patients' future healthcare seeking behaviors. As discussed, participants sought healthcare for many reasons. This study found that the majority of participants primarily sought treatment for illness, managing disabilities and preexisting health conditions, or seeking gender-affirming care, and they continued to seek care to address their needs regardless of how their healthcare interaction experience was with their provider. This suggests that although participants' satisfaction of care depended upon how providers approached the conversation about patients' ace identity, the healthcare encounter did not ultimately impact patients'

motivation to seek future care for their healthcare needs. However, participants who sought sexual healthcare or needed support navigating their ace identity shared that the healthcare interaction experience did influence their future healthcare seeking behaviors. As previously discussed, for many cisgender women and AFAB participants, their ace identity is intricately linked to their sexual healthcare. For example, several participants like Holly who shared having a negative healthcare encounter with their sexual healthcare provider stated that they "have been hesitant to go back for regular gyno care because I know that I'm gonna have to relive all this again with a new provider." Participants like Emerald added that they have been "scared-off by going to mental health professionals because aphobia and all that stuff just really kinda distance you from healthcare professionals." Participants' narratives align with findings from previous studies that found that some asexual individuals may delay seeking care or avoiding care entirely from general healthcare providers and mental health professionals in fear of being pathologized, stigmatized, or dismissed (Flanagan & Peters, 2020; Foster & Scherrer, 2014; Glyde, 2021, Scherrer, 2008; Schneckenburger et al., 2023; Yule, Brotto, & Gorzalka, 2013). This suggests that ace participants continue to face barriers seeking affirmative sexual and mental healthcare. This also suggests that for some ace individuals, the hesitancy to seek future care may compromise their well-being, suggesting that ace individuals may experience sexual and mental health disparities which are not being documented.

Tied to future healthcare seeking behaviors, several participants noted that their healthcare interaction experience made them more intentional about how they sought future care. One of the proximal outcomes that emerged from this intentionality was the decision to keep or change healthcare providers. As seen in the narratives, participants who reported having a negative healthcare encounter primarily sought different providers, such as Clover noting that

she would “go to local planned parenthood because I know that they see queer people all the time.” On the other hand, participants who reported having a positive encounter are continuing to seek care from the same provider. However, it is important to note that institutional factors also had an impact on this proximal outcome, a unique finding in this study. As seen in Ocean’s narrative, many participants highlighted the challenges of affordability and availability within the U.S. healthcare system. Participants having to change providers due to avoiding further negative healthcare encounters can have negative financial implications, as can be seen in Nova’s narrative where she dropped her General Practitioner who she was able to see at no cost through a community health care plan for another provider where she would have to pay $100 for a visit. Other participants like Marine shared they had to travel across state lines to see providers that met their expectations for care, illustrating challenges in accessibility and availability. Many participants like Laurel expressed their frustrations that due to these barriers, they ended up having to settle with the providers they had a negative encounter with. Several participants like Everest also noted having to settle because their experiences took place when they were minors, with having to rely on their guardians to make healthcare decisions on their behalf. These findings add to existing literature that suggests that asexual individuals often feel like they must struggle or settle when choosing providers for care (Glyde, 2021; McInroy et al., 2021; Schneckenburger et al., 2023; Woodruff, 2020). On the other hand, some participants like Sky who had positive experiences with their provider expressed their dismay having to switch providers due to logistical challenges with retaining insurance coverage. Adding to the findings by Johnson and Nemeth (2014), findings from this study suggest that the proximal outcome of deciding to keep or change providers were influenced by both the interactions that occurred during the healthcare encounter and institutional factors.

Additionally, participants noted that their healthcare interaction experience also impacted their decision to disguise or disclose their ace identity from providers in a future healthcare encounter. As seen in the previous discussion about "Disclosure of Asexual Identity," participants engaged in an involved decision-making process, contemplating whether it is necessary and safe to disclose their ace identity to providers. As discussed previously, participants like Hazel who had a positive healthcare interaction with providers after disclosing their ace identity often stayed with the same provider, sharing that the experience "made me feel safe and confident that I can go back to this provider, and that I don't have to, like, you know, skirt around my sexuality and, like, go out of my way not to tell them about it." This aligns with existing research that found that patients who had asexual-friendly providers were more comfortable seeking health services and discussing asexuality at their visits (Flanagan & Peters, 2020; Schneckenburger et al., 2023). However, many folks who shared having a negative healthcare encounter with providers often disguised their ace identity from future providers they sought. For example, Rain shares that they do not feel safe disclosing their ace identity because of a past negative experience with a provider who did not have the cultural competency to work with SGM patients:

> I've definitely trotted around questions about sexual health, or like, "are you in a relationship? Do you have a partner?" Like, I just say no, and I just, like, move on because I feel, like, to divulge any more information it's just gonna dig me into a hole… I just say no immediately because I don't, say, feel safe in the environment, then I'm not gonna divulge that information.

Winter also shared that she worried about her current therapist pathologizing her identity, since her previous provider made assumptions and was dismissive about her experience as an ace woman:

> I feel like I'm hiding [ace identity] a little bit from my current therapist. I have, on the intake form that I sent to her, I said like I think I am probably ace. But I'm worried that

> she's gonna pathologize it as like my not wanting to date because of past trauma, as opposed to just, like, this is my identity. So I'm just, I'm, like I said, not hiding it, hiding it. But I'm also just not talking about it with her.

These narratives suggest that not only does patients' feeling of safety play a role in patient-provider relationships during an initial healthcare encounter, but it also impacts how patients navigate future healthcare encounters. Similar to the concept of psychological safety, patients' feeling of safety can be defined as being in an environment in which people can feel respected and comfortable speaking up and expressing their ideas, opinions, and concerns (Fukami, 2023). According to Mollon (2014), the feeling of being cared for, providers exercising competency and having effective presence, and feeling mutual trust among patient and provider contributes to the patients' feeling of safety - which also align with the elements needed to establish an effective patient-provider relationship, as seen in the previous discussion. Mollon (2014) also adds that patients' feeling of safety is considered a contributing factor to patients' overall well-being. While in this context patients' feeling of safety influences whether patients disclose or disguise their ace identity, it may also allude to how comfortable patients may feel being transparent about their health with providers. For example, some participants like Clover noted that because her health history is tied to her ace identity, she did not feel safe being forthcoming about her health condition with future healthcare providers after having a negative encounter with her General Practitioner:

> I think, you know, interactions with that GP (from negative experience), and just like general interactions with healthcare providers have kind of left me with the impression of like, you know, I need someone that I can tell this [health condition] about. Because I think I'm at an age where there are certain kinds of healthcare I need, and I'm not getting it. And I wanna make sure that I can get that with somebody who is going to be understanding of the fact that, you know, I am ace, that I have never been sexually active, all of that stuff. But, you know, it's really hard to find someone or to know, like. If I tell you this, are you gonna, you know, pathologize it? Or, are you gonna be dismissive about it, you know? Or, can I actually have a conversation with you about how I identify and what the implications are for my health?

Clover's experience aligns with findings from previous studies that found providers who exhibited anti-asexual microaggressions, made assumptions about why ace individuals sought healthcare, and did not create a safe space for ace patients to be transparent about their health concerns may have missed addressing ace patients' genuine health needs, illustrating a potential barrier to ace individuals' overall well-being (Flanagan & Peters, 2020; Foster & Scherrer, 2014; Schneckenburger et al., 2023; Steelman & Hertlein, 2016). This finding suggests that in order to effectively serve ace patients and promote their well-being, it is imperative for providers to create a safe space to enable patients to feel safe to disclose their identity, which will further enable patients to feel safe to be transparent about their health.

Participants who reported being dissatisfied with their healthcare interaction experience, particularly participants like Ray who sought support with navigating their ace identity, described seeking out knowledge from external sources post-interaction, such as the internet or their friends. This proximal outcome aligns with existing literature that suggests patients' dissatisfaction with a physician is assumed to be a primary driver of post-visit information seeking (Johnson & Nemeth, 2014; Lee et al., 2014; Tustin, 2010). This dissatisfaction of care leading to patients seeing support from external sources has been found to be associated with providers' lack of empathy, competency in addressing patients' needs, quality of time given to patients, and patients' distrust in providers (Lee et al., 2014; Tustin, 2010). There are certain implications needed to be considered regarding this proximal outcome. A unique experience shared among nearly all ace participants is that the internet offered a wealth of knowledge and support regarding asexuality, and is typically considered to be the primary avenue where folks learn about asexuality, as seen throughout many of the participants' narratives. As previously discussed, the formation of online forums like AVEN during the rise of internet use among the

general public allowed ace folks across the globe to connect to share their experiences and offer support. As seen in Galena's narrative, she was happy that the Asexual subreddit she subscribed to provided a support space she needed to cope with the interpersonal challenges she faced in school, especially since she was not able to find support in-person through her peers nor her therapist. Galena's experience illustrates that due to the continued general lack of knowledge about asexuality, in-person support for ace individuals is often unavailable, causing ace individuals to seek information and support online. This unique finding also illustrates how the online community can serve as a protective factor for ace individuals in particular, which further suggests that the current conceptualization of "Community Protective Factors" used in Public Health Education should expand to include online forums as "a source of support and connectedness" (CDC, 2024). While these external sources can be beneficial for folks to manage their health, especially in regards to knowledge being more available and accessible to the public, patients often rely on their healthcare providers as a primary sources for "highly trusted" health information (Asan, Yu, & Crotty, 2021). As seen in Ray's narrative, she primarily sought a mental health therapist for professional guidance on navigating her sexuality and trauma. However, because Ray's therapist was unable to effectively support her, she coped in unhealthy ways. Ray's narrative illustrates the importance of healthcare professionals to have the knowledge and skills to effectively care for patients as they are often the primary line of support. Ray's unhealthy coping further highlights the implication of lack of provider competency in delivering care having a negative impact on patients' health outcomes, where patients who rely on external sources for treatment or support may delay or avoid seeking care from a professional.

5.2 Key Takeaways

Participants' narratives offered valuable perspective into the lived experiences of asexual individuals navigating healthcare in the U.S. Their rich stories offered unique insights and added further context to existing findings in asexuality research. The synthesis of findings from participants' narratives suggests that the existent lack of knowledge and understanding of asexuality in healthcare settings continues to have an impact on ace individuals' healthcare experience. While this is a key issue, findings also suggest that the interplay between the lack of knowledge and understanding of asexuality in healthcare, provider attributes, and institutional factors ultimately impacts patients' healthcare experience, which drives patients' future healthcare behaviors. This section will highlight the key findings from this study and offer conclusions.

5.2.1 Key Finding #1

The continued lack of knowledge and understanding of asexuality and influence of compulsory sexuality in healthcare results in non affirmative approaches to care, which negatively impacts ace patients' healthcare experience. While existing literature in the last decade has illustrated the importance for healthcare providers to have an understanding of asexuality in order to develop asexual-competent practices, there continues to be a deficit in asexual affirmative approaches in healthcare. As previously discussed, the majority of participants shared having non asexual affirmative healthcare experiences within the last 1 month to 6 years, indicating that healthcare spaces, notably spaces that deal with patients' sexual and mental healthcare such as Primary/General Care, Mental Health, and Sexual and Reproductive Healthcare clinics, largely continue to be unwelcoming for ace individuals. Participants'

narratives highlighted the following areas of healthcare where the persistent lack of knowledge and understanding of asexuality impacts patients' healthcare experience: *Providers' Lack of Knowledge and Understanding of Asexuality, Inadequate Collection of Sexual Orientation and Gender Identity (SOGI) Data,* and *Non Asexual-Affirmative Procedures.*

Providers' lack of knowledge and understanding of asexuality. As previously discussed, the patient-provider relationship is considered a fundamental element of a patients' overall healthcare experience as it drives patients' future healthcare practices. To establish an effective patient-provider relationship, providers are expected to have the competency in delivering appropriate care. As seen in the participants' narratives, providers who were not aware of asexuality were not able to provide patients affirmative care as their practice was guided by compulsory sexuality. Providers, even those who have been reported to be queer-friendly, were found to have engaged in anti-asexual microaggressions, such as attempting to establish a cause for the participant's asexuality and making assumptions about their lifestyles. Similar to the findings in existing literature, findings from this study suggest providers who do not have the knowledge and understanding of asexuality may perpetuate harmful misconceptions and the pathologization of asexual identities. Additionally, this study uniquely highlighted that the lack of knowledge and understanding of asexuality may lead to medical negligence, as seen in Maple's case where her Primary Care Provider had the misconception of asexuality being gender dysphoria, and making an incorrect referral for support which delayed Maple's care. Aligning with findings from existing literature, participants have engaged in the following proximal outcomes to avoid pathologization, stigmatization, invalidation, and dismissal of their ace identity by providers: switching providers, not disclosing their identity, and avoiding or delaying seeking care.

Inadequate collection of SOGI data. In order to effectively serve patients from the SGM community, it is imperative that effective health-related data collection methods are in place as the data informs healthcare practice. Many SGM individuals argue the importance of collecting SOGI data because "if we are not counted, we do not count" (LGBTQIA+ Health Education Center [HEC], 2023). However, the lack of knowledge and understanding of asexuality in healthcare results in the continued inadequate collection of SOGI data from ace individuals. For example, the majority of participants reported not seeing or not remembering seeing asexuality mentioned on intake forms when being asked to share sexual orientation. According to the University of California Los Angeles Williams Institute Scholars (2020), health assessments often do not measure asexuality because asexuality is generally confused as being celibate and not as a sexual orientation, illustrating a gap in effective SOGI data collection as ace individuals are not being considered. This also indicates that the health needs of ace individuals are not being captured. As there is evidence of SGM individuals experiencing health disparities, this suggests that ace individuals experience disparities which are not being captured. Because the experiences of ace individuals are not being effectively documented, this leads to providers not having the knowledge and understanding of asexuality to make appropriate referrals or deliver asexual affirmative care, as will be discussed next.

Non-asexual affirmative procedures. To the investigator's knowledge, this is the first study where participants' narratives explicitly called attention to existing healthcare procedures that are non affirmative to ace individuals. For example, Lotus pointed out how the item "interest in sex" on the Beck Depression Inventory (BDI) alludes little to no interest in sex is an indicator of depressive symptoms, which pathologizes the experience of ace individuals who may be sex-adverse or repulsed. As the BDI is a widely used tool to screen for depression and to measure

depression severity, this also poses a potential concern for providers who are not knowledgeable about the diversity of asexuality to use this item on the inventory to make an inaccurate determination about an ace patient's mental health.

In addition, several participants pointed out that cervical screening exams and current procedures for obtaining treatment for hormone regulation and Accutane are non asexual affirmative. As these clinical procedures were primarily noted to be non-affirmative by participants who identify as cisgender women or AFAB, this illustrates how ace individuals from this population face additional barriers to equitable care. Participants reported that their concerns and decisions regarding their sexual and reproductive health were largely ignored, invalidated, or dismissed by providers, suggesting that medical misogyny, heteronormativity, compulsory sexuality, and the lack of knowledge and understanding of asexuality all contribute to their experiences. As a result, cisgender ace women and ace individuals who are AFAB often do not feel respected or welcomed in healthcare, and many report avoiding or delaying seeking care that involves their sexual health. To the investigator's knowledge, this is one of the first studies to begin to explicitly illustrate the intersectional experiences of ace individuals in healthcare, with a focus on the experiences of cisgender ace women and ace individuals who are AFAB.

5.2.2 Key Finding #2

Ace patients report having positive healthcare experiences with healthcare professionals who exercised cultural competency and humility, and provided care in a patient-centered, trauma-informed care approach. Although the majority of healthcare professionals have been reported to not be knowledgeable about asexuality, participants shared having a positive healthcare experience with providers who demonstrated empathy, sensitivity,

and open-mindedness, which suggests that ace individuals prefer providers who exercise cultural competency and humility. Examples of how providers demonstrated cultural competence working with SGM individuals include acknowledging participants' ace identity as a sexual orientation and physically signaling acceptance of queer identities through usage of inclusive signage and intake forms. Participants appreciated when providers would admit that they were not knowledgeable about asexuality and would take the initiative to learn to help understand their patients and provide guidance. Additionally, participants expressed their appreciation for when healthcare professionals provided care from a patient-centered, trauma-informed care approach, where providers created collaborative partnerships that involved transparency, validation, and empowering patients in their own healthcare decision-making. As seen in the participants' narratives, because of providers' lack of knowledge and understanding of asexuality, ace patients are at risk for re-traumatization due to experiencing microaggressions, dismissal, and invalidation during healthcare encounters, which further suggests that the trauma-informed approach is imperative for delivering affirmative care to ace patients.

As such, participants expressed satisfaction of care with providers that demonstrated cultural competency, humility, and provided care from a trauma-informed approach, and reported returning to seek care with their respective providers as they felt welcomed, respected, validated, and safe. This suggests that providers that exercise the above-mentioned qualities and approaches to care are able to establish an effective patient-provider relationship with ace participants. This further implies that ace patients are more comfortable to seek future care and discuss their asexuality with providers who exhibit these attributes.

5.2.3 Key Finding #3

Institutional factors need to be considered to understand ace patients' overall healthcare experience. While findings suggest that the lack of knowledge and understanding of asexuality in healthcare and providers' attributes largely influence ace patients' future healthcare behaviors, participants' narratives also illustrate the influence of institutional factors impacting their overall healthcare experiences. Notably, participants' narratives highlighted that the affordability and availability of care influenced how they navigated in their healthcare journey. As the majority of participants reported having health insurance, finding an available in-network healthcare professional who specialized in the specific treatment or support participants sought primarily guided participants' decisions in selecting their providers. Although for the majority of participants the health services they were seeking were physically accessible to them, some participants reported having to travel long distances, even out of state, to find available healthcare, illustrating an added barrier ace patients may face on their healthcare journey. As such, this alludes to ace patients having to make additional considerations when seeking healthcare, one of them being how they navigate healthcare encounters with providers. Sharing Winter's sentiments, many participants express that:

> [Finding ideal care as an ace individual is] Complicated… There's just always a sense of like, you know, I'm always trying to find, obviously, doctors who are skilled and know what they're doing, and you know, that sort of thing. And then there's also this, this added layer of like 'are they going to accept who I am? Am I going to say something that is gonna weird them out?'... It feels like, sometimes I am hiding parts of myself from various doctors which may or may not be relevant to the care I'm getting, but doesn't feel good.

In addition, institutional factors influence the proximal outcomes of ace patients post healthcare interaction. For example, participants who had experienced a negative encounter with a provider had to consider the affordability and availability of the healthcare services they were seeking

when deciding if they could switch providers or having to settle. On the other hand, some participants who had positive healthcare encounters were forced to switch providers due to logistical challenges with retaining insurance coverage. This alludes to that due to institutional factors, ace patients often do not receive fully affirming care as they have to be methodical with how they seek treatment or support.

5.2.4 Conclusions from Key Findings

The findings from this study suggests that ace individuals continue to face barriers in receiving equitable care. As demonstrated in this discussion, various factors influence ace individuals' healthcare experience, which ultimately drive their future healthcare seeking behaviors. A primary factor influencing ace individuals' proximal outcomes is the effectiveness of a patient-provider relationship. As seen in participants' narratives, ace patients often experience negative encounters with their providers, indicative of an ineffective patient-provider relationship. Findings from this study suggest that this ineffective patient-provider relationship is attributed to the lack of knowledge and understanding of asexuality in healthcare, as it results in non asexual affirmative approaches to care. This study further illustrates how institutional factors, such as availability of care and medical misogyny, presents as additional barriers for ace individuals from obtaining equitable care. As a result of these factors, many ace individuals report changing providers, avoiding or delaying seeking care to prevent future negative healthcare experiences, suggesting that ace individuals do not feel welcome in healthcare spaces, particularly spaces that involve mental and sexual healthcare. Others report having to settle with providers due to the institutional challenges of affordability and availability which prevents them

from seeking care elsewhere, further illustrating that most ace patients continue to receive unsatisfactory care.

Although inquiring about ace participants' health outcomes were not within the scope of this study, findings suggest that factors contributing to ace patients' negative healthcare experiences may have negative implications on their health. For example, ace individuals often experience stigmatization as a result of compulsory sexuality, which was evident in various participants' narratives of their providers' unprofessional reactions when discussing asexuality. As existing literature illustrates the association of stigma on negative health outcomes, there is reason to believe ace individuals are at an increased risk of experiencing poor health outcomes. Furthermore, due to ineffective SOGI data collection methods as a result of lack of knowledge and understanding of asexuality in healthcare, and evidence of SGM individuals and individuals with multiple marginalized identities experiencing health disparities, there is reason to believe that ace individuals, especially those who hold many marginalized identities, may also experience health disparities that are not being captured.

This study offers recommendations for improvements to make healthcare more welcoming to ace individuals, which will be further discussed in the following sections. To summarize, primarily, healthcare in general needs to acknowledge and accept asexuality as a sexual orientation, which can be best conceptualized as a spectrum or umbrella of identities that suggests multiple ways of experiencing little to no sexual attraction, desire, or practice. The knowledge and understanding of asexuality in healthcare will allow for effective SOGI data collection which is needed to inform ways to deliver asexual affirmative care. Secondly, as illustrated in participants' narratives, participants prefer seeking care from providers who engage in patient-centered, trauma-informed care, which suggests these approaches to care are

affirmative for ace patients. Lastly, more inclusive signaling in healthcare spaces needs to be implemented that explicitly indicates the acceptance of ace identities to help ace patients feel more welcome. Participants offered specific ideas on how healthcare can incorporate these improvements, which will be discussed next.

5.3 Participants' Ideas of Making Healthcare More Welcoming for Ace Individuals

Participants offered various ideas of improvements to make healthcare more welcoming for ace individuals. The ideas provided are in alignment with the *Healthy People 2030* objectives of 1) Increase the proportion of adults who get recommended evidence-based preventive health care — AHS-08, 2) Increase the ability of primary care and behavioral health professionals to provide more high-quality care to patients who need it — AHS-R01, and 3) Decrease the proportion of adults who report poor communication with their health care provider — HC/HIT-02. The goal of this section is to use participants' suggestions to drive the discussion of implications for health education practice and policy. This section addresses the last aim of this study.

5.3.1 Implications for Health Education Practice

All participants emphasized the need for healthcare to have sufficient knowledge and understanding of asexuality in order to provide affirmative care to ace individuals. The discussion of implications for health education practice will begin with identifying the specific healthcare spaces in which improvements are needed to be made to make healthcare more welcoming for ace individuals. Sharing Ruby's perspective, participants highlighted:

> [A]nybody who's a general practitioner who'll be asking questions about, like, relationships or sexuality. Anybody who sends people onto more specialities. Anybody

> who does anything relating to relationships or sexuality or genitalia or bodies in that way. And, I pretty much think every mental health provider in general.

Adding to this shared sentiment, Laurel further specified that spaces:

> [L]ike pediatricians. They're like, that's when people, when most people, recognize their sexual identities. And so, having a great amount of understanding there is very important. And, in general, with primary care, just an understanding that not everyone has a libido, and that's fine. Or, and even separate from libido, just, not everyone wants sex and there isn't something innately wrong with that.

Similar to Laurel's sentiments of healthcare spaces needing to depathologize asexuality, Autumn highlights that mental healthcare space in particular:

> I feel like that's the biggest area of healthcare that ace individuals have, like, most negative interactions. Just because, again, like, it kind of depends on the specific person that you get and, like, how knowledgeable they are personally about queer identities. And, like, how much they know about asexuality can influence, like, how accepting they are. And a lot of them try to say that it's, like, a hormonal balance, or like mental illness. Or like, there's something wrong with you. Which, you know, in some people that might be the case. But, you know, for a lot of people, probably isn't. It probably is their identity. And just understanding that, you know, some people are asexual, and some people are sex repulsed and don't want to have sex, and that can be, you know, completely okay. I feel like it's something that is not a popular opinion amongst mental health professionals.

Star adds her personal narrative of how providers making assumptions about her lifestyle prevents her from seeking future sexual healthcare, further emphasizing spaces that:

> [D]eal with reproductive health care should probably have an understanding of [asexuality]. I will say that, like I don't go to the gynecologist as often as I should, because at the gynecologist, there is an assumption that I'm having sex. And they're like 'well, you have those, you have the reproductive organs. Therefore, you have to be having sex with them.' And I'm like, 'no.' Especially the fact that I don't have sex, I don't have much use in my sexual region, and that can impact my comfort level of getting examed down there.

For inquiry, participants were also asked to identify areas of healthcare where they believe it is not important for providers to be knowledgeable about asexuality. Areas identified by participants include optometry, dentistry, oncology, pulmonology, orthopedic, cardiology, neurosurgery, gastroenterology, and orthopedic surgery. Although participants noted that these

areas of healthcare were not relevant to their asexuality, some participants like Storm argued that:

> Honestly, I feel like they all should know at least a little bit. I feel like they learn so much about everything that, like, at least what they can do is learn like the letters where it's LGBTQIA at bare minimum, and are at least open to learning like the "+", you know, if, like, someone is identifying as something else.

Sharing Storm's sentiments, Coral adds, "It would be good to know, like, just in general, about the person you are taking care of… It will always feel better if someone knows you."

Participants offered specific ideas for improvements that can be made in these healthcare spaces to make it more welcoming for ace individuals. The discussion will be further divided into the following sections: *Provider-Level Improvements, Ideas for Asexual-Affirmative Care, and Office-Level Improvements.*

Provider-Level Improvements. Majority of participants like Rosemary asserted that "provider training is probably the most important" area where improvements should be made. Participants offered various suggestions in provider training which can be further divided into the following categories: *Exercising positionality* and *practicing cultural competence and humility.*

Exercising positionality. Some participants like Everest pointed out that providers often do not "think about implicit biases and how you're treating patients that are not of your own identity." To reduce the possibility of the providers' implicit and explicit biases having a negative impact on patient care, providers should reflect on their positionality. Positionality refers to where an individual is located in relation to their various social identities, such as gender, race, class, ethnicity, ability, etc., and how the combination of these identities and their intersections shape how one engages with the world (Queen's University, n.d.). Healthcare providers should reflect on their positionality as a healthcare provider and their respective

identities may put them in a place of power and how their personal beliefs and values can perpetuate stigma, discrimination, and re-traumatization for their patients (Gupta, 2017; Schneckenburger et al., 2023). Doing so will allow providers to pin-point competency training they need to better serve their patients.

Practicing cultural competence and humility. As discussed, participants reported having positive healthcare experiences with providers who demonstrated cultural competency and humility, illustrating the importance for providers to attain these attributes to be able to effectively deliver affirmative care to ace patients. Participants like Maple emphasized the need for providers to have the cultural competency to work with asexual patients, and highlighted that providers being able to effectively support ace patients serves as a protective factor for ace individuals as they often do not have ample in-person support:

> [Ace people] are made to feel, like, isolated, and, like, feeling isolated is just not a good feeling to have. And so, just, feeling like you're part of a community is special. Like, with the social work classes that I'm working in now - in some of the public health classes that I've taken before, like, having a strong social network, and like just feeling like you're able to talk about things not only with friends, but also with, like, different kinds of providers, it's like a huge protective factor against a lot of things.

Participants suggested ways providers can obtain cultural competency training. Many participants like Everest highlighted the importance of, "adding cultural competence within, like, med school curriculum right off the bat," as that is where providers begin learning how to provide patient care. Other participants like Ocean emphasized the need for regular continuing education:

> And, particularly in the fields of queer-related healthcare, I know there's like, comparatively speaking, not a lot of research… I have friends who are teachers, and they have continuing education requirements, and I don't know whether that's a thing for doctors. That's not something I've specifically heard of. But I think that's something that is important. So that particularly, you know, doctors who've been practicing for a while, so they know, sort of, common best practices of new information that's coming out, and not just whatever they were taught in med school 30 years ago.

Participants shared various ideas of what they thought constituted culturally competent training. Lotus emphasized the importance for providers to have the foundational knowledge and understanding of the diversity within the greater SGM community:

> [D]efinitely [have] training on the different sexualities, and also what experiences [patients] might have. I mean, that's the hard thing, is, like, everybody has a different experience. So you can't really lump everybody in a box. But I think just having knowledge of what's out there would be one big step.

As illustrated in this study, a unique experience among ace participants, especially among those 30 years of age and older, is that many folks learned about and identified with asexuality recently. This emphasizes the need for providers who typically guide patients with their identity development, such as pediatricians and mental health professionals, to have ample understanding of asexuality. Adding to Lotus' sentiments, Hazel expressed, "doctors ask about your sexuality, like, if they are asking about your sexuality, then they should be prepared to know about what [asexuality] is…" Onyx further noted that in order for providers to best serve ace patients, they must have an efficient understanding of the identities within the asexuality spectrum:

> There is a lot of denial, a lot of aphobia, a lot of lack of understanding… People don't realize all the other parts of the asexuality spectrum. They think it's just an all-or-nothing thing. There needs to be more discussion about the middle ground, in all that.

Similarly, Laurel emphasized that providers should understand that "libido and sex and sexual identity is different. Like, there's a big idea that if you're ace, that means you have no libido whatsoever. And so, that's where a lot of misunderstanding lies," as some ace individuals may experience physiological arousal. As demonstrated in participants' narratives, Ocean highlighted the need for providers to understand how ace individuals' various intersecting identities shapes their healthcare experiences:

> [H]aving sort of a basic understanding of a lot of different marginalized identities and ways that those can show up in a healthcare setting. Whether it's being ace, or being

> autistic, or like, I have a lot of friends who have ADHD, and that impacts their ability to access healthcare…

While all participants affirmed the need for provider training at the institutional level, many participants stressed the importance of providers learning from the lived experiences of ace individuals themselves. Existing literature illustrates that medical and professional school training of the SGM identities often collapse SGM experiences into a monolith, which leaves out nuances and unique needs of diverse communities, including the asexual community (Borgogna et al., 2019; McInroy et al., 2020; Pinto, 2014, Schneckenburger et al., 2023). As such, participants like Emerald emphasized the need for providers to understand the nuances of asexuality. She suggested that required training intended to educate providers about asexuality, like continuing education programs, should be led by ace individuals themselves, and should be conducted in-person rather than in an online modular format so providers are more receptive to the information they are taught:

> I had to do, like, sexual harassment trainings, and, like, literally everything like different identities. All that stuff, like, what you're gonna see, like, how to treat people. Those, I feel like, are very unreliable because people will not be as receptive to a computer screen as they are going to be to another person. So I feel like having in real-life trainings for healthcare professionals will definitely help them become more empathetic, but more able to do their jobs without being, like, blocked by, like a certain premonition. Or just, like, a certain specific person that they expect to see. I feel like having in real-life, not just, like, meetings. But like, having talks given by, like, certain, maybe ace identifying doctors, come in to talk to doctors and whatnot about their experiences… People come in and give talks, like TED Talks and all that stuff. People are more receptive when it comes to someone that they feel like, that has the information like that. They're looking for someone that they feel like could answer all their questions, or someone they feel like they could learn from… So I feel like these online training courses, that's not gonna cut it.

Similarly, many participants underscored the need for providers to ask patients any questions without making assumptions about them (LGBTQIA+ HEC, 2020). As previously discussed, participants stressed the importance of asking patients to describe what being ace means to them,

as there is a diversity of experiences within the ace community that is not adequately captured by the foundational definition of asexuality. Participants like Galena similarly emphasized the importance for healthcare professionals to not solely rely on their prior knowledge when providing care as their interpretations may not be accurate to their patients' experience:

> Listen. Try to understand. Just because something doesn't match up with the textbook, or you have a specific idea of something that's going on does not mean that that is what is actually happening. There are so many things in the medical, in medical textbooks that may not be right. To my knowledge, I believe there are certain colleges that are still teaching that Black people have a higher pain tolerance than White people, even though that is absolutely incorrect. There is a lot of women who are under-diagnosed for a lot of things, like for heart attacks, for example, because doctors think that they're just panic attacks. Don't automatically dismiss something. Do the tests. Listen, try and understand. I know that doctors went to school for all these years, and they are probably burnt from seeing so many patients. But as an educator, what I can say is just because you're burnt doesn't give you the excuse to fail someone.

Sharing Galena's sentiments, Winter also asserts that providers should come from a place of curiosity and humility to deliver competent care:

> This is a tall order, but getting rid of that doctor arrogance thing, you know. Getting rid of this assumption that doctors know more about the person in front of them than the person knows about themselves. And just coming from a stance of curiosity and openness, and that I am in charge of my body, not you. You know, give me the information I need, but don't treat me like you know better than me… That requires some humility that requires some curiosity.

Topaz notes that assumptions and biases can be exhibited through verbal and nonverbal communication, and further emphasizes the importance of providers needing to be reflective and intentional about how they deliver care to patients:

> I think, it'd be good for [providers] to be mindful and aware of, like, how they're responding, and what kind of impression that's sending, even if it's like nonverbal. And I think that they can just be, like, very extra thoughtful when they're saying things to make sure that, like, "Oh, like, am I making some kind of broad, sweeping statement?" Or, like, "what kind of assumptions or biases do I have here? Is this based on, like, actually having knowledge from, hearing from, say, in this example, like ace people's experiences?" Or like, "where did I hear this from?" Like, I think those kind of things, like just to be more for them to be more thoughtful and intentional about what they're communicating, and like what they believe and where that came from.

In essence, by demonstrating competency of ace identities and exercising humility, providers will be able to present themselves as trustworthy to ace patients, allowing for improved patient-provider relationship. Healthcare professionals should have an understanding that asexuality is an umbrella term individuals use to describe a spectrum of experiencing not as much to no sexual attraction, desire, and or practice. In addition, providers should be aware of the various sub labels some ace individuals may use to help further describe their experiences, such as reciprosexual which is used to describe "someone who is does not experience sexual attraction until they know that the other person is sexually attracted to them first," (SeventhQueen & asexuals.net, n.d.). A non-exhaustive list of sub labels folks use can be found in **Appendix A**. It is important to note that however an individual chooses to identify themselves is valid. As such, to understand each individual patient to best support their needs, it is essential for providers to always ask something along the lines of "what does being asexual mean to you?"

Furthermore, providers can utilize existing resources developed by the ace community to help guide their practice. For instance, the Resources for Ace Survivors (2015) developed the "Asexuality: Basics for Health Professionals" handout that gives provider basic understanding of asexuality and best practices when seeing an ace patient. Similarly, active online community forums managed by asexuality activists such as "The Asexual Agenda" (n.d.) offers various "101 Resources" designed to introduce asexuality to those learning for the first time, which both providers can use for themselves and can refer patients to. Additionally, asexuality activists and ace patients from respective communities should be invited to the development and dissemination of provider training and continuing education to ensure the content is appropriate and relevant.

Ideas for Asexual-Affirmative Care. Participants asserted the implementation of asexual-affirmative practices in healthcare is crucial in ensuring ace individuals receive equitable care. Participants offered various ideas for affirmative practices, the discussion of which can be divided into the following categories: *Hearing from asexual individuals, moving away from the Medical Model, using trauma-informed and intersectional approaches to care, effective collection of Sexual Orientation and Gender Identity (SOGI) data, and ace-affirmative procedures.*

***Hearing from asexual individuals*.** As demonstrated in this discussion, due to the influence of compulsory sexuality in healthcare, ace patients often do not receive affirmative care. Maple highlights that, "culturally speaking, there's so many, like, assumptions around sexuality, and how it's so, like, ingrained. And I think by focusing on that, you know, that ace people are left out of the conversation." Sharing Maple's sentiments, a general consensus among participants is the need to include the perspectives of ace individuals in healthcare to ensure the development and delivery of asexual-affirmative healthcare practices. Some participants like Ray suggested the best way to incorporate ace perspectives in healthcare is to expand medical school admissions to ensure more ace individuals have the opportunity to become medical professionals:

> Med school is such a weed out process that, like, those that are most privileged are the ones that get into med school, and not just the ones that get in - the ones that make it through and the ones that match. And they don't have like, I'm sure some of them are great doctors, but like, I just want more diverse experiences, like, coming out of med school.

Similarly, having more ace healthcare professionals in research and practice will allow for improvement of existing educational resources, curricula, clinical practice guidelines, and training on serving SGM patients - ensuring that biases, stereotypes, assumptions, myths, and

stigmas against asexual individuals are challenged before reaching care environments (Flanagan & Peters, 2020; Herbitter et al., 2021; Jones et al., 2017; Schneckenburger et al., 2023). In addition, to ensure care practices are relevant and effectively addresses the current health needs of ace patients, Delta recommends for providers to, "Learning from people from those communities. Or like, even just like crowdsourcing ideas from their patients, like, that would be nice too. Or just saying 'What can we do better?' And actually showing, like, follow up." Delta's suggestion is in alignment with The LGBTQIA+ HEC's (2023) recommendation for the development of Community Advisory Boards (CAB), a coalition of representatives from the community being served and healthcare providers who work together to address the community's health needs. The CAB will allow for providers to learn how to best serve their patients, assess barriers to care, and to ensure the accountability of affirmative care. The best way for providers to form coalitions with representatives in the ace community is by reaching out to ace activist groups, such as Aces and Aros and The Ace and Aro Advocacy Project (TAAAP), who have established many local communities across the U.S. and can offer a wealth of resources and support.

Moving away from the Medical Model. The general consensus among participants is the need for healthcare practices to shift away from relying on the Medical Model, "the concept that mental and emotional problems are analogous to biological problems—that is, they have detectable, specific, physiological causes and are amenable to cure or improvement by specific treatment" (APA, 2018). Several participants like Topaz assert that providers solely operating from the medical perspective are unable to provide effective care as they will miss systemic factors that initially lead patients to seek support or treatment, and may even unintentionally place blame on the patient for their health concerns:

> I think some providers, like, have this really, kind of classic medical model way of looking at things where they're, like, "okay, you have some kind of problem that needs to be fixed, like, it's a biological problem. So we need to treat it in a biological way." Or like, "we're trying to treat the symptoms. We're gonna use, like, medication or some kind of procedure." But I think, like, I've learned over time, a lot of my health issues are not effectively treated like that. Like, the origins may be unclear in terms of, like, the biological aspect. And maybe it's just coming from, like, environmental stress, or like, intergenerational trauma. And I think, like, if their assumption is just that, like everybody by default, should be healthy in a certain way. And, like, sometimes that can lead to - the way they try to support me, or treat me as being very like, even unintentionally, like ableist, or like very individualistic, like, kind of assuming that it's me who's not doing enough to take care of myself.

Sharing Topaz's sentiments, Umbra notes that "healthcare, but just health education, it's very heteronormative," further stressing the need for healthcare practices to challenge sexual normativity as it impacts patient care. Adding to the shared sentiments, Marine highlights the interplay of providers tending to practice solely from the Medical Model and heteronormativity in healthcare leads to the pathologization of ace identities. Marine emphasizes not only there needs to be knowledge and understanding of asexuality in healthcare, but providers need to move away from using a medical model to perceive the range of experiencing not as much to no sexual attraction, desire, or practice through a sexual orientation model instead, a perspective supported by existing literature (Lund & Johnson, 2015; Pinto, 2014; Schneckenburger et al., 2023):

> I think there's probably an overarching expectation that, like being ace, is something that can be, like, diagnosed, and it's a problem that can be treated. And it's very much pathologized… like, you know, treating like there's something wrong with you, and it could be fixed. And, like, it's a hormone problem. "Get on some medicine," that sort of thing. And I've heard that narrative, like from all sides of the world. So I think just, like, validating that it is an orientation and not, like, something diagnosable, in general, like, just not treating it like a problem to be solved. And I think it's confused a lot with, like, low libido… So just, like, recognizing that [asexuality] is something of its own. And it's different from like medically diagnosable problems. That'd be a big step for the medical community.

Many participants like Ivy asserts that their asexuality "is often quite healthy for me," further illustrating the need for medical practices to acknowledge experiencing not as much to no sexual

attraction or desire as a valid orientation. Aligning with existing literature, participants emphasize the need for healthcare to understand and acknowledge that asexuality is a spectrum of diversity of experiencing little to no sexual attraction or desire to anyone of any gender (Bogaert, 2006). Ace individuals may still engage in sexual behavior, and may experience physical arousal or romantic attraction (Bogaert, 2006; Hinderliter, 2013; Rothblum et al., 2018; Schneckenburger et al., 2023). Like other sexual orientations, asexuality can be fluid and is based on subjective sexual attraction or desire. Participants further emphasized sexual healthcare providers to acknowledge that sexual attraction, desire, or practice is not necessary to be healthy (Conley-Fonda & Leisher, 2018; Flanagan & Peters, 2020; Schneckenburger et al., 2023).

Using trauma-informed (TIC) and intersectional approaches to care. As previously discussed, TIC is suggested to be an affirmative approach to care for ace patients as the approach centers around patients' needs and providers are trained to prevent retraumatization in their practice and promote a safe environment of healing and recovery. Participants, in particular, highlighted appreciating when providers established a collaborative partnership that involved transparency, validation, and empowering patients to make their own healthcare decisions, elements which are inherent in the TIC approach. In addition, some participants like Topaz emphasized that in order for providers to effectively center their care around patients' needs, they need to approach from an intersectional lens:

> I feel like my race, or like ethnicity, is something that definitely, also, unfortunately, like, comes up... [T]hat can certainly shape like, I guess, what assumptions, like, oftentimes for mental health care providers are making about me. Like, for example, like, if they think like, "oh, like, you know, you're having these fights with your parents or whatever." And if they're, like, trying to put it in terms of like this East-West individualistic-collectivist binary, or like, assuming that these are just like generational conflicts or something… Like, I think, like, that makes me feel like "okay, you're limited on how much you can support me with these issues because you don't have that much personal understanding of it." Or like, "you're not able to see those nuances, or like, kind of deal with it, like, based on things that aren't, you know, outside of your assumed

> dominant or normative perspective."… I think that also is important for them to understand… It's not that I'm just one thing in one context, like I could be trans and Chinese and disabled. And all those things happen are all part of me. It's not like they can just take one of those things in isolation.

Although existing literature demonstrates the need for healthcare professionals to practice from an intersectional approach to provide equitable care, the sentiments shared by Topaz and others, along with participants' varying intersectional experiences from this study, demonstrates that providers largely do not practice from an intersectional lens. Thus, there is a need for providers to be effectively trained to understand how patients' health experiences and outcomes are shaped by multiple sociodemographic factors like race, ethnicity, insurance status, income, and to be able to deliver or refer patients to receive care that is tailored to their needs (Vohra-Gupta, Petruzzi, Jones, & Cubbin, 2023).

Effective collection of Sexual Orientation and Gender Identity (SOGI) data. As previously discussed, ace individuals continue to be left out of standard SOGI data collection due to ineffective inquiry, which results in a gap of knowledge of the specific health needs of ace individuals. This has further implications on how insurance companies cover services, as there may be "not enough information available to compare utilization and spending to suggest ways to improve existing inequities" (Liu et al., 2023). As such, the majority of participants have various ideas of questions healthcare professionals can ask to effectively capture the experiences of ace individuals. Initially, due to the history of medical mistrust, participants like Ocean emphasized the need for providers to be transparent about why SOGI data is collected:

> If there is a form for sexual orientation, like, if they're asking that, I sort of, I want there to be a good reason, like. Are they collecting it because they need this demographic information for some reason? Are they collecting it because, you know, there will be different suggestions provided based on that?

As discussed previously, participants further emphasized that if providers are asking about certain SOGI information, they need to have an understanding of the items they are asking patients to ensure that data collected is accurately recorded.

Regarding inclusive intake inquiry, either via intake forms or interview sessions, participants noted that providers should typically inquire about the following from patients: preferred name(s), pronouns, sex assigned at birth, gender identity, sexual orientation. However, the general consensus among participants is that more inquiry can be done to effectively capture the experiences of ace individuals. Primarily, when inquiring about a patient's sexual orientation, providers should understand that 'asexual' is an orientation patients could identify with. Amber added that as there is a diversity of experiences within the asexual community, "I wish they asked 'how sex positive/favorable are you, where on the greyscale are you." Similarly, many participants like Delta shared that they "do appreciate when [providers] ask you about your romantic orientation," with Hazel adding that it is important for providers to understand the diverse partnerships ace individuals may have, such as "being informed about polyamory," and how it may impact their healthcare:

> I wish [providers] would ask specifically, "Do you have a sexual partner?" instead of, like, "Do you have a partner?" because that assumes that I am going to have sex with a partner… Where, like, I don't have to ask, like, "what do you mean?" Because then it always ends up being in a weird territory where I have to explain… I'm not gonna say I don't have a partner just because I'm not having sex with my partner. And so, I wish there was some sort of standard question where it specifically asked, like, "is this a sexual partner? Romantic partner? Etc." Or like, maybe a follow-up question like, "are you sexually intimate with this partner? Do you have a risk of an STI?" Or something like that.

Participants further emphasized that providers should understand that asexuality is an orientation, and not to confuse it as sexual behavior. Laurel suggests once patients disclose they identify as

ace or on the ace-spectrum, providers should follow-up with appropriate questioning about sexual behavior:

> The biggest help is [providers] just understanding that there are some people that are fine with [having sex], and some people that are not interested… And [them saying], "okay so you're interested in it. Now I'm going to talk to you about this, because there are additional questions about your health, if you are going to be doing this." And I think that would be a lot more inclusive instead of just assuming everyone inherently wants to have sex.

Similarly, Ruby emphasized that providers asking comprehensive questions like, "Are you aromantic, are you allo romantic?... Do you have a kink identity?" not only signals to patients that providers have the cultural competency to provide appropriate care, but also indicates to patients that they are accepting - "that you would be okay if you were [this]."

To help with developing effective SOGI health questionnaires comprehensive to ace individuals' experiences, collaboration with The Ace Community Survey team is recommended. Led by many members of the ace community, the team has been developing surveys well-regarded by the community since 2014 that collect valuable information on the demographics and experiences of members in the ace community. It is further recommended that academic and medical communities utilize these annual Ace Community Surveys to help inform research and practice as details about ace individuals come directly from the community and it is currently the only large source to receiving current information about experiences and needs of ace individuals.

Asexual-affirmative procedures. As illustrated in this study, participants identified the Beck Depression Inventory (BID), cervical screening exams, and procedures for obtaining treatment for hormone regulation and Accutane as non-asexual affirmative. Regarding the BID, Lotus emphasized that the item on 'interest in sex' "needed to be revised" to prevent an inaccurate evaluation of ace individuals' mental health status, which further suggests the need to

improve existing diagnostic manuals, such as the DSM, to be considerate of asexuality. As seen in the previous discussion regarding the decision to undergo cervical screening exams, participants largely emphasized the need for providers to respect patients' autonomy to make decisions surrounding their sexual and reproductive healthcare, sharing Jade's sentiments, "I live inside my body, so in a way, I'm the expert."

Similarly, participants expressed their frustrations for having to perform pregnancy tests for certain procedures and treatments, such as to obtain Accutane and other hormone regulation treatments, as they felt providers did not believe their reproductive health status. A sentiment shared by many participants, Orchid expressed:

> I think the pregnancy stuff is my main point of improvement. I think a lot of the time it's very normative, where they look at me, they hear me talking about my period, so they're like, "we need to talk about pregnancy." And then, there's usually a focus on, like, "Okay, right now you don't want to be pregnant." And, like, I've said to multiple doctors, "You don't know. I never want to be pregnant. I have absolutely no plans."... I would appreciate where we would have the conversation one time where I say "I have no plans to ever become pregnant," and they say "Okay. If you change your plans, you tell me. Otherwise, we never talk about it again."... I do think there's flexibility, because I do know ace people that still have sex, so I don't want to exclude them, but you know, just approaching the conversation with, "Okay, you're asexual. Are you active? Or do you plan to become active? No? Okay, we don't need to talk about it again." So there's, like, I want [providers] to come in with slightly more knowledge in the first place, and then I want them to believe me when I say I have no plans for this, and stop bringing it up every single time.

Adding to Orchid's sentiments, Marine explicitly noted that the current procedures for obtaining Accutane were a waste of time as they were not applicable to her, and she emphasized the need for tailoring procedures to each patient:

> I think if the dermatologists had an option similar to MyChart at the gynecologist, where they could, like, intake some of that data right off the bat. Or, like, maybe just do, like, a screening that just asked, "Are you sexually active?" Or like, "Is this something that you want to have follow up conversations?" And then they would know how to kind of base the conversation moving forward. Because I just had to sit and listen to so much, like, unnecessarily wordy speeches about options, options, "Here's what you do." And I'm, like, tuning out the entire time because none of it, like, applies to me or my personal life.

> And if there were a way that they could kind of filter the content that they're presenting. I mean, I know it's probably like a government program that, you know, they have to have everyone enroll in no matter what. But if they could, kind of, tailor it to the patient's needs a little better.

Office-Level Improvements. As previously discussed, participants noted they feel welcomed in healthcare spaces where offices would explicitly signal that they are accepting of diverse patients, which aligns with the LGBTQIA+ HEC (2023) recommendation for healthcare providers to have necessary visual cues that indicate the facility is an inclusive space. Recommendations from the LGBTQIA+ HEC include having staff wear pronoun badges, having all-gender bathrooms, observing important awareness days, having patient intake forms inclusive of identity, and setting the tone and expectations of an SGM-friendly environment by employing representative staff (LGBTQIA+ HEC, 2023). Participants shared additional ideas of how offices can improve signaling their inclusivity to ace individuals, which will be discussed in this section. *Explicit signage indicating acceptance of asexuality, inclusive intake forms, inclusive educational materials, hiring of staff who are representative of the community or advocates for patients from the community, and improving accessibility.*

***Explicit signage indicating acceptance of asexuality*.** The general consensus among participants is that healthcare spaces need to incorporate more signage, such as flags, signs, and pins, inside and outside of offices to signal their acceptance of ace individuals. It is important to note that a number of participants shared that they primarily have remote health visits with providers. As such, providers should be considerate of explicit signaling in their virtual background. Sharing Hazel's sentiments, many participants appreciated seeing the Pride flag displayed in offices, but wished they "saw an ace flag amongst other flags that kind of show that 'we are acknowledging that there is more complexity to the queer community, and we want to specifically acknowledge each of these identities'." Sharing this sentiment, Topaz adds that the,

"general Rainbow Pride flag, I think a lot of people at least knows what it is," so providers adding an "ace or aro flag" gives patients "more of an indication like, 'Oh this person actually knows about something that's maybe less commonly known about'." Some participants like Lotus shared that she "enjoy whenever I do see an ace flag or demi flag, like, it's just, like 'Oh I feel seen'," especially in "fear of political climate" that is becoming less accepting of SGM identities. Adding to Lotus's sentiments, Amber emphasized the importance for healthcare professionals to explicitly signal their acceptance of SGM identities, especially those who practice in areas that are less accepting of SGM individuals, as it indicates their intentionality to be welcoming to all patients:

> I know that the queer community, and, like, other communities, are seen to be political… And, you know, [people generally] say, "doctors are not supposed to be political". Like, no, everything is politics. I feel more comfortable in places that are, like, they know they're intentionally doing this. They intentionally went out and bought that sign and put it here. Whether or not it actually is a safe space, that's a different story. But they think that they are. They're choosing to be. And they are trying to communicate this to patients. And someone intentionally putting out, like, having just a frigging Pride pin on their lapel tells me way more than anything else. It's, like, they could be wearing that for fun, you know. They could be wearing it because their friend gave it to them. I don't care. You still chose to put that on. And you understand the ramifications of what that can mean. You're also inviting any hate that might be geared towards that group. And to me, if you're willing to risk getting backlash for supporting the Pride community, that's good enough for me.

Furthermore, Section 1557 of the Affordable Care Act (ACA) requires healthcare practices to post notices of non-discrimination across facilities to indicate the prohibition of discrimination on the basis of race, color, national origin, age, disability, or sex (U.S. Department of. Health and Human Services [USDHHS], 2016). Offices having explicit signage indicating the protection of ace identifying individuals, and ensuring that office accountability systems are in place to prevent discrimination, can contribute to establishing a welcoming environment for ace patients. In essence, providers explicitly signaling the acceptance of ace identities not only indicates that

they are accepting of ace individuals, their explicit support helps with getting rid of societal stigma of asexual experiences.

***Inclusive intake forms*.** Participants highlighted inclusive intake forms are effective in signaling acceptance of diversity of identities. However, as discussed, more improvements to intake forms need to be made to be inclusive of asexuality to not only make ace individuals feel more welcome, but to also improve SOGI data collection. As previously discussed, "asexual or on the asexual-spectrum" identity should be indicated as "sexual orientation or sexuality identity." Sharing Emerald's sentiments, participants in general emphasized that intake forms asking patients to share their identity should include a mixture of selection and fill-in-the-blank options, allowing patients to be recognized as they choose:

> It is very, very necessary to have the [intake] form be not only, like, inviting. But just something that gives people the option to put, like, their information down so they can feel recognized as a person. So it's, like, something that has enough, like, boxes and to have the option to fill in, like, "hey, you don't need to tell us, but if you feel that you're not being recognized as who you are, please fill in blank, blank, blank," you know.

Participants like Amber further emphasized that patients should be allowed to select multiple options, "because not everybody fits just one label," with Ocean adding, "if there are check boxes, it shouldn't just be a check one, like, I am both gay and asexual. I'm not one or the other." Participants like Brook also noted that it is important to include a "prefer not to answer" to "keep you safe in an unsafe situation, but still gives you the opportunity to indicate what you're comfortable with."

Inclusive educational materials. When inquired about the availability of health education materials related to asexuality, all participants noted not receiving or encountering any materials which discussed asexuality. This dearth of resources for ace patients is attributed to the lack of knowledge and understanding of asexuality in healthcare. Existing literature has also

found that health resources designed to support SGM individuals often erase asexual experiences (Conley-Fonda & Leisher, 2018; Jones et al., 2017; Kim, 2011; Schneckenburger et al., 2023). Many participants like Willow wished to see more brochures about asexuality available in healthcare spaces. Participants like Lotus, who identified with asexuality recently, wished she would have learned about it sooner, and emphasized that healthcare spaces that deal with patients' sexuality and identity development need to have educational materials available that introduces patients to asexuality so patients are able to readily access knowledge:

> Like going to a doctor's office in which, you know, you try to understand your body… [I]t would be wonderful if there were pamphlets about each of these [identities], and it was generally accepted as a normal thing for people to experience different orientation… If I had come across a pamphlet a long time ago, like, I would, just be more educated. And I didn't have to, like, find out via social media.

In consideration of patients' access to knowledge, and for any needed accommodations, providers should have educational materials in various formats, such as having the materials available online in a repository patients can reference. Additionally, Delta added having health education materials related to asexuality available in offices would also help with signaling, and she wished to see materials that discusses the intersection of health and identity:

> I think it would just be nice to, especially when you're sitting at the, you know, the lobbies. I feel like, that's, like, kind of the first impression of an office. I've always liked it when the offices show their health pamphlets… Having more health pamphlets that maybe cover, like, intersection between your health and your various identities.

It is recommended that healthcare spaces begin supplying various educational handouts developed by activist organizations like Aces and Aros that provide basic, well-regarded information about asexuality and information about how to reach local communities for support. As current health needs of ace individuals are not captured in healthcare, more research on asexuality and active collaboration between healthcare professionals and members of the ace community is needed in order to develop appropriate and relevant health educational materials

targeting the needs of ace patients. As discussed previously, healthcare professionals can reference the well-regarded Ace Community Survey to gain insight into the current potential health needs of ace individuals.

***Hiring of staff who are representative of the community or advocates for patients from the community*.** To better serve ace patients, it is best to recruit healthcare providers who are from the ace community. Having representative staff members not only displays to the patients that they are welcomed into the space, the facility can also incorporate the staff's lived experiences to improve affirmative care (LGBTQIA+ HEC, 2023). Although no participants noted being seen by a healthcare professional who identified as ace, and participants like Ray expressing they would ideally seek a provider who identifies as ace, some participants expressed they were motivated to seek care from providers who engaged in activism within the SGM community as it demonstrates their genuine devotion to caring for their SGM patients. For example, Camellia shared how seeing her provider advocating for gender-affirming care on Twitter made her feel like she chose the right provider for her care:

> … Something about like gender affirming care recently… I think there were threats of, "oh, this is what, like, doctors could, like, revoke your access, or not provide [care]." And [my provider] was all over Twitter like… it was good to see. Basically, he was saying, "oh, anybody who needs gender-affirming care come to me, you will never be denied, etc."... It made me feel like I chose the right provider. It also, it makes me want to stick with him.

Similarly, Winter noted seeing her provider engaging in advocacy for trans healthcare on social media made her feel that her provider would be able to understand her experiences as someone who is ace:

> [S]omebody who's open, and kind of understanding that there's not just one path in life… The fact she was doing advocacy, and I think she did some training for provider about, you know, trans inclusive and affirmative care. So that made me feel good. And so going in, I had an expectation that she would probably be better than the norm.

As patients typically seek providers via the internet, Camellia's and Winter's narratives further illustrate the need for providers to signal their acceptance of SGM identities through online platforms, ideally explicitly acknowledging having competency working with asexual individuals. Additionally, their narratives highlight the importance for healthcare professionals to engage in advocacy for sustainable policy changes that promote patient well-being through implemented protections and policies ensuring patients' right to affirmative care, which will be further discussed in the following section. Emerald adds that providers should "put on your website that we are open to these identities so we don't have to be invalidated when we go in," illustrating how many patients seek queer-accepting providers for affirmative care. It is recommended that providers increase their presence of queer-acceptance through social media platforms, practice websites, and on provider directories on insurance websites.

Additionally, Umbra recommended hiring culturally competent patient advocates who can serve as liaisons should SGM patients need additional support during their healthcare visits. She further recommended that systems should be set in place for patients to request a patient advocate confidentially whenever they need, such as through an office text message system, as it may be uncomfortable to ask a provider for one directly:

> My healthcare provider has a sign that says, you know, "if you're uncomfortable, you can get an advocate in the room." Well, I think that's great. I think that they could do it better, because, honestly, even seeing that, I don't know if I would ask for an advocate because of even getting over that hurdle of asking. I think it would be important to say, you know, "I want a queer-friendly advocate," or, "I want a queer advocate." But I think, maybe, asking that in your, like, [appointment] confirmation, where you just say, you know, "Text 'Y' to confirm." I think it would be more helpful to have it in that scenario where it's like, "do you want an advocate here?" Because I'd be much more likely to say, "Oh, yeah, I need something like," then in that moment.

Improving accessibility. A common sentiment shared by participants is "inclusivity to one is inclusivity to all." Many participants pointed out several barriers to accessibility needing

to be addressed to make healthcare welcoming and inclusive to all patients, and it is recommended that offices incorporate the following suggestions. Primarily, several participants emphasized the need to improve the ability for patients to schedule appointments with providers. One of the challenges Ocean noted include finding, "appointments that are actually available. Or are your working hours [providers'] working hours, and you can't get an appointment for that reason." Aurora pointed out how scheduling appointments with providers through hospital systems can pose as a barrier for some folks as there may be many touch-points they have to navigate, and urged for a more stream-lined way to improve patients' ability to schedule visits:

> I know a lot of people who want to get checked out, or want to go to the hospital for something and they just don't know what process to do, how to do it, to get that set up… If I was doing [appointment scheduling] myself, I would have to give the hospital a call. And once I get picked up, just say "I'm trying to set up, like, check-up," or whatever I'm looking for. And then from there, I get transferred to the right area or whatever, and they help me finish from there.

Several participants noted physical considerations for offices to make to help patients feel welcomed. Amber recommended having chairs that are, "extra wide to accommodate those larger bodies, or, just for people who want more personal space, or just need a little bit more leg room." Orchid emphasized the need to immediately establish effective accommodations in consideration of patients who may have special needs, and offered various ideas which were shared by many others:

> First of all, the translation stuff. I think it is really important to have a sign up that says in the language that [patients] might be speaking, "If you need an interpreter, you need to call this number."... I think [the office] also has to be physically accessible. That's really important, especially for doctors' offices. Obviously it should be common sense, you know, ramps at every entrance, not just the inconvenient back entrance where you have to walk a block just to walk in. The same doors as everyone else, automatic doors… I wish all doctor's offices required masks still. It's very frustrating to me that they don't. I have a lot of immune conditions that make me high- risk for getting COVID and having bad COVID, so it's frustrating to walk into a doctor's office and see people, like, coughing without a mask on, and then being told like, "no, we can't require it. Just pray."

Similarly, participants like Ivy added that offices need to be considerate of environmental sensory factors, such as crowds, noise, scents, and lighting, for patients with sensory sensitivities. Ivy recounted how he "rarely encountered a week where I didn't go home at least one day with a massive headache," due to a previous provider who "wouldn't hear any request for compromise" to accommodate his sensitivity to the fluorescent lights in the office, illustrating how lack of reasonable accommodations can be detrimental to patients' well-being.

Additionally, many participants recommend for providers to offer the flexibility for remote health visits, should it be applicable. Ivy expressed that the wide availability of telehealth is a "massive boon for accessibility," especially for the disability community and for individuals who experience transportation challenges. Delta shared the availability of telehealth allowed her to see a queer friendly provider in the city as she no longer had to make the "hard, hour long trek" to seek care. Sharing Delta's sentiments, Ray further noted that "it was a huge factor" for her to be able to join visits virtually as she prefers "being in my own space." Drawing from Ray's sentiments, oftentimes patients prefer to speak on potentially difficult topics from the safety of their homes, so having an option for teleconference is a way for providers to effectively deliver trauma-informed care (LGBTQIA+ HEC, 2023).

5.3.2 Implications for Policy

Findings from this study surfaced a number of policy implications. It is important to note that although the discussion of policy implications will center around the ace community, many of the suggestions for improvement may benefit many communities in general. Discussion of policy implications will be divided into the following sections: *Policies for Patient Protection* and *Policies to Improve Access to Equitable Care*.

Policies for Patient Protection.

Explicit Federal and State protections of Asexual and Sexual and Gender Minority patients. As discussed, studies have consistently shown that SGM individuals experience greater health disparities compared to heterosexual and cisgender individuals (Hsieh & Shuster, 2021, p. 325; NIH Office of Disease Prevention, 2022). Disparate and poor health outcomes in the SGM community have been attributed to disproportionate exposure to inequitable and poorer-quality health care, marginalization and/or discrimination, and reduced access to health-promoting resources (Ayhan et al., 2020; Salcedo-Betancourt et al., 2022). Thus, in aims to protect lesbian, gay, bisexual, and transgender individuals, the Affordable Care Act Section 1557 (USDHHS, 2016).), applying title VII of the Civil Rights Act of 1964, was codified to prohibit health programs or facilities that receive federal funds from discriminating based on one's sex, gender, disability, age, race, and national origin (USDHHS, 2016).

Despite this progress, SGM individuals still lack full non-discrimination protections in over 29 states in the U.S. (The White House, 2021). According to the 2022 survey conducted by the Center for American Progress, about 9 percent of lesbian, gay, and bisexual individuals are turned away by healthcare providers due to their perceived sexual orientation, and 32 percent of transgender or nonbinary respondents reported being turned away (Medina & Mahowald, 2022). In addition, there are ambiguities regarding the current federal nondiscrimination protections for SGM patients under the ACA (2016). Title VII of the Civil Rights Act of 1964, which was applied in the ACA (2016), defines the terms "because of sex" or "on the basis of sex" as "not limited to, because of or on the basis of pregnancy, childbirth, or related medical conditions" (USDHHS, 2016). After the landmark decision of *Bostock v. Clayton County* on June 15, 2020,

the Supreme Court held that the "because of sex" terminology includes "sexual orientation" and "gender identity" (Bostock v. Clayton County, 2020). However, this appended definition is inaccurate, as sex is not synonymous to sexual orientation and gender identity - each is its own separate element. Thus, the U.S. House of Representatives proposed the federal Equality Act, which would amend the Civil Rights Act of 1964 to provide explicit discrimination protections on the basis of sex, sexual orientation, and gender identity (The White House, 2021). The federal legislation would codify the anti-discrimination protection across an expanded range of public accommodations recognized under civil rights law, which would include healthcare settings (Santos, Medina, & Gruberg, 2021; The White House, 2021). The current status of the bill is that it has been reintroduced in the 118th Congress in June 2023 in the House of Representatives (Human Rights Campaign, 2023).

In addition, a string of newly enacted and proposed federal and state policies across the U.S. threaten to make the situation worse (Miller, 2022). In 2023 alone, over 520 anti-LGBTQ+ bills have been introduced in state legislatures across the U.S. (American Civil Liberties Union [ACLU], 2023). Currently, 22 states, including Arkansas and Florida, have enacted legislation that allows medical service providers to turn away patients based on their own "conscience - religious, moral, or ethical beliefs and principles" (ACLU, 2023; U.S. Senate, 2021). Additionally, in 2023, over 15 laws have been enacted across state legislatures preventing healthcare providers and insurance companies from providing and covering gender-affirming care for transgender and non-binary youth (ACLU, 2023). 26 states currently do not have laws providing SGM-inclusive insurance protections (Movement Advancement Project [MAP], 2023). Only 15 states and Washington DC have laws in place preventing insurance discrimination based

on sexual and gender identity (MAP, 2023). It is expected that hostile legislation will continue to be introduced and passed, which calls for immediate action to protect SGM individuals.

This has several implications for the ace community. As this study illustrates some of the many intersecting identities ace individuals have, many ace folks like Coral may be directly impacted by state legislations restricting gender-affirming care, which emphasizes the need to establish immediate protections at federal and state levels to ensure SGM patients have protection and access to necessary healthcare. Similarly, although the Equality Act aims to explicitly prohibit discrimination on the basis of "sex, sexual orientation, and gender identity" at the federal level, the act is still under consideration in Congress, which demonstrates SGM patients in the U.S. currently do not have explicit nondiscrimination protections. Furthermore, the Equality Act remains largely ambiguous regarding protection for ace individuals. The clause "discrimination based on sexual orientation includes discrimination based on an individual's actual or perceived… sexual attraction to other persons, or lack thereof, on the basis of gender" may allude to asexuality (Section 2.3, 12). However, this definition is ineffective in capturing the diversity of asexuality. Similarly, Section 1101.5 defines sexual orientation as "homosexuality, heterosexuality, or bisexuality," illustrating how the exclusion of "asexuality" from the definition alludes to ace individuals not being explicitly protected by the Equality Act. In addition, the AMA established guidelines to support the "equal rights, privileges and freedom of all individuals and opposes discrimination based on sex, sexual orientation, gender identity, race, religion, disability, ethnic origin, national origin or age" in medical and public health care (AMA, 2024). Although patient-centered anti-discrimination policies regarding sexual orientation aims to instill protections for lesbian, gay, bisexual, transgender, and queer individuals, current policies largely center around lesbian, gay, bisexual, and transgender

individuals, illustrating other SGM populations like the ace community largely remains unprotected in healthcare settings. As seen in participants' narratives, the lack of knowledge and understanding of asexuality in healthcare, along with providers' inadequate training working with SGM patients, results in ace patients being subjected to anti-asexual microaggressions, further necessitating the establishment of anti-discrimination policies protecting ace individuals.

As such, this study offers a few recommendations for policy improvements to explicitly ensure the protection of asexual individuals from discrimination. Initially, the proposed federal Equality Act should be amended to include asexuality within the definition of "sexual orientation" in Section 1101.5. Similarly, Section 2.3 should update clause 12 to acknowledge the spectrum of experiences of sexual attraction and desire to be inclusive of asexuality. Subsequently, to further ensure ace individuals are protected from discrimination in healthcare settings across the U.S., the AMA should establish patient-centered policy explicitly noting the protection of asexual patients, similar to "H-65.976 Nondiscriminatory Policy for the Health Care Needs of the Homosexual Population." To further ensure protection of ace individuals not explicitly covered by federal and healthcare policies, state-level non-discrimination policies should be instated. According to the MAP (2023), 32 states, 1 U.S. territory, and D.C. currently have anti-discrimination policies in place protecting sexual orientation. New York's Sexual Orientation Non-Discrimination Act (SONDA) is the only state-level anti-discrimination protection policy in the U.S. that explicitly protects ace individuals, as they define sexual orientation as "heterosexuality, homosexuality, bisexuality, or asexuality, whether actual or perceived" (New York State Attorney General, 2003). As such, it is recommended that existing state anti-discrimination policies based on sexual orientation should be amended to include

asexuality within its definition of "sexual orientation". Similarly, states that do not have existing policies should establish protections and ensure the inclusion of asexuality.

Sexual and reproductive healthcare protections. Reproductive healthcare rights have become a "hot-button issue" in the U.S. over the recent decades, and it has implications for many folks in the ace community (Bailey, Guldi, & Hershbein, 2013). As illustrated in this study, a major concern among ace women and ace individuals AFAB is not having autonomy over their sexual and reproductive healthcare decisions. The U.S. Supreme Court's decision in 2022 to overturn *Roe v. Wade*, which removed the constitutional right to seek abortion, allowing for states to outright ban access, underscores how the right to bodily autonomy is jeopardized for many individuals living in the U.S., especially for Black, Indigenous, Women of Color, Trans, and non-binary women and individuals AFAB who have disproportionately poor reproductive health outcomes (Center for Reproductive Rights [CRR], 2024; Coen-Sanchez et al., 2022). As of 2024, abortion is illegal in 13 states, 12 states expressed a desire to prohibit abortion entirely, and 3 states having no explicit protections (CRR, 2024; KKF, 2024). Additionally, 10 states will have abortion measures on their ballots for the 2024 election cycle seeking whether protections should be codified in their respective state constitution (CRR, 2024; KKF, 2024). These proceedings raise further questions about its implications on patients' access to contraception, assistive reproductive technologies, essential medicines or services, including how far the government will go in surveilling people's bodies (Coen-Sanchez et al., 2022; McGovern, 2022). In addition, state legislations have implications on funding facilities that offer sexual and reproductive health services through state-funded Medicaid programs or ensuring coverage of relevant services through private health insurance entities (CRR, 2024). Non-profit clinics like Planned Parenthood have been impacted by restrictive state legislations on abortion access,

forcing many clinics to reduce their services or shutting down (Luthra & Carranza, 2024). This has further implications on many members of the ace community. A number of participants reported primarily seeking sexual and reproductive healthcare services from Planned Parenthood due to their SGM affirmative approaches to care. In addition, Planned Parenthood facilities provide a wide range of services to patients, including sex education, mental health care, and wellness and preventative care. This further illustrates the implications of how interruptions to the operation of Planned Parenthood clinics may have detrimental effects on patients, especially for those who may be reliant on their services due to challenges of availability of general health education and healthcare in their communities. As such, this further calls for the immediate codification of reproductive healthcare protections for individuals at the federal level, beginning with restoration of the protections outlined in *Roe v. Wade*. To further ensure protection of reproductive healthcare rights of individuals, protections should be instated within every state's respective constitutions.

Policies to Improve Access to Equitable Care.

Improving affordability and availability of affirmative care. As illustrated in this study, affordability and availability of care are determinant factors of patients' healthcare experiences, and many participants expressed that more could be done to improve patients' access to equitable care. A perspective shared by others, Topaz described how the current inflexibility of healthcare costs and delivery of services can present as additional barriers to marginalized populations, and emphasized that practices can prove their intentionality of being welcoming to all patients by addressing these barriers:

> I think what really needs to be factored in more with, like healthcare, too, is like class, and how it affects the access to care. Like, I'm fortunate, at least, that I can generally

> afford my healthcare expenses even with a high deductible plan. And I have full time employment with benefits. But I think, like, for a lot of people, like, who say, for example, are poor or like, maybe it's hard for them to even get transportation and time, paid time off, or like, not risk losing their job to go to an appointment. Like, I think, like there's times when I feel like when I work with providers, like, sometimes they're very inflexible, being like, "we're only open 9 to 5, Monday through Friday," like, "you can only call during those hours, you can only make appointments during those hours."... Or like, only insisting on in-person and not offering telehealth, even though they could easily do it… And also, just generally like, understand there's a whole, like, issue with, you know, like insurance doesn't reimburse them much or something. But providers who don't take insurance, but then also, like, they don't offer any sort of things like payment plans, or like sliding scale, or like even, like, reduced or free spots for anyone, I see that as also especially egregious when it's, like, a provider that's claiming to be like, "we're here to really support people who are multiply marginalized." But then the only things they have are like, "we don't take insurance, and it's $200 for an appointment." Like, I think that's something where I understand it's like a bigger issue than what maybe individual providers can do… I think, like, if the more mindful [providers] can be and intentional, I think the better, instead of, like, kind of being, "Oh, you can't afford it? Sorry, that's your problem."

Topaz's sentiments illustrate how access to care—including whether it is available, timely and convenient, and affordable—affects health care utilization, further alluding to the need for policy changes to improve the flexibility of practices' functioning (National Academies of Sciences, Engineering, and Medicine, 2018). For example, federal and state level policies can be instilled to financially support practices to operate beyond typical business hours, allowing ample opportunity for patients to seek care. Additionally, practices should be supported to offer services in various modalities, if appropriate for care, such as virtual appointments or allowing for providers to make house calls. Having various modalities can be beneficial for many communities, for example, the flexibility of healthcare delivery will allow for affirmative care to reach patients located in rural areas, to patients who have physical accessibility concerns, and patients who would prefer to be in the safety and comfort of their own homes. Similarly, many participants like Gale shared that it is difficult to find queer-friendly providers in her area, so availability of virtual care will allow for patients to seek care from queer-accepting providers

across the nation. Additionally, as highlighted in this study, a number of participants expressed their discomfort seeking care locally as the institutions were largely faith-based practices. As such, policies should be implemented allowing for patients to seek care anywhere in the nation without having to pay additional costs. Similarly, providers should be able to obtain licensure to practice across the nation, especially for those who can deliver care virtually. Ultimately, systems should be in place to ensure patients are able to seek care without incurring financial burdens. Coral expressed "free healthcare would be nice," a sentiment shared by many others. As highlighted by Topaz, practices universally should be financially supported to offer services to patients on payment plans, discounts, or sliding scales.

Patient companion support and proxy considerations. Both Ocean and Rain uniquely highlighted how normative assumptions about relationships may present as barriers for some ace individuals seeking healthcare. As emphasized, there is a diversity of experiences within the ace community, which includes the various types of significant relationships ace individuals may engage in. Some ace individuals may choose not to engage in committed relationships, others may choose to engage in romantic relationships (monogamous and non-monogamous; celibate and involving sexual contact, not involving sexual contact, etc.); non-romantic/non-normative partnerships such as Queer Platonic Relationships (QPR), commonly referred to as "a committed relationship that is not romantic, nor purely platonic, but is something else that cannot be easily described or defined"; conventional friendships, etc. (Chasin, 2019; hemogoblin, 2023). As such, this has implications on the support ace patients may receive in healthcare. Ocean shared a personal anecdote of needing a medical procedure done and being "very worried I just was not going to be able to get this surgery because I didn't have any options [to] find someone to help

[accompany] me with this surgery," illustrating the normative assumption that all patients have committed partner(s) to accompany for any healthcare support:

> There's, there are a number of healthcare things where there's just, sort of an assumption that, like, you know, you will have a person who will be able to accompany you. And whether that's, you know, needing help after surgery. Or even just like, you need someone to drive you home after, you know, you get a tooth pulled, or, you know, have your eyes dilated or something. And there's just sort of this assumption that, like, you know, "Of course you have a significant other. Who's gonna help with that." And I don't. I don't really know how to fix that. Because there are certainly plenty of scenarios where you really do need someone to help. But the assumption that, that is easy to find is a very frustrating one.

As Ocean noted, patients are expected to make arrangements to have a companion accompany them home post outpatient procedure. Due to liability concerns, if patients are not able to arrange a companion, providers will "always reschedule the procedure until the patient can make proper arrangements," illustrating a barrier preventing patients from getting timely care (American Medical Resource Institute, 2022). Although not widely available, some healthcare facilities may offer medical transportation services or in-patient rehabilitation accommodations. However, in most cases, patients "need to pay for this service," which poses a financial barrier as these services may be costly (Mayo Clinic, 2024). To relieve the burden off of patients and to guarantee patients receive the support they need, policies should be instituted to ensure healthcare facilities nationwide can offer patient companionship services or in-patient rehabilitation accommodations at no cost to the patient.

Additionally, Rain shared their concerns about how the normative assumption that a patient's emergency contact is most likely a romantic or sexual partner has implications on if they are able to request the person they would like support from in a time of need:

> Because I experience and prioritize things outside of romantic and sexual relationships, I think [my ace identity] is relevant [to my healthcare] as well because when they're asking, "who is your emergency contact?" Or, if I were to get into an accident… I have a chronic illness, so there are times where I need to go to the hospital. And that, I need, you

> know, support from friends or family. But it's like, common practice to only allow, like, if you're married, the partner or the, you know, boyfriend or girlfriend, or whatever into the room. And so I think my asexuality, and my like, that I don't desire a partner, or I don't have a partner matters in those cases. So that [healthcare providers] can see that "Okay, maybe a best friend should be prioritized just as much as a partner or a family member" in those instances. And that's really not a common practice in Emergency ERs, or you know, like, units, like that. That's not common practice to allow somebody who isn't, like, a spouse of an ace person. So it does matter, I think it is one of the biggest instances where it matters.

Rain's concerns allude to the implications this may have on providers identifying an individual to assume decisional authority over a patient's healthcare should they become incapacitated, an apprehension further shared by Ocean:

> When someone is in a position where, like, you know, they're incapacitated, and can't make decisions themselves. The assumptions about, like, "who sort of does that?" There will be a person who can make those decisions. And, you know, if there isn't, you know, a significant other or something who's available for that, will [the patient] actually be taken seriously? It is definitely a big, a specific concern.

Currently, if a patient does not legally appoint a healthcare decision surrogate prior to their incapacitation, state legislation appoints a default surrogate following "hierarchical priority," typically starting with the person's spouse or domestic partner, then an adult child, a parent, a sibling, and then possibly other relatives (DeMartino et al., 2017; Pope, 2023). As this has implications for many SGM individuals, the Human Rights Campaign (HRC; n.d.) emphasizes the need for SGM patients to establish a Healthcare Proxy, a Durable Power of Attorney for Healthcare, to ensure the agent of the patients' choice is legally able to serve as a healthcare decision surrogate. The Healthcare Proxy will allow the chosen agent to "be given first priority to visit patients at the hospital, receive personal property recovered by any hospital at the time of incapacitation, and authorize medical treatment and surgical procedures" (HRC, n.d.). As such, considerations should be made to allow for the Healthcare Proxy to be widely used and recognized. All patients should be encouraged to complete a standardized proxy which would be

honored nationwide at no cost to the patient. Patients would be reminded on a regular basis to update the proxy to ensure the person indicated is still who they wish to appoint as an agent. The established proxy should be housed in national database, allowing for providers nationwide to access if needed.

5.4 Researcher's Recommendations for Practice and Policy

As seen in the previous section, participants offered a wealth of ideas for improvements in practice and policy to make healthcare more welcoming for the ace community. While all ideas offered should be incorporated, there are certain recommendations which should be considered for immediate implementation – aiming for effective, universal implementation within 5 to 10 years. The goal of this section is to amplify participants' ideas by synthesizing their suggestions into recommended action steps. It is important to note that although there is a universal need for improving SGM patient care in the U.S., and many of the recommendations made by participants apply to the greater SGM community, this section focuses on amplifying recommendations related to asexuality in healthcare practices.

As previously discussed, findings suggest ace patients feel unwelcomed in healthcare spaces that largely deal with patients' sexual and mental healthcare. Specifically, based on participants' narratives, it is imperative for Primary/General Care, Psychology, Psychiatry, and Gynecological Care spaces to be knowledgeable about asexuality and to begin making recommended improvements to their practices. Primary Care and General Care providers are often patients' first encounter, so it is vital for physicians to be knowledgeable about asexuality to be able to effectively guide their patients and make appropriate referrals for specialized support – especially to prevent scenarios of medical negligence and delay of care due to

inaccurate referrals as experienced by Maple. Similarly, it is imperative for Mental Health Therapists, Psychologists, and Psychiatrists to be knowledgeable about asexuality to be able to effectively guide patients seeking support with navigating their identities and interpersonal relationships without pathologizing the patients' asexuality. As indicated by Lotus, there is a need to reevaluate existing mental health screening tools like the Beck Depression Inventory (BID) for its applicability in ace populations. Similarly, several procedures and protocols in Gynecological and related practices have been identified to be non-ace affirmative, such as cervical screening exams and preliminary procedures to obtain certain treatments. Current protocols need to be reevaluated as ace patients often feel their concerns are being dismissed and their decisions for their sexual and reproductive healthcare are being overridden. Some recommendations for protocol improvements will be provided later in this section.

A key finding from this study identified healthcare providers' continued lack of knowledge and understanding of asexuality has negative implications on delivering affirmative care to ace patients, as healthcare professionals may engage in anti-ace microaggressions and often do not have enough understanding of asexuality provide effective guidance with care relevant to patients' identity, relationships, and lifestyles. As such, more culturally competent, trauma-informed training initiatives need to be implemented to prepare healthcare professionals to effectively serve the needs of ace patients. For example, providers should have the competency of approaching care from an intersectional approach and having the skills to conduct motivational interviewing patients. To support this initiative, improvements need to begin at the medical and professional school level. Initially, there needs to be more advancements made to the commitment of Diversity, Equity, and Inclusion (DEI) enrollment efforts to ensure students from various racial, ethnic, gender, sexuality, religious, etc. backgrounds have the opportunity to

become providers – particularly ensuring the enrollment of more ace. As seen in patients' narratives, in certain cases, it is imperative for providers to have deep understanding of the various nuances of asexuality to best guide patients, such as the need for mental health therapists to be able to effectively guide patients seeking support navigating their ace identities and trauma. Someone who would be able to navigate this is a provider who identifies as ace themselves. As such, institutions should actively seek underrepresented applicants to enroll. Subsequently, in addition to the need of incorporating more SGM patient care focused curriculum in medical and professional schools, institutions need to incorporate additional curriculum that specifically educate providers about asexuality and how to best serve ace patients. To assist with curriculum development and training of prospective providers, institutions can incorporate a wealth of knowledge generated from well-regarded ace community organizations, such as the Asexual Outreach. Additionally, institutions and training programs should invite ace activists and ace patients to share their experiences to further bring insight into best practices healthcare should adopt. In the long term, accreditation evaluation similar to the HCR's HEI need to be conducted that incorporates criteria to ensure medical schools and health care professional schools are educating prospective providers with relevant and effective education about asexuality, and further ensuring these institutions are committed to fostering DEI on their campuses.

For continuing education, it is imperative for healthcare professionals to receive regular training on SGM issues to ensure their practices are relevant and appropriate for their patients. States across the U.S. need to implement a similar requirement as the District of Columbia to require providers to complete LGBTQ+ competency training every two years to maintain their licensure. Because existing SGM trainings do not effectively discuss asexuality, similar to the recommendations made for medical and healthcare professional school curriculum, continuing

education programs should offer separate training specifically to teach about asexuality and its intersection with healthcare, and this training should be developed with the guidance from members of the ace community. Additionally, to allow providers to have an effective understanding of existing gaps in ace patient care, training programs should invite ace patients to share their testimony and allow for an engaging question and answer session with providers. In the long term, existing SGM competency curricula should expand to include a comprehensive discussion of asexuality.

In addition, several improvements need to be made in healthcare practices to ensure facilities are welcoming to ace patients. To begin, it is also imperative for healthcare facilities to be committed to advancing DEI, which includes hiring of representative staff as they would be better equipped to guide and support patients. As such, facilities serving ace patients should strive to hire staff who also identify with asexuality. All hired personnel should be required to be up-to-date with SGM cultural competency training, which should include competency serving ace patients. Additionally, supporting the recommendations made by participants, facilities should ensure their physical spaces maintain standards to be inclusive to all patients. This includes ensuring ample accessibility accommodations are available and signage to indicate the facility is a SGM welcoming and accepting space. Because asexuality is not commonly acknowledged, it is recommended practices explicitly welcome ace identities, either with displaying of ace flags or having educational materials available which discuss asexuality. As previously discussed, it is recommended for facilities to disseminate educational materials discussing asexuality that have been specifically developed by ace organizations. It is important to note that it is imperative for staff to be knowledgeable and have basic understanding of asexuality if they do have explicit signage discussing asexuality – otherwise it is performative

and can be misleading for patients who specifically seek support related to their identity. Additionally, providers and staff who are specifically trained in ace topics or are ace themselves should also explicitly advertise as such on their respective office websites, social media pages, and insurance network websites so ace patients are readily able to access the services. Furthermore, it is imperative for facilities to implement accountability measures to ensure the protection of ace patients from discrimination, especially since there are no existing protections at state and federal levels. As previously mentioned, existing anti-discrimination policies should updated to explicitly mention protections against aphobia. To ensure accountability, advisory boards comprising of providers and members of the ace community should be developed where they convene to address any issues that may arise. These advisory board meetings can also serve as feedback sessions for providers to ensure their current practices are ace affirmative for their patients. Similarly, offices can implement a feedback system, such as climate surveys, asking ace patients how providers can best serve them. Ultimately, in the long run, facilities need to participate in HEI accreditation evaluations to ensure they are engaging in equitable and inclusive practices when caring for SGM patients. As mentioned previously, improvements need to be made to the existing HEI criteria to include evaluating effective affirmative care given to ace patients.

Lastly, based on participants' ideas, this section will provide some recommendations to protocols and procedures that should be considered for immediate implementation. To emphasize, providers need to approach their care from a trauma-informed approach to ensure the protocols and procedures they need to follow are ace affirmative. As mentioned, currently no standardized SOGI collection procedures are in place to effectively capture the health needs of ace patients. As such, it is imperative for providers to inquire about patients' sexual and gender

identities during intake (either on forms or during interviews), and to be transparent that they are collecting their SOGI to be able to give proper guidance based on their needs. When patients disclose that they identify with asexuality, providers should always follow up with asking patients "how do you personally describe your asexuality?" or "what does being ace personally mean to you?" to best understand their patients' experiences. Similarly, it is imperative for providers to ask comprehensive questions about patients' health while being sensitive to patients. For example, emphasizing that asexuality should not be misconceived for celibacy, some ace individuals may have a sexual history that need to be considered when providing sexual and reproductive healthcare. As such, when inquiring about ace patients' sexual health history for the first time, providers should say something similar to, "I understand that you define your asexuality in xyz way, I need to ask you these sexual health questions just so I am not missing any information that may be important to your health. I typically ask all of these questions to patients each time we meet. Since this is our first time meeting, I do need to ask you all of these questions. However, if you do feel uncomfortable answering any of these questions and do not wish to be asked certain questions again, please let me know so I can make note of it. I will be mindful for the next time we meet." For following encounters, providers should say, "Last time when I asked you about your sexual health history you mentioned xyz. Has anything changed?" These recommendations also apply to protocols such as asking individuals of childbearing potential to take a pregnancy test. For procedures like surgeries where pregnancy tests are part of mandatory protocol, if patients share that they have no sexual history that would require them to take a pregnancy test, providers should acknowledge patients and be transparent about why they are asking them for a pregnancy test. If not taking a pregnancy test prior to a procedure or treatment is not detrimental to the patients' health, patients should be allowed to refuse without

facing any consequence and providers should be able to respect patients' refusal. Providers should be given the ability to respect patients' refusal and document their refusal, but still be able to proceed with the patients' care. In a similar vein, although the standard protocol for the iPLEGDE program allows for patients select "abstinence" as a form of birth control, providers should allow ace patients to choose that as an option without casting doubt.

All in all, providers should be devoted to effectively serving their patients. As such, it is imperative for them to begin incorporating many of these recommended changes immediately into practice. In addition, as seen in this study, institutional factors have an influence on ace patients' healthcare experiences. As such, providers must continually engage in advocating for healthcare policy changes that directly affect their patients' access to equitable care, such as advocating for affirmative care and reproductive healthcare rights.

5.5 Limitations

This study was limited in several ways that must be considered when interpreting the results and conclusions. Discussion will be divided into following sections: *The Study's Conceptualization of Asexuality and Methodology*.

5.5.1 The Study's Conceptualization of Asexuality

As discussed in **Chapter 1**, academic literature largely defines asexuality as "enduring lack of sexual attraction of others" (Bogaert, 2012; Brotto & Milani, 2022), which sparks contention among the ace community as the term "lack" has a pathologizing connotation, insinuating something is missing or needs to be fixed (Chen, 2020; Decker, 2015). It is important to note that there is ongoing discourse among the ace community regarding the acceptance of the

mainstream definition of asexuality as “a person who does not experience sexual attraction towards individuals of any gender” (Hinderliter, 2009; LGBT Center UNC-Chapel Hill, 2021). Many folks argue that although this definition was initially aimed to achieve inclusivity (Siggy, 2023), and it was helpful in bringing visibility to the asexual community (Hinderliter, 2009), it fails to effectively capture the diversity of experiences of sexual attraction, desire, or practice within the community. Additionally, having a standardized definition to conceptualize asexuality may lead to the issue of identity essentialism/prescriptivism - for example, insinuating that a person can only “qualify” to identify as asexual if they do not experience sexual attraction - which excludes “all other elements of personal experience, such as boundaries, desires, priorities, relationship styles, community history, and degree of identification or disidentification with certain narratives” (Coyote, 2021), the antithesis of the mission of inclusivity the ace community aims to achieve. As such, there has been a recent rise in asexuality research exploring ways to holistically conceptualize asexuality (Chasin, 2019). The general consensus among the ace community is that although helpful, the substantive multiplicity of aceness makes it difficult to define asexuality in terms of anything other than self-identification (Chasin, 2019). Hence, it is emphasized that however an individual chooses to identify their asexuality is valid.

As such, this has several implications in this study. Due to the confines of academic research requiring the usage of existing empirical literature as primary sources to support claims, there was very limited usage of relevant, community-driven knowledge from reputable ace forums referenced in this study. As a result, much of the literature review and analysis used outdated conceptualizations of asexuality. In efforts to have readers gain a more relevant, foundational understanding of asexuality, a definition needed to be proposed in this study to guide the discussion. It is important to note that although the proposed definition aimed to be

inclusive of all experiences within the ace community, the unintended consequence of producing a definition is that the conceptualization of asexuality is ultimately delimited by the researcher. Researchers who define asexuality or aceness differently than the ace community will produce research findings about a population that presumably overlaps with members of the ace community, but which is "substantially different both theoretically and practically" (Chasin, 2019). Because the findings from this study were generated based on this proposed definition, there is a possibility that these findings may apply to individuals in the ace community in limited ways. This has further implications for how asexuality is conceptualized in healthcare. A standardized definition would need to be developed in order for healthcare professionals to have a foundational understanding of asexuality and to guide affirmative approaches to health care. However, this poses the risk of providers using the standardized definition to "qualify" or "disqualify" a patient of being ace based on their subjective understanding of asexuality - e.g. "ruling out" a patient of being asexual because they experience physiological arousal - which would especially impact patients who primarily seek support with navigating their identity.

Although not within the scope of the research aims, this study attempted to address the above mentioned limitations regarding the conceptualization of asexuality. Placing emphasis on the value of community-driven knowledge, this study was designed to amplify the lived experiences of ace individuals, using their narratives as primary source of data. In addition to helping with guiding the understanding of how their asexuality played a role in their healthcare experiences, participants were asked at the beginning of the interview to define "What does being ace mean to you?" in efforts to further highlight the diversity of the ace community which cannot be effectively captured within a singular definition (how participants personally define being ace can be found in **Chapter 4)**. Regarding the implications in healthcare practice

approaches, it is emphasized that providers should let patients take the lead in the discussion of how they identify themselves. Providers should have the foundational understanding that asexuality is, in essence, experiencing sexuality that is different from the normative understanding. If patients seek support navigating their identity, providers should have the necessary knowledge to educate and help guide patients to make the decision themselves of what identity fits best with their experiences - providers should never be the ones identifying patients. This study further emphasizes the use of community-generated knowledge in healthcare practice and research, such as recommending the utilization of the Ace Community Survey for preliminary needs assessments, utilization of informational pamphlets created by ace advocacy groups to help with patient and provider education, and inviting ace patients to provider training sessions to share their lived experiences to help inform affirmative practices.

It is also important to note that throughout this study the terms “asexual,” “ace spec,” and “ace” were used interchangeably in the discussion intending to be inclusive of all of the identities and experiences within the asexual spectrum. The usage of these terms interchangeably may have had the unintended consequence of being interpreted as being exclusive of certain experiences, such as interpreting the usage of the term “asexual” to only refer to folks who do not experience sexual attraction, desire, or practice.

5.5.2 Methodology

Sampling. There are a few limitations to consider regarding the sampling in this study. The first limitation is participant self-selection bias. There is a possibility that volunteers who chose to participate in this study were interested in speaking on a past healthcare experience that had strongly impacted them. As previously discussed, all participants mentioned regularly seeing

more than two healthcare providers for their care, which may indicate having more healthcare encounters than an average person. As such, findings cannot be generalized as the final sample of participants could have considered the topic of navigating healthcare as an ace individual more than other members of the greater ace population.

A second limitation is the potential of oversampling bias. Since this study solely recruited ace individuals online, this sample was limited to folks who could access the internet. As seen with previous studies that exclusively engaged in online recruitment, individuals who were mostly active on the internet were more likely to be White, female, young, well educated, and from urban areas (Carrigan et al., 2013; Ekman, Dickman, Klint, Weider-pass, & Litton, 2006; Foster & Scherrer, 2014; Ross et al., 2005; Schneckenburger et al., 2023). This also appeared to be the case within this study as majority of the participants were young, White, well-educated, cisgender women. As such, this limits the generalizability of findings across ace populations of all demographic characteristics and intersections. Future research may consider quota sampling methods to ensure every intersectional experience within the ace community are represented.

Untrustworthy Participants. As described in **Chapter 3**, to prevent further recruitment of untrustworthy participants and data contamination, cynical approaches were taken, which had implications on the sampling, data collection, and data analysis in this study. For instance, all 3 questionable interviewers were recruited from *Reddit*. Although many genuine participants were recruited from this forum, to prevent further inclusion of imposter participants affecting data quality, it was decided that future recruitment from *Reddit* would be suspended, and any scheduled interviews with participants recruited from the forum were canceled. Taking this approach may have resulted in missing many genuine participants who may have had valuable, diverse insights. Additionally, the researcher had decided to completely eliminate data from the 3

untrustworthy participants from analysis to prevent data contamination, which may had implications on data analysis.

Investigator's limitations. It is important to note that this study was conducted by a sole investigator who is a graduate student. As a growing researcher, this was their first time conducting a qualitative research study as a requirement for completing a doctoral degree in Health Education. As such, there are certain considerations needing to be made when interpreting the findings of this study. For example, in regards to study design, the investigator developed their own questions for the semi-structured interview. There were some questions the investigator developed that they realized were not effective in capturing certain phenomena and were not included in final analysis (e.g. attempting to evaluate elements of patient-provider on a scale from 0 to 10 – they realized it was hard to analyze because patients' responses were subjective.) The investigator realized there were some questions they wished they had asked to help with data analysis - e.g. asking participants for the zip codes of their providers' practices to be able to effectively discern any patient-provider relationship patterns across various U.S. regions. In addition, as discussed above, initial methodological considerations were not made regarding preventing data contamination by imposter participants, which may have influenced the overall study design.

While thematic analysis is widely recognized for its flexibility and depth in qualitative research, it demands a careful and meticulous approach to ensure reliability and validity (Hecker & Kalpokas, 2024). As being new to conducting thematic analysis, the investigator may have ineffectively explored the data, such as analyzing data at a superficial level or overlooking certain complexity and interconnectedness of themes. Similarly, the interpretative nature of the analysis relied heavily on the investigator's perspective, in which the variability can question the

consistency and reliability of findings (Hecker & Kalpokas, 2024). The positionality of the investigator being a cisgender aro ace woman whose personal healthcare experiences inspired the design of the study influenced how themes were generated. It is possible that the investigator may have missed certain themes that may have been relevant to the research aims. However, this does not mean that interpretations made in this study are right or wrong - rather the investigator's subjectivity is a strength where their analytical process of meaning-making of the data may have brought unique insights (Braun & Clarke, 2022; Nadar, 2014).

Additionally, the investigator's presentation of participants' quotes may have implications on how findings are interpreted. The aim of this study was to amplify voices of the ace community. As seen in this chapter, direct quotes from participants were embedded throughout the discussion of the findings. While the investigator aimed to evenly quote each participant, some participants were quoted more than others because their quotes captured the sentiments of multiple participants, allowing for a more succinct discussion of findings. As such, this had the unintended consequence of some voices being amplified over others.

5.6 Recommendations for Future Research

This exploratory study was aimed to bring light to the lived experiences of ace individuals navigating healthcare to inform ways healthcare can be improved to make it welcoming and inclusive to ace individuals. Participants' rich narratives elucidated many intriguing topics to explore. However, due to the limited scope of this study, much of the interesting findings were not included in the analysis and discussion. As such, this section will offer a number of recommendations for future research.

In general, there needs to be more empirical research conducted on asexuality, with emphasis on incorporating more community-driven knowledge. As illustrated in the previous discussion, the conceptualization of asexuality evolved within the ace community over the years to best be inclusive of the diversity of experiencing sexual attraction, desire, or practice. However, much of academic research in asexuality continues to utilize outdated conceptualizations, which further distances the literature from practical relevance. As such, one of the recommendations is for researchers to engage in collaborative discourse with members from the ace community to develop an effective working conceptualization of asexuality for practical applications - e.g. ensuring healthcare professionals have an appropriate and relevant foundational understanding of asexuality to help guide affirmative care approaches. Furthermore, when participants in this study were asked to share what being ace meant to them, many shared how their romantic identity and/or their personal attitudes towards having sex - e.g. being sex-favorable, indifferent, or averse - shaped the conceptualization of their own asexuality. Many research in asexuality, including this study, tend to exclude these experiences as it adds complexity to the analysis and discussion of certain research questions. As such, it is recommended that future research should have an exclusive focus on how individuals' experiences and attitudes shape their identity - e.g. investigating if people find it helpful to conceptualize their romantic identity as an independent orientation or interconnected to their asexuality.

Similarly, there needs to be more empirical research conducted investigating the intersection of asexuality and healthcare. The Ace Community Survey has regularly illustrated the various physical and mental health needs of the ace community over the years which need to be considered in healthcare practice to understand potential health disparities. As such, a

potential follow up case study can be conducted to further investigate if healthcare experiences are correlated with health outcomes. Findings can further inform affirmative care practices, including the development of relevant health education materials to support patients needs.

In addition, results from this preliminary inquiry study warrants further investigation to clarify certain phenomena and delve deeper into interesting findings. As briefly discussed, the investigator initially did not consider asking participants to disclose details of where they are located in the U.S. or the location of where they regularly sought care in efforts to protect their identity. However, all participants self-disclosed certain details of where they were located when discussing their healthcare experiences, such as sharing which state they reside in. As such, the investigator wished they asked participants to share the zip code of their residence and the zip code of the healthcare facilities where they sought care to help with further analyses of physical access to care and discerning possible patterns of provider attributes and patient-provider relationships across U.S. regions. Similarly, further research can be conducted to investigate if regional differences have an influence on 1) provider attitudes, 2) types of patient care training received, and 3) how local and state policies may impact patients' access to affirmative care.

Moreover, discussion with participants further revealed how many individuals under the age of 26 continue to receive health insurance through guardians' insurance policies. This raises several questions that warrants further investigation. For example, it would be helpful to know if ace patients, who may have additional intersecting SGM identities, ever disclosed their identity to guardians, as being dependent under guardians' health insurance has implications on access to receiving affirmative care. More research is needed to figure out how to address associated barriers - e.g. are there alternative health coverage plans that can be offered to patients through the community or state patients at no cost? Similarly, more research is needed to understand

existing support systems for ace patients and how this has implications on seeking support with navigating their identity - e.g. is it easier for ace patients to disclose their identity to providers because they have come-out to their family and have their support? Additionally, many of the younger participants interviewed discussed healthcare experiences they had as minors, and discussed their challenges of speaking about sexuality with providers because either 1) their guardians were in the room when providers inquired about their sexual orientation and they felt awkward discussing their sexuality in their guardians' presence, or 2) they expressed concerns about confidentiality where they were worried their providers would share details of their conversations with their guardians. This further raises the question about children's access to sex education and where they are able to receive support with navigating their identities - i.e. are they receiving education or support at home, at school, online, or at the pediatricians' office? More research is needed to address these barriers and to figure out best practices to support children through their identity development.

As illustrated in the previous discussion, considering the investigator's positionality and the demographics of the sample, findings from this study largely centered around the experiences of ace women and individuals who were AFAB. As such, the experiences of participants with other multiple intersecting identities - e.g. patients whose asexuality intersected with their transgender, disability, or racial minority identities - were not effectively captured within the findings of this study. Future research should further explore how the various intersectional identities of ace patients have an impact on their healthcare experiences and health outcomes. To effectively represent various identities and experiences of ace patients, the following research approaches could be considered: 1) designing an exploratory lived-experience study utilizing quota sampling to ensure each intersectional experiences are evenly represented, or 2)

developing multiple studies delving deeper into the experiences of a specific group of ace individuals with shared intersectional identities.

Further healthcare provider-centered research should be considered in light of the findings from this study. One of the key findings suggest that a number of providers do not have the necessary competency to serve SGM populations. As such, evaluative studies can be developed to investigate 1) if providers are receiving any education regarding caring for SGM patients in medical/professional school or through continued education training, 2) how relevant and appropriate the education is in real-life application, and 3) if providers are actually applying the acquired knowledge in practice. In addition, the research scope can be further narrowed to focus on providers' knowledge and understanding of asexuality, evaluating 1) if providers received any education on asexuality, 2) what the education entailed, 3) how applicable is the knowledge in terms of providing ace affirmative care to ace patients, and 4) how effective of an understanding providers have of asexuality. Furthermore, as findings from this study illustrated how a number of providers were unprofessional in their communication when participants discussed their asexuality, research can be conducted to investigate providers' beliefs and attitudes about asexuality and other SGM identities and how it impacts their ability to provide care to patients.

Additionally, further exploration of how patient-provider relationships influence patient care and health outcomes is needed. As briefly discussed, current measures of important care delivery constructs, such as empathy, are ineffective, making it challenging to effectively conduct empirical research investigating patient-provider relationships. As such, future research should entail developing effective evaluative tools to measure empathy, trust, and respect. Similarly, more validity and reliability testing of existing patient-provider relationship measures,

such as the PDRQ-9 and HCR Trust Scales is needed, and further testing of its applicability in various demographics and populations. Due to the qualitative nature of this study, these scales were not implemented. Furthermore, a unique finding from this study is that a few patients like Amber and Topaz noted that sharing the same cultural background as their healthcare provider had implications on their patient-provider relationship, where they felt uncomfortable discussing topics of sexuality. As such, future studies can further investigate how elements like culture may have an impact on effectiveness of patient-provider relationships.

As this study illustrated certain current procedures to be non-asexual affirmative, more research is needed to address this concern. For instance, the construct validity of the BDI may need to be reevaluated to ensure this tool is effective in screening for depression in ace populations. Similarly, as the influence of medical misogyny was demonstrated to have an impact on the administration of certain sexual healthcare procedures, like cervical screening exams, more research is needed to effectively address this prevalent bias in healthcare. Furthermore, to ensure healthcare professionals are not unintentionally engaging in microaggressions when providing support to patients, more research is needed to develop guidelines for providers to discuss topics of trauma and relationships with ace patients in an affirmative way that does not invalidate patients' asexuality. To further emphasize, it is crucial for future research to incorporate the input of the ace community when developing ways to deliver affirmative care.

As noted in Chapter 3, one participant's interview was excluded from this study as the participant shared their experiences navigating healthcare in Canada. Although their interview was not included in the analysis, their interview offered valuable insight into how patients navigate the free public healthcare system in Canada. Future research can investigate 1)

Canadian providers' knowledge and understanding of asexuality, 2) patient-provider relationships 3) access to asexual affirmative care in Canada, and 4) make further comparisons with the U.S. healthcare system.

Epilogue

This study explored the lived experiences of ace individuals in healthcare to inform ways healthcare can be improved to be welcoming to ace individuals. The goal of this study was use the voices of the ace community to highlight existing gaps in healthcare needing to be addressed. Findings suggested that the continued lack of knowledge and understanding of asexuality, and the influence of compulsory sexuality in healthcare, continues to have negative implications on ace patients' healthcare experiences. However, ace patients describe having positive experience with providers that demonstrate SGM cultural competency, humility, and provide care from a trauma-informed and patient-centered approach. These experiences further impact ace patients' future healthcare seeking behavior, which has implications on health outcomes. Understanding the various institutional barriers in place preventing ace patients from receiving equitable care, it is imperative for providers to take onus on improving patient-provider relationships and to ensure they are able to provide effective care to patients. Based on patients' narratives, improvements need to made in healthcare spaces that deal with patients' sexual, mental, and reproductive health – specifically in Primary/General Care, Psychology, Psychiatry, and Gynecological Care spaces. Participants in this study offered a wealth of ideas on improvements that can be made at provider, office, and policy levels. As such, this study can not only inform health education practice and policy initiatives, this study aims to bring further recognition and acceptance of asexuality.

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Appendix A: Glossary

This glossary of terms will be divided into the following tables:

Table 1: Definition of Terms Used in the Study.

The following table lists terms which were used throughout the dissertation.

Ace	Colloquial abbreviation of "asexual." Often used to refer to asexual individuals in a similar manner as "gay" or "straight" are used to refer to homosexual or heterosexual people, respectively. Ace also includes gray-asexual and demisexual individuals.
Allo	A colloquial abbreviation of "allosexual," "alloromantic," or both, depending on the context in which it is used.
Allosexual	A term used to describe an individual who experiences sexual attraction. Allosexual individuals include heterosexual, homosexual, bisexual, pansexual, and queer identities.
Allosexuality	Describes experiencing sexual attraction.
Asexual	A term an individual may use to specifically describe that they do not experience sexual attraction towards individuals of any gender or do not wish to engage in sexual behavior.
Asexual Umbrella, Asexuality Spectrum, Ace Spectrum, or Ace-spec	The grouping of asexual, demisexual, and gray-asexual identities under a single umbrella or related sexual orientation.
Asexuality	A spectrum or umbrella of identities that suggests multiple ways of experiencing an absence of sexual attraction, desire, or practice.
Bisexual	An individual who is sexually attracted to two genders.
Cisgender	Individuals who are cisgender have a gender identity that matches their sex assigned at birth – i.e. an individual sexed male would be a man, and an individual sexed female would be a woman.
Demisexual	A term to describe an individual who does not experience sexual attraction unless they form a strong emotional connection with someone. Demisexuality is seen as a specific sexual orientation in between "asexual" and "sexual."
Gender Minority	Individuals whose gender identity does not match the sex they were assigned at birth. Term is inclusive of identities such as, but not limited to, transgender, gender nonconforming/genderqueer, agender, two-spirit, and more.

Gray-Asexual, Gray-Sexual, Gray-A	Terms used to describe individuals who feel as though their sexuality falls somewhere on the spectrum of sexuality between "asexual" and "sexual." Gray-A differs from demisexuality because it is a highly unspecific catch-all used to describe any forms of attraction between "asexual" and "sexual." Individuals who identify as Gray-A may infrequently experience sexual attraction, may be unsure if they have, or may experience low sexual desire, yet will generally identify as being close to asexual.
Heterosexual	An individual who is sexually attracted to an individual of the opposite gender.
Homosexual	An individual who is sexually attracted to an individual of the same gender.
Pansexual	An individual who is sexually attracted to others regardless of gender.
Sexual and Gender Minority (SGM)	An umbrella term that encompasses populations whose sexual orientation and gender identity or expression vary from traditional, societal, and cultural constructs of sexual orientation, gender, and/or sex (National Institutes of Health Sexual and Gender Minority Research Office [NIH SGMRO], n.d.).
Sexual Minority	Term is inclusive of identities such as, but not limited to, gay, lesbian, bisexual, pansexual, queer, asexual, and more.
Sexual Orientation	Describes an individual's pattern of sexual attraction based on a person's gender(s).

Table 2: Ace Identities Used By the Asexual Community

In addition to the asexuality identities listed above, the following table lists a non-exhaustive list of Ace identities used within the Ace Community. This is to illustrate the diversity of experiences within the Ace Community. It is important to note folks may use these specific identity labels to help further describe their experiences, whereas others may only use the umbrella term of "Asexual" or "Ace." To emphasize, however an individual identifies their asexuality is valid.

The list of identities and their definitions were collected from ***asexuals.net***.

Aceflux	When individuals feel their sexual orientation changes but generally stays on the asexual spectrum. For example, some individuals may be on different sides of the spectrum at different times, others may feel allosexual at times.
Acespike	This identity is for those who usually don't feel sexual attraction. However, on occasion have rare, sudden, and intense spikes of sexual attraction that last for a very short amount of time. After this they return, just as quickly, to asexuality.

Aegosexual	This label describes people on the asexual spectrum who have a disconnection between themself and the subject of arousal. Individuals may have sexual fantasies or watch/read erotic content. They may also. But you feel little to no sexual attraction and usually don't desire to have sex with others. Examples include fantasizing aboout sex without involving self. Alternatively, fantasies are made highly unrealistic, as adding realistic elements would make it less or not appealing.
Apothisexual	Someone who is on the asexual spectrum and is also sex-aversed (or sex-repulsed) is called an apothisexual. They are averse to the idea of engaging in sexual activities themselves but are okay with sexual activities that do not involve them directly. Others may be repulsed by the idea of sex all together. Sex-repulsion does not mean someone is against people having sex. It simply indicates that someone finds sex and sexual activities disgusting. This is a singular feeling of oneself with sex. This means that – usually – apothisexuals do not mind what others are doing, as long as it does not involve/impacts them.
Bellussexual	It describes people who have interest in certain (aspects of) sexual actions, and/or the aesthetic of a sexual relationship. However, they do not feel sexual attraction and do not want a sexual relationship.
Caedsexual	Someone who feels they were allosexual at some point in their life but are now asexual due to past trauma. The label caedsexual should only be used by trauma survivors and those with PTSD themselves.
Cupiosexual	Those who do not experience sexual attraction yet desire a sexual relationship. Cupiosexuals are commonly sex-favorable.
Fictosexual	Fictosexual is a term used for people who experience sexual attraction exclusively towards fictional characters. Or, alternatively, whose sexuality is influenced by fictional characters.
Fraysexual	They feel sexual attraction at first but lose this attraction once they get to know the other person and form a deep bond.
Lithosexual/ Akoisexual	Some consider this label to be leaning more towards the greysexual identity than asexual. This is because akoisexual may experience sexual attraction. However they do not want this reciprocated. An akoisexual person may be uncomfortable at the thought of someone being sexually attracted to them, or they may lose their sexual feelings if they learn it's reciprocated.
Myrsexual	Someone who identifies as myrsexual is on the asexual spectrum but might feel confused as to where exactly as they can experience multiple asexual identities at once. They can also rapidly fluctuate. For example someone who considers themself to be both demisexual as well as graysexual. Or fictosexual as well as graysexual. It can often be confusing for people which is why myrsexual can be a more comfortable label to identify with.

Quoisexual	Describes people who don't relate and/or understand experiences or concepts of sexual attraction and orientation. Differently put, a quoisexual is someone who is unsure of what sexual attraction is and/or is unsure if they experience sexual attraction.
Reciprosexual	Someone who does not experience sexual attraction until they know that the other person is sexually attracted to them first.
Requissexual	Someone who has very limited or no sexual attraction and interest due to some form of emotional exhaustion. The reason of emotional exhaust may have many reasons such as past experiences dealing with sex or other emotionally draining reasons.

Appendix B: Recruitment Flyer

Appendix C: Social Media Recruitment Scripts

To Admins:

Hello [insert contact/group name]

My name is Mohima Meera (she/her) and I am an Ed.D. student in the Health Education program at Teachers College, Columbia University. I am conducting a research study investigating the experiences of Asexual identifying individuals navigating the healthcare systems to improve our understanding of how to make healthcare more inclusive. I am reaching out to ask if it is possible for me to share a flyer with a brief description of my study in hopes of recruiting some members who may be interested in participating in the study.

Interested participants will be asked to participate in a 45-minute interview via Zoom, and they will be compensated for their time with a $50 Visa Gift Card. There are no known risks involved in this research. Folks who are interested in participating can fill out a survey, or reach out to me via my direct messages, or via email at mmm2419@tc.columbia.edu.

Please let me know if you have any questions. I appreciate your time and consideration!

Mohima Meera
mmm2419@tc.columbia.edu

To Group:

Hello [insert contact/group name]

My name is Mohima Meera (she/her) and I am an Ed.D. student in the Health Education program at Teachers College, Columbia University. I am conducting a research study investigating the experiences of Asexual individuals navigating the healthcare systems to improve our understanding of how to make healthcare more inclusive. Interested participants will be asked to participate in a 45-minute interview via Zoom, and they will be compensated for their time with a $50 Visa Gift Card. There are no known risks involved in this research.

If you are interested in participating, please complete this survey.

Please let me know if you have any questions. You can reach out to me via my direct messages, or via email at mmm2419@tc.columbia.edu. I appreciate your time and consideration! I look forward to hearing from you!

Mohima Meera
mmm2419@tc.columbia.edu

Appendix D: Pre-Eligibility Screener Consent Form

TC IRB

INSTITUTIONAL REVIEW BOARD
TEACHERS COLLEGE

ELIGIBILITY SCREENER INTRODUCTION	
Research Title:	A Study Investigating the Lived Experience of Self-Identifying Asexual Individuals Navigating Healthcare
Principal Researcher Name, Title, Email, & Phone Number:	Mohima Meera, M.A.Ed., Ed.D. Candidate, mmm2419@tc.columbia.edu, 646-902-4411
Protocol Number:	23-254
Additional Details:	Dr. Charles Basch, Ph.D., Faculty Sponsor Dissertation Research, Pilot Study

INTRODUCTION

The purpose of this screener is to see if you meet the criteria for taking part in our research study, "A Study Investigating the Lived Experience of Self-Identified Asexual Individuals Navigating Healthcare." This survey will take approximately 5 minutes. After this session, the researcher will notify you if you are eligible to participate in this study. Eligibility depends on the study aims. We are looking to recruit individuals who self-identify as Asexual (Ace) (this includes all identities under the Asexual umbrella, such as asexual, demisexual, gray-a, etc.), are 18 years of age or older, are willing to share their experience seeking healthcare as an Ace individual and are comfortable speaking in English for a 45-minute interview.

Screener Activities: You will be asked to complete a survey with a short list of questions regarding your eligibility to participate in this study. You may choose not to answer these questions. You also may choose to stop participating. If you refuse to answer the questions or stop answering them at any time, there will be no penalty.

Confidentiality: Your information will be recorded in a Google Form, kept as confidential, as required by law. If you are eligible and interested in the study, then I will keep record of your name and contact information; this information will be kept confidential. If you are not interested in the study, then I will destroy any personal information you provided.

Risks & Benefits: The risk to taking part in this interview is minimal. There is no benefit to you of taking part in this eligibility screener. However, you may find out whether you are eligible to participate in the main study.

Compensation: You will not be paid for answering questions in this eligibility screener as it is only designed to see whether you are eligible to take part in the study.

Teachers College, Columbia University
Institutional Review Board
525 W. 120th St. Box 151, New York, NY 10027
212-678-4105 | IRB@tc.edu | RH 13 | tc.edu/IRB

Agree to participate in the eligibility screener: Do you agree to answer a series of questions regarding your eligibility to participate in our study?

Teachers College, Columbia University
Institutional Review Board
525 W. 120th St. Box 151, New York, NY 10027
212-678-4105 | IRB@tc.edu | RH 13 | tc.edu/IRB

Appendix E: Pre-Eligibility Survey

Research Eligibility Survey

Page 1 of Google Form:
Thank you for your interest in taking part in this research! The goal of the study is to learn more about the experience of self-identifying asexual individuals navigating healthcare. This study has some specific eligibility requirements, so please complete this brief form sharing a bit about your identity. If you are eligible based on these responses, you will get an email response inviting you to schedule an interview.

The purpose of this screener is to see if you meet the criteria for taking part in our research study, ***"A Study Investigating the Lived Experience of Self-Identifying Asexual Individuals Navigating Healthcare."*** This survey will take approximately 5 minutes. After this session, the researcher will notify you if you are eligible to participate in this study. Eligibility depends on the study's aims. **We are looking to recruit individuals who self-identify as Asexual (Ace) (this includes all identities under the Asexual umbrella, such as asexual, demisexual, gray-a, etc.), are 18 years of age or older, are willing to share their experience seeking healthcare as an Ace individual and are comfortable speaking in English for a 45-minute interview.**

Screener Activities: You will be asked to complete a survey with a short list of questions regarding your eligibility to participate in this study. You may choose not to answer these questions. You also may choose to stop participating. If you refuse to answer the questions or stop answering them at any time, there will be no penalty.

Confidentiality: Your information will be recorded in a Google Form, and will be kept confidential, as required by law. If you are eligible and interested in the study, then I will keep a record of your name and contact information; this information will be kept confidential. If you are not interested in the study, then I will destroy any personal information you provided.

Risks & Benefits: The risk of taking part in this interview is minimal. There is no benefit to you from taking part in this eligibility screener. However, you may find out whether you are eligible to participate in the main study.

Compensation: You will not be paid for answering questions in this eligibility screener as it is only designed to see whether you qualify to take part in the study.

EMAIL ADDRESS: _____

DO YOU AGREE TO ANSWER A SERIES OF QUESTIONS REGARDING YOUR ELIGIBILITY TO PARTICIPATE IN OUR STUDY?

- Yes (will continue to the second page)
- No (will lead to the end of the survey)

Page 2 of Google Form:

FULL NAME: _____

PREFERRED NAME: _____

PRONOUNS: _____

AGE: _____

WHAT COUNTRY ARE YOU FROM?: _____

DO YOU USE THE ASEXUAL IDENTITY LABEL TO DESCRIBE YOUR SEXUAL ORIENTATION (THE ASEXUAL IDENTITY LABEL REFERS TO ALL IDENTITIES UNDER THE ASEXUAL UMBRELLA, SUCH AS ASEXUAL, DEMISEXUAL, AND GRAY-A)?

- Yes

- No
- Unsure/Questioning
- Prefer not to answer

ARE YOU COMFORTABLE WITH SHARING YOUR HEALTHCARE EXPERIENCES?

- Yes
- No

ARE YOU COMFORTABLE WITH BEING INTERVIEWED IN ENGLISH?

- Yes
- No

Page 3 of Google Form:

Thank you for your interest. The principal investigator will reach out to you with more information if you are eligible.

Appendix F: Informed Consent Form

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
525 West 120th St. New York, NY 10027
212-678-3000 | www.tc.columbia.edu

INFORMED CONSENT

Protocol Title: A Study Investigating the Lived Experience of Self-Identifying Asexual Individuals Navigating Healthcare

Principal Researcher: Mohima Meera, M.A. Ed. | Teachers College, Columbia University
(646) 902-4411, mmm2419@tc.columbia.edu

INTRODUCTION

You are invited to participate in this research study called "A Study Investigating the Lived Experience of Self-Identifying Asexual Individuals Navigating Healthcare." You eligible to take part in this research study because you are 18 years of age or older, you self-identify with the asexual (ace) identity label (this includes all identities under the Asexual umbrella, such as asexual, demisexual, gray-a, etc.), you are willing to share your experience about seeking healthcare as an ace individual, and you are comfortable speaking in English for an interview session. Approximately forty people will participate in this study, and it will take about 45 minutes of your time to complete. After the completion of the interview, you will be given $50 in thanks for your participation.

WHY IS THIS STUDY BEING DONE?

There is a lot of research about discrimination of lesbian, gay, bisexual, and transgender individuals in healthcare, but there is not a focus on self-identifying ace individuals. This study is being done to include the experience of ace individuals navigating healthcare because our experiences may differ from the majority.

WHAT WILL I BE ASKED TO DO IF I AGREE TO TAKE PART IN THIS STUDY

If you decide to participate, you will be interviewed by me, the principal investigator (PI), who identifies as asexual. During the interview, you will be asked to share your experience seeking and receiving healthcare, such as medical and mental healthcare. You will also be asked for ideas of for how healthcare professionals can improve their care to be more accessible for you. These personal questions may be uncomfortable; you are welcome to skip any questions you do not wish to answer at any time.

You will be invited to choose when you want to hold the online interview, which will happen on Zoom. The interview will take about 45 minutes. The interview will be audio recorded, which is required for participating. If you do not wish to be audio-recorded, you

will not be able to participate. However, video recording is optional. If you wish to keep your camera on for the recording, your name and facial features will be recorded, and the recording will be securely stored. The PI will also give you time to change your name on Zoom before they start the recording, if you wish to do so. After the audio recording is written down (transcribed) the audio recording will be deleted – except for the part where you provide your consent to be audio recorded. You will be given an opportunity to review a summary of your interview to clarify anything you think was written down incorrectly and to identify anything you said that you do not wish to be included in the study.

You will be given an ID number instead of your name in order to keep your identity confidential. Your name will not be identified anywhere in the study.

WHAT POSSIBLE RISKS OR DISCOMFORTS CAN I EXPECT FROM TAKING PART IN THIS STUDY?

This is a minimal risk study, which means the harms or discomforts that you may experience are not greater than you would ordinarily encounter in daily life while taking routine physical or psychological examinations or tests. However, there are some risks to consider. You might feel embarrassed to discuss problems that you experienced when visiting a healthcare professional. **You do not have to answer any questions or share anything you do not want to talk about. You can stop participating in the study at any time without penalty. Your name will not be identified anywhere in the study, and the contents of your interview will be confidential.**

The PI is taking precautions to keep your information confidential and prevent anyone from discovering or guessing your identity. These precautions include using a participant ID number instead of your name, and keeping all information on a password protected computer. Any names of people or health care facilities you provide during the interview will be redacted from the transcript and replaced with [omitted] so no one will be able to tell who or what place you're talking about. If you disclose any sensitive health information during our conversation, that information will also be redacted from the transcript and replaced with [omitted].

WHAT POSSIBLE BENEFITS CAN I EXPECT FROM TAKING PART IN THIS STUDY?

There is no direct, immediate benefit to you for participating in this study. A possible benefit will be improvement of healthcare delivery to be more inclusive to self-identifying ace individuals, based on your ideas and input.

WILL I BE PAID FOR BEING IN THIS STUDY?

Participants who complete the interview will be given a thank you of $50.

WHEN IS THE STUDY OVER? CAN I LEAVE THE STUDY BEFORE IT ENDS?

The study is over when you have completed the individual interview. However, you can leave the study at any time even if you have not finished the questions. You will also have the opportunity to provide feedback on a summary of your interview.

PROTECTION OF YOUR CONFIDENTIALITY

The PI will keep all materials in a password protected folder hosted in a local password protected cloud service. What is on the audio recordings will be written down and the recordings will then be destroyed – except for the part where you provide verbal consent to be audio recorded. The transcripts and your audio consent will be kept indefinitely. There will be one record matching your real name with your participant number; this will be stored in a password protected folder on the principal investigator's computer, which is also password protected. It will not be stored in the same folder as all the other research materials. This document will be deleted 3 years after the study is completed.

For quality assurance, members of the Teachers College Institutional Review Board (IRB) may review the data collected from you as part of this study. Otherwise, all information obtained from your participation in this study will be held strictly confidential and will be disclosed only with your permission or as required by U.S. or State law.

HOW WILL THE RESULTS BE USED?

The results of this study will be used primarily towards the principal investigator's Doctorate in Education (EdD) dissertation. They may also be published in journals and presented at academic conferences and community meetings. **Your identity will not be included** in any data you provide and therefore will not be included in publication or use for educational purposes.

CONSENT FOR AUDIO AND OR VIDEO RECORDING

Audio recording is part of this research study. Video recording is optional. You can choose whether to give permission to be recorded. If you decide that you don't wish to be audio recorded, you will not be eligible for this study. You will be asked to provide verbal consent for being audio recorded at the start of the interview.

_____I give my consent to be recorded

_____I **do not** consent to be recorded

WHO MAY VIEW MY PARTICIPATION IN THIS STUDY

__I consent to allow audio and/or video-recorded materials viewed at an educational setting or at a conference outside of Teachers College, Columbia University

__I **do not** consent to allow audio and/or video-recorded materials viewed outside of Teachers College, Columbia University

WHO CAN ANSWER MY QUESTIONS ABOUT THIS STUDY?
If you have any questions about taking part in this research study, you should contact the primary researcher, Mohima Meera, at (646) 902-4411 or mmm2419@tc.columbia.edu.

If you have questions or concerns about your rights as a research subject, you should contact the Institutional Review Board (IRB) (the human research ethics committee) at 212-678-4105 or email IRB@tc.edu or you can write to the IRB at Teachers College, Columbia University, 525 W. 120th Street, New York, NY 10027, Box 151. The IRB is the committee that oversees human research protection for Teachers College, Columbia University.

PARTICIPANT'S RIGHTS

- I have read the Informed Consent Form and have been offered the opportunity to discuss the form with the researcher.
- I have had ample opportunity to ask questions about the purposes, procedures, risks and benefits regarding this research study.
- I understand that my participation is voluntary. I may refuse to participate or withdraw participation at any time without penalty.
- The researcher may withdraw me from the research at the researcher's professional discretion.
- If, during the course of the study, significant new information that has been developed becomes available which may relate to my willingness to continue my participation, the researcher will provide this information to me.

- Any information derived from the research study that personally identifies me will not be voluntarily released or disclosed without my separate consent, except as specifically required by law.
- De-identified data may be used for future research studies, or distributed to another researcher for future research without additional informed consent from you.
- I should receive a copy of the Informed Consent Form document.

My verbal consent means that I agree to participate in this study.

Appendix G: Interview Schedule

Semi-Structured Interview Schedule

Protocol Title: A Study Investigating the Lived Experience of Self-Identifying Asexual Individuals Navigating Healthcare
Principal Investigator: Mohima Meera, Teachers College
(646) 902-4411 - mmm2419@tc.columbia.edu

INTRODUCTION

Thank you so much for taking the time to speak with me today about your experience seeking healthcare as a self-identifying asexual, or ace individual. I'm hoping that by talking with you and others, we can gain perspective about ace individuals' experiences navigating healthcare to inform changes to make healthcare more inclusive.

Before we get started, I just wanted to confirm that you have received the "Informed Consent" form I sent to you by email. Did you get a chance to go over it? I will review the "Informed Consent" form with you at this time. I will be sharing my screen.

REVIEW THE INFORMED CONSENT FORM

The top of this consent form gives you basic information about this study. As I have mentioned, the purpose of this study is to gain the perspective of ace individuals navigating healthcare to better inform healthcare practices. This interview should take about 45 minutes to complete, and you will receive $50 in thanks for your participation.

During the interview, you will be asked to share your experience seeking healthcare, which includes medical and mental healthcare. You will also be asked for ideas on how healthcare professionals can improve their care to be more accessible for you. If do you not feel comfortable answering any questions, you are welcome to ask me to skip them answer at any time.

This interview will be audio recorded, which is required for participation. But video recording is optional. In order to participate, you have to consent to the audio recording. You have the option of keeping your camera on or off before I start the recording. Once I have transcribed our conversation, I will destroy the recording, except for the part where you verbally consented. Everything you say will be strictly confidential - no one will know your name or even that you've talked to me unless you tell them. Your name will not be identified anywhere in this study. I will be using an ID number in place of your name. If you disclose any sensitive health information during our conversation, that information will also be removed from the transcript.

This is a minimal-risk study, which means the harms or discomforts that you may experience are not greater than you would ordinarily encounter in daily life, like taking a routine physical exam

at the doctor. There is no direct, immediate benefit to you for participating in this study, but your participation may contribute to informing inclusive healthcare practices.

The last few pages describe your rights as a participant, which are given to you for your reference.

Lastly, you can find my contact information on the last page, and you are more than welcome to contact me if you have any questions.

I will now stop sharing my screen.

OBTAINING VERBAL CONSENT

Before Recording

- Do you have any questions about the study or the consent form that I have reviewed with you?
- Do you wish to participate in this research study?
- Do you agree to the recording of our interview session?

Are you ready for the recording of the interview?

I will go ahead and start recording. I will ask you the same three questions again so that your consent is recorded.

[START RECORDING]

- Do you have any questions about the study or the consent form that I have reviewed with you?
- Do you wish to participate in this research study?
- Do you agree to the recording of our interview session?

INTERVIEW QUESTIONS

"GROUNDING" QUESTIONS		
As you know, the purpose of this study is to find out more about your healthcare experiences as an ace individual. I wanted to begin our discussion by asking some general questions.		
	1	**What does being ace mean to you?**
	2	**What providers do you visit for your healthcare?**
DEMOGRAPHICS		
Before we begin our conversation, I would like to get to know a little more about you. I will be asking you a few demographic questions. I will use this information to describe all the folks who participated in the study.		

	3	**What is your racial identity?**
	4	**What is your ethnic identity?**
	5	**What is your gender identity?**
	6	**What is your sexual identity?**
	7	**What is the highest degree or level of school you have completed?**
	8	**What is your employment status?**
	9	**Is there anything else you would like for me to know about you that I have not asked about?**
HEALTHCARE EXPERIENCE AS AN ACE INDIVIDUAL: PROVIDER & SYSTEMS FOCUS (NEGATIVE)		
Now let's shift to talk about your healthcare experiences. We'll start our discussion by talking about navigating healthcare **as an ace individual.**		
Aim 1: What have been the experiences of asexual individuals when receiving healthcare?	**10**	**Can you tell me a story of a NEGATIVE healthcare encounter you had that stands out in your mind?**
Thank you for sharing your story. I am so sorry that you have experienced that. If it is okay with you, I would like to ask you a few more questions about the provider and the interaction you had with them.		
	11	**What type of healthcare does this provider give?**
	12	**How long have you been seeing this provider?**
	13	**How often do you visit this provider?**
	14	**Would you be willing to share approximately how many years ago this experience took place?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**15**	**Besides what you shared earlier, was there anything else the provider said or did that made you feel uncomfortable?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**16**	**Did you ever 'push back' about the provider's behavior or reaction?** ● *If yes:* ○ **What was their reaction?** ○ **How did their reaction make you feel?** ● *If no:* ○ **Did you want to push back but felt that you couldn't?** ○ **Why**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**17**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the level of trust you have with this provider?** ● **Why did you give that score?**

Aim 3: How do asexual individuals describe their patient-provider relationship?	**18**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the level of respect you felt as a patient during this encounter?**	
		● **Why did you give that score?**	
Aim 3: How do asexual individuals describe their patient-provider relationship?	**19**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the provider's level of empathy?**	
		● **Why did you give that score?**	
Aim 3: How do asexual individuals describe their patient-provider relationship?	**20**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the quality of care you received from this encounter?**	
		● **Why did you give that score?**	
Aim 3: How do asexual individuals describe their patient-provider relationship?	**21**	**Did you ever share that you identify as Ace or under the Ace umbrella with your provider?**	
		● *If yes:*	
		○ **Can you tell me what your experience was like?**	
		○ **How did you feel?**	
		○ **What was your provider's reaction?**	
		○ *If they mentioned the provider is queer-friendly:* **Is your provider knowledgeable about asexuality?**	
		○ *If Negative:*	
		■ **Did you ever 'push back' about the provider's behavior/reaction?**	
		■ *If yes:*	
		○ **What was their reaction?**	
		○ **How did their reaction make you feel?**	
		■ *If no:*	
		○ **Did you want to push back but felt that you couldn't?**	
		○ **Why?**	
		● *If no:*	
		○ **Can you tell me why you did not share your identity with your provider?**	
		○ **Did anything else prevent you from sharing your identity with your provider?**	
Aim 3: How do asexual individuals	**22**	**Have you gone back to see this provider again?**	
		● *If yes:* **Did this experience impact your choice to see this provider again?**	

describe their patient-provider relationship?		● *If no:* **Did this experience impact your choice to NOT see this provider again?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?	**23**	**What do you wish this provider would have said or done differently to make your experience a better one?**
Thank you so much for sharing. I wanted to ask you a few more questions about this experience. I will start off with asking you about your experience finding this provider and then I will ask questions about the facility they work in.		
	24	**Can you tell me a little bit more about your <u>experience seeking this healthcare provider</u>? What was that like?**
		● *Probe:*
	25	○ **For this healthcare need, what qualities in a provider were you looking for?**
	26	○ **Did your ace identity play a role into the process of finding this provider?**
	27	○ **Do you feel that it is important to seek out queer-friendly providers?**
		■ *If yes:*
		○ **How important is it to you?**
	28	○ **Are queer-friendly providers accessible to you?**
		■ *Probe:*
		○ **Is the provider in your insurance network?**
		○ **Is it affordable to see this provider?**
	29	○ **Did you specifically seek out queer-friendly providers?**
		■ *If yes:*
		○ **How was that experience?**
		■ *If no:*
		○ **Why not?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?	**30**	○ **Were you able to find a queer-friendly provider?**
		■ *If yes:*
		○ **How was that experience trying to look for that provider?**
		○ **Is this provider in your insurance network?**
		○ **Is it affordable to see this provider?**
		○ **How long did it take you to find this provider?**

		○ **How was your visit with this provider?**
		○ **Were they knowledgeable about asexuality?**
		■ *If no:*
		○ **Can you tell me a little bit more about the challenges you faced trying to find a queer-friendly provider?**
		○ **Did you find a different provider that was not explicitly listed as queer-friendly for that specific health need?**
		● *If yes:*
		○ **How was the experience finding that provider?**
		○ **How long did it take you to find this provider?**
		○ **How was your visit with that provider?**
		○ **What led you to the decision of selecting this provider?**
		■ **Did you feel like you were settling for this provider?**
		○ *If yes:*
		● **How did that make you feel?**
	31	● **Did this provider meet the qualities of a provider you were looking for that you mentioned earlier?**
Now I would like to ask you some questions about the healthcare facility where you have visited this provider.		
	32	**Is this healthcare facility in an urban, suburban, or rural area?**
	33	**How would you describe this healthcare facility? For example, is it a private office, in a hospital, or urgent care?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?		**Do you remember what the intake forms looked like when you visited this provider?**
		● *Probe:* **Do you remember if these intake forms used inclusive language in terms of sexual and gender identity?**
		○ *If yes:*
		■ **How did that make you feel?**
		■ **Can you tell me what it looked like?**
		■ **Did the intake form explicitly mention asexuality?**
		○ *If no:*
		■ **How did that make you feel?**
	34	■ **What do you wish the intake form looked like?**
		Do you remember any flyers, posters, or signage posted around the facility?
	35	● *Probe:* **Do you remember what the flyers, posters, or signs were about?**

		○ **Can you tell me what they were about?**
		○ **Was any of that information related to sexual and gender identity?**
		■ **Was this a sign that indicated that this was a queer-friendly space?**
		■ **Was the language used on these flyers/posters/signage inclusive?**
		○ *If yes:*
		● **How did that make you feel?**
		● **Can you give me an example of what was said that made it inclusive?**
		● **Did this information explicitly mention asexuality?**
		○ *If yes:* **Can you tell me what was mentioned about asexuality?**
		○ *If no:*
		● **How did that make you feel?**
		● **What do you wish the flyers/posters/signs would have mentioned to make you feel welcome?**
		Do you remember receiving any health education materials when you visited?
		● *Probe:* **Do you remember what the educational material was about?**
		○ **Can you tell me what they were about?**
		○ **Was any of that information related to sexual and gender identity?**
		■ **Was the language used on these educational materials inclusive?**
		○ *If yes:*
		● **How did that make you feel?**
		● **Can you give me an example of what was said that made it inclusive?**
		● **Did this information explicitly mention asexuality?**
		○ *If yes:* **Can you tell me what was mentioned about asexuality?**
		○ *If no:*
		● **How did that make you feel?**
	36	● **What do you wish the educational materials included?**
HEALTHCARE EXPERIENCE AS AN ACE INDIVIDUAL: PROVIDER & SYSTEMS FOCUS (POSITIVE)		
Aim 1: What have been the experiences of asexual individuals	**37**	I appreciate you sharing your negative experience. **Now I would like to know about a POSITIVE healthcare encounter you had. Does one experience come to mind?**

when receiving healthcare?		
Thank you for sharing your story. I am glad to hear that you had a pleasant experience. I would like to ask you a few more questions about this provider and the interaction you had with them.		
	38	**What type of healthcare does this provider give?**
	39	**How long have you been seeing this provider?**
	40	**How often do you visit this provider?**
	41	**Would you be willing to share approximately how many years ago this experience took place?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**42**	**Besides what you shared earlier, was there anything else the provider said or did that made you feel comfortable?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**43**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the level of trust you have with this provider?** ● **Why did you give that score?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**44**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the level of respect you felt as a patient during this encounter?** ● **Why did you give that score?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**45**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the provider's level of empathy?** ● **Why did you give that score?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**46**	On a scale of 0 being extremely low to 10 being extremely high, **How would you describe the quality of care you received from this encounter?** ● **Why did you give that score?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**47**	**Did you ever share that you identify as Ace or under the Ace umbrella with your provider?** ● *If yes:* ○ **Can you tell me what your experience was like?** ○ **How did you feel?** ○ **What was your provider's reaction?** ○ *If they mentioned the provider is queer-friendly:* **Is your provider knowledgeable about asexuality?** ○ *If Negative:* ■ **Did you ever 'push back' about the provider's behavior/reaction?**

		■ *If yes:*
		○ **What was their reaction?**
		○ **How did their reaction make you feel?**
		■ *If no:*
		○ **Did you want to push back but felt that you couldn't?**
		○ **Why?**
		● *If no:*
		○ **Can you tell me why you did not share your identity with your provider?**
		○ **Did anything else prevent you from sharing your identity with your provider?**
Aim 3: How do asexual individuals describe their patient-provider relationship?	**48**	**Have you gone back to see this provider again?**
		● *If yes:* **Did this experience impact your choice to see this provider again?**
		● *If no:* **Why not?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?	**49**	**Besides what you shared earlier, is there anything else your provider said or did that made you feel welcomed?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?	**50**	**Is there anything you wish your provider said or done to make you feel more welcome?**
Thank you so much for sharing. I wanted to ask you a few more questions about this experience. Again, I will start off with asking you about your experience finding this provider and then I will ask questions about the facility they work in.		
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?	**51**	**Can you tell me a little bit more about your <u>experience seeking this healthcare provider</u>? What was that like?**
		● *Probe:*
	52	○ **For this healthcare need, what qualities in a provider were you looking for?**
	53	○ **Did your ace identity play a role into the process of finding this provider?**

		○ **Do you feel that it is important to seek out queer-friendly providers?**
		■ *If yes:*
	54	○ **How important is it to you?**
		○ **Are queer-friendly providers accessible to you?**
		■ *Probe:*
		○ **Is the provider in your insurance network?**
	55	○ **Is it affordable to see this provider?**
		○ **Did you specifically seek out queer-friendly providers?**
		■ *If yes:*
		○ **How was that experience?**
		■ *If no:*
	56	○ **Why not?**
		○ **Were you able to find a queer-friendly provider?**
		■ *If yes:*
		○ **How was that experience trying to look for that provider?**
		○ **Is this provider in your insurance network?**
		○ **Is it affordable to see this provider?**
		○ **How long did it take you to find this provider?**
		○ **How was your visit with this provider?**
		○ **Were they knowledgeable about asexuality?**
		■ *If no:*
		○ **Can you tell me a little bit more about the challenges you faced trying to find a queer-friendly provider?**
		○ **Did you find a different provider that was not explicitly listed as queer-friendly for that specific health need?**
		● *If yes:*
		○ **How was the experience finding that provider?**
		○ **How long did it take you to find this provider?**
	57	○ **How was your visit with that provider?**
		○ **What led you to the decision of selecting this provider?**
		■ **Did you feel like you were settling for this provider?**
		○ *If yes:*
	58	● **How did that make you feel?**

		● Did this provider meet the qualities of a provider you were looking for that you mentioned earlier?
Now I would like to ask you some questions about the healthcare facility where you have visited this provider.		
	59	**Is this healthcare facility in an urban, suburban, or rural area?**
	60	**How would you describe this healthcare facility? For example, is it a private office, in a hospital, or urgent care?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?	**61**	**Do you remember what the intake forms looked like when you visited this provider?**
		● *Probe:* **Do you remember if these intake forms used inclusive language in terms of sexual and gender identity?**
		○ *If yes:*
		■ How did that make you feel?
		■ Can you tell me what it looked like?
		■ Did the intake form explicitly mention asexuality?
		○ *If no:*
		■ How did that make you feel?
		■ What do you wish the intake form looked like?
	62	**Do you remember any flyers, posters, or signage posted around the facility?**
		● *Probe:* **Do you remember what the flyers, posters, or signs were about?**
		○ **Can you tell me what they were about?**
		○ **Was any of that information related to sexual and gender identity?**
		■ Was this a sign that indicated that this was a queer-friendly space?
		■ Was the language used on these flyers/posters/signage inclusive?
		○ *If yes:*
		● How did that make you feel?
		● Can you give me an example of what was said that made it inclusive?
		● Did this information explicitly mention asexuality?
		○ *If yes:* **Can you tell me what was mentioned about asexuality?**
		○ *If no:*
		● How did that make you feel?
		● What do you wish the flyers/posters/signs would have mentioned to make you feel welcome?

		Do you remember receiving any health education materials when you visited?
		● *Probe:* **Do you remember what the educational material was about?**
		○ **Can you tell me what they were about?**
		○ **Was any of that information related to sexual and gender identity?**
		■ **Was the language used on these educational materials inclusive?**
		○ *If yes:*
		● **How did that make you feel?**
		● **Can you give me an example of what was said that made it inclusive?**
		● **Did this information explicitly mention asexuality?**
		○ *If yes:* **Can you tell me what was mentioned about asexuality?**
		○ *If no:*
		● **How did that make you feel?**
	63	● **What do you wish the educational materials included?**

Thank you so much for sharing a negative and a positive healthcare experience. Besides what you have shared earlier about both experiences, I would like to ask in general.

Aim 3: How do asexual individuals describe their patient-provider relationship?		**Has a provider ever put you in a position where you did not feel comfortable sharing health information because you are ace?**
		● *If yes:*
		○ **Can you tell me what they did or said that made you feel this way?**
	64	○ **What do you wish they would have said or done to make you feel comfortable sharing with them that you identify as ace?**
Aim 3: How do asexual individuals describe their patient-provider relationship?		**Did you feel that you had to lie about your health because talking about it would mean that you had to share that you identify as ace?**
		● *If yes:*
		○ **Can you tell me a little bit more about that moment?**
	65	○ **Can describe how you felt in that situation?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?	**66**	In general, **what do you wish healthcare professionals would do to make it comfortable for you as an Ace individual to receive healthcare?**

HEALTHCARE EXPERIENCE: IDENTITY FOCUS		
Thank you so much for sharing. Now, I will now ask you some more general questions about your healthcare experiences in relation to your identity. For the first set of questions, I would like for you to think about your ace identity.		
Aim 2: Does a person's asexual identity influence healthcare-seeking behavior?	**67**	**Do you feel that your ace identity is important to your healthcare?**
Aim 2: Does a person's asexual identity influence healthcare-seeking behavior?		**Does identifying as Ace ever influence your decision to seek healthcare?**
	68	● *If yes:* **Can you elaborate?**
		Are there any areas of healthcare where you think it is important for your provider to be knowledgeable about asexuality?
		● *If yes:*
		○ **Can you tell me which ones?**
	69	○ **Can you tell me why you think it is important for them to be knowledgeable about it?**
		On the other hand, are there any areas of healthcare where you think it is not important for your healthcare providers to be knowledgeable about asexuality?
		● *If yes:*
		○ **Can you tell me which ones?**
	70	○ **Can you tell me why you think it is not important for them to be knowledgeable about it?**
Thank you so much for sharing. For the next set of questions, I would like for you to think about all of the identities that are important to your healthcare, like sexual, gender, racial, ethnic, cultural, religious, and disability identities.		
	71	**What identity or identities do you feel is most relevant to your healthcare?**
		● **As a [identity/identities the participant identifies as most relevant], how would you describe your overall experience seeking healthcare?**
		○ **Can you tell me more about that, about what makes your experience [good/bad/neutral?].**
		○ **Can you give me an example that would best describe that experience?**
		■ **Do you face any challenges seeking healthcare as [indicated identity/identities]?**
	72	○ *If yes:* **Can you tell me a little more about your experience?**

		● As a [identity/identities the participant identifies as most relevant], how would you describe your overall experience receiving healthcare?
		○ Can you tell me more about that, about what makes your experience [good/bad/neutral?].
		○ Can you give me an example that would best describe that experience?
		■ Do you face any challenges receiving healthcare as [indicated identity/identities]?
		○ *If yes:* **Can you tell me a little more about your experience?**
	73	**○ Did you feel that your provider was knowledgeable about your [indicated] identity/identities?**
Aim 4: Do asexual individuals have ideas about improvements in healthcare to make healthcare more welcoming to self-identifying asexual individuals?		**What do you wish healthcare professionals would do to make it comfortable for you as an [identity/identities] individual to receive healthcare?**
	74	**● Do you have any ideas of what healthcare professionals or facilities can do to make this possible? These can be ideas for provider training or improving healthcare spaces.**
CONCLUSION		
I have one last question for you.		
	75	**Is there anything else you would like to share that we have not touched on regarding your healthcare experience?**

Appendix H: Member Checking

File Name: Participant ID # - Follow-Up

Participant ID: 12345

Follow-Up

Thank you again for participating in the study! Just so that I have correctly understood your experience, I wanted to share a few bullet points of what I gathered from our conversation.

Please find the summary I have created below. I would appreciate it if you could let me know if:

1) the summary points that I have made match your experience
2) there is anything you wanted to change, and
3) there is something I missed that you would like to add.

Please go ahead and make any changes and add your thoughts to your document.

Note: To ensure your confidentiality, please do not share this Google Doc link with anyone else.

Summary:

- Insert bullet points

Appendix I: Mental Health Resources

Resources List Collected from the Ace Community Survey Resources

Global

Befrienders Worldwide
https://www.befrienders.org/

IMALIVE
https://www.imalive.org/

7 Cups of Tea
https://www.7cups.com/

Find a Helpline
https://findahelpline.com/

Your Life Counts
https://yourlifecounts.org/find-help/

LetsConnect
https://letsconnectproject.com/

International Helplines:
https://togetherweare-strong.tumblr.com/helpline

United States

National Suicide Prevention Lifeline
1-800-273-8255 (English) [988 as of July 16, 2022, although 1-800-273-8255 will always remain available even after 988 is launched]
1-888-628-9454 (Spanish)
1-800-273-8255 (Video Relay Service)
1-800-799-4889 (TTY)
1-800-273-8255 (Voice/Caption Phone)
https://www.suicidepreventionlifeline.org/chat/ (Chat)

The Trevor Project
The Trevor Project is a phone and internet chat hotline for LGBTQ people, whose volunteers receive training on asexuality.
1-866-488-7386
https://www.thetrevorproject.org/get-help/

Trans Lifeline
(877) 565-8860

https://www.translifeline.org/

National Human Trafficking Hotline 1-888-272-7888
National Sexual Violence Resource Center 1-877-739-3895
National Center for Missing & Exploited Children 1-800-THE-LOST(843-5678)
Cyber Civil Rights Initiative 1-844-878-2274
FBI Internet Crime Complaint Center 1-800-CALL-FBI (225-5324)

NAMI (National Alliance on Mental Illness) HelpLine
1-800-950-NAMI (6264)
helpline@nami.org
https://www.nami.org/help

Crisis Text Line
741741
https://www.crisistextline.org/

Teen Line
800-852-8336
839863
https://www.teenline.org/

SAGE National LGBT Elder Hotline
877-360-LGBT(5428)
https://www.sageusa.org/what-we-do/sage-national-lgbt-elder-hotline/

Games and Online Harassment Hotline
23368
https://gameshotline.org/

National Domestic Violence Hotline
800-799-SAFE (7233)
88788
https://www.thehotline.org/

National Sexual Assault Hotline
800.656.HOPE (4673)
https://hotline.rainn.org/online
https://www.rainn.org/

1in6 National Helpline
https://1in6.org/

Lifeline (National Suicide Prevention Line)
1-800-273-8255
https://suicidepreventionlifeline.org/

Appendix J: Participant Identity Data

	Pseudonym	Pronouns	Age	Gender Identity	Sexuality Identity	Romantic Identity	Race/Ethnicity	Highest Level of Education	Employed?
1	Amber	She/Hers	28	Female	Asexual, Sex Positive		East Asian/Chinese	Bachelors	Yes
2	Amethyst	Any/All	19	Any/All	Aromantic Asexual	Aromantic	White/White	Currently in college	Yes
3	Aspen	She/Her	27	Female	Asexual		White/White	High School	Yes
4	Aurora	He/Him/His	22	Male, but don't fit the stereotypes	Demisexual		White/Non-Hispanic Latino	Associates, working on Bachelors	Yes
5	Autumn	They/Them	33	Agender, but AFAB	Greyromantic Asexual	Greyromantic	Biracial, half White half Black/American	Doctorate	Yes, Pharmacist
6	Brook	She/Her	20	Female	Asexual		White/Non-Hispanic Latino	2 years of college	Yes, Daycare
7	Camellia	She/Her	25	Female	Asexual		Caucasian, White/Same	Some college	Yes, self-employed
8	Clover	She/Her/Hers	22	Cis Woman	Aromantic Asexual	Aromantic	White/White, somewhere in Europe	Bachelors, working on Masters	Yes
9	Coral	They/Them	20	AFAB but Gender-Queer	Asexual		White, Caucasian/US	High School working on Bachelors	No
10	Delta	She/They	24	Genderqueer	Asexual		Asian American, born in China/Chinese	Masters	Yes
11	Diamond	He/Him (No preference)	23	Male, but not picky	Asexual		White/White, 7th generation Irish American	High School	Yes
12	Emerald	She/Her	20	Cis Female	Aromantic Asexual	Aromantic	Caucasian/American	Associates, working on Bachelors	Yes
13	Everest	She/Her	18	Cis Gender [Woman]	Asexual		Filipino-American/Asian Filipino	High. school working on Bachelors	No
14	Gale	She/Her	32	Woman	Asexual/Pansexual	Panromantic	Asian; First Generation Canadian Indo-Caribbean/Indian Middle Eastern Caribbean mix	Graduate Degree	Yes
15	Galena	She/They	21	Non-Binary	Asexual/Changes, sometimes ace	Aromantic	White, European, German, Poland, Scotland,	Some college	Yes

					sometimes aegosexual		Ireland/European American		
16	Hazel	She/Her	25	Cis woman	Asexual		White/European	Bachelors	Yes, full time
17	Holly	She/They	34	Agender	Asexual		White	Masters	Yes
18	Ivy	He/Him	30	Male	Asexual Heteroromantic	Heteroromantic	White/White	Bachelors	Yes
19	Jade	She/Her	38	Female	Ace		White/American	Masters	Yes
20	Juniper	She/Her	23	Female	Asexual	Aromantic	African American	High School	Yes
21	Laurel	He/They	18	Agender	Asexual		Mixed/Mixed	High School	No
22	Lavender	She/They	18	Female	Demisexual		Asian/Southeast Asian	High School, working on Bachelors	No
23	Lotus	She/Her	39	Female	Ace		Armenian	Bachelors	Yes
24	Maple	She/Her	29	Cis Female	Asexual, somewhere in the spectrum	Heteroromantic, but currently questioning	White/Scottish, Irish, Italian, Sicilian	Bachelors, working on Masters	No
25	Marine	She/Her	27	Female	Heteroromantic Asexual	Heteroromantic	American/German	Masters	Yes
26	Mist	She/Her	19	Female	Queer Asexual		Caucasian/Italian	High School	Yes
27	Nova	She/Her	32	Female	Aromantic Asexual	Aromantic	White Caucasian/Non Hispanic	Bachelors, some graduate	Yes
28	Ocean	He/They	27	Between male and Agender	Ace and Gay	Homoromantic	White/Mixed, Ashkenazi Jew, Cherokee, other Caucasian mix	Bachelors	Yes, part time
29	Onyx	He/Him	33	Male	Asexual spectrum		Black American/Non hispanic Latino	Bachelors	Yes
30	Opal	They/Them	26	Non-Binary	Asexual, grey ace		Half White Half Filipino/Non Hispanic Latino	Bachelors	Yes
31	Orchid	She/Her	29	Cis Female	Asexual	Aromantic	White/White	Masters	Yes
32	Rain	They/Them	23	AFAB, non-binary	Greyromantic Asexual	Greyromantic	White/German, English	Bachelors	Yes
33	Ray	She/Her	24	Cis Female	Asexual		White/Jewish, Slavic	Bachelors, working on Masters	Yes
34	Rosemary	She/They	22	Female	Aromantic Asexual	Aromantic	Middle Eastern/Middle Eastern	Bachelors	No
35	Ruby	She/They	30	Female, demigirl	Ace (sort of feels like an asterisk)		White/Western European, British, Welsh	Some graduate school	No
36	Sky	She/Her	32	Female, woman	Grey Asexual or demisexual		White/Caucasian	High school, some college	Yes

37	Star	She/Her	32	Cis gender, use she/her pronouns	Asexual	Aromantic	White/Western European American	Bachelors	Yes
38	Storm	She/Her	24	Female	Asexual		Half Mexican, Half Portuguese/Hispanic Latino	Bachelors	No
39	Summer	She/Her	25	Female	Asexual panromantic		White, Caucasian/American	Masters	No
40	Topaz	They/Them	27	Non-Binary, Trans	Demisexual, demipanromantic	Demipanromantic	Asian/Chinese	Bachelors	Yes
41	Umbra	She/Her	26	Female	Asexual		White/Caucasian	Bachelors	Yes
42	Willow	She/Her	27	Female	Ace		Half Chinese Half White	Bachelors	Yes
43	Winter	She/Her	47	Female	Ace		White/Lithuanian, Polish, Greek	Masters	Yes

Appendix K: Codebook

Healthcare Journey	Code Categories		Codes	Definition	Source
PRE-HEALTHCARE INTERACTION	***FACTORS THAT INFLUENCE SEEKING HEALTHCARE***	***Institutional Factors***	Affordability	Any mention of cost of healthcare services or insurance.	*Inductive Code*
			Access to/Availability of Healthcare	When participants discuss the availability and or accessibility of healthcare providers or services within their vicinity.	*Inductive Code*
HEALTHCARE INTERACTION	***PROVIDER ATTRIBUTES***	***Knowledge***	LGBTQ Affirmative Knowledge	Providers giving information that reflect knowledge of LGBTQ health	*Johnson & Nemeth (2014) Rossman, Salamanca, & Macapagal (2017)*
			Lack of LGBTQ Knowledge	Providers indicating that they have a lack of knowledge of LGBTQ health	*Johnson & Nemeth (2014) Rossman, Salamanca, & Macapagal (2017)*
			Knowledgeable About Asexuality	Participants share that their providers are explicitly knowledgeable about asexuality.	*Inductive Code*
			Lack of Knowledge About Asexuality	Participants share that their providers are not knowledgeable about asexuality.	*Inductive Code*
			Managing the Emotions	The ability to be aware of his/her emotions and control them	*Razzaghi & Afshar (2016)*
			[Open] Mindfulness	The ability to consider the internal and external forcible factors	*Razzaghi & Afshar (2016)*
			Scientific Knowledge	The physician's expert knowledge	*Razzaghi & Afshar (2016)*
		Communication	Comfortable	Providers indicate their comfort with patient disclosure	*Johnson & Nemeth (2014) Rossman, Salamanca, & Macapagal (2017)*
			Uncomfortable	Providers indicate their discomfort with patient disclosure	*Johnson & Nemeth (2014) Rossman, Salamanca, & Macapagal (2017)*
			Positive Reaction	Patients feel that providers reacted positively to disclosure	*Rossman, Salamanca, & Macapagal (2017)*

			Absence of Reaction	Provider did not react to patient disclosure	*Rossman, Salamanca, & Macapagal (2017)*
			Microaggressions	Providers indicate negative feelings about LGBTQ identity through verbal or nonverbal communication	*Rossman, Salamanca, & Macapagal (2017)*
			Provider LGBTQ Identified	Providers were also LGBTQ identified	*Rossman, Salamanca, & Macapagal (2017)*
			Queer-Friendly	Any discussion of queer-friendly. Applicable to providers explicitly sharing they are queer-friendly, procedures/services/treatment, or office signage.	*Inductive Code*
			[Active Listening] Effective Presence	Effective listening, appreciating the patient's experience of illness and empathy	*Razzaghi & Afshar (2016)*
		Attitude [Conveyed Through Communication]	Acceptance | Non-judgmental Behavior	Providers behave in an accepting manner after disclosure	*Rossman, Salamanca, & Macapagal (2017) Razzaghi & Afshar (2016)*
			Professionalism	Providers behave in a professional manner attitude after disclosure	*Rossman, Salamanca, & Macapagal (2017)*
			Respect	Providers behave in a respectful manner after disclosure	*Rossman, Salamanca, & Macapagal (2017)*
			Empathy	Discussion of the level of empathy patients felt their providers displayed.	*Inductive Code*
			Friendliness	Providers behave in a friendly manner after disclosure	*Rossman, Salamanca, & Macapagal (2017)*
			[Unprofessional or] Discriminatory Actions	Providers behave in a[n unprofessional or] discriminatory manner following disclosure	*Rossman, Salamanca, & Macapagal (2017) Inductive Code*
	PATIENT-PROVIDER RELATIONSHIP		Shared Decision-making	Engaging patients in diagnostic and therapeutic decision-making	*Razzaghi & Afshar (2016)*
			Educating the Patient [Informed Care]	Explaining medical terminology in an understandable language for the patient and educating them to follow the care tasks	*Razzaghi & Afshar (2016)*

				Guidance	Using authority to encourage the patient to follow medical advice. [Empowering patients to make decision and respecting the autonomy of their decision].	*Razzaghi & Afshar (2016)*
				Trust	Discussion of the level of trust patients felt with their providers.	*Inductive Code*
OUTCOMES	***OUTCOME FROM HEALTHCARE INTERACTION***	***Proximal Outcomes***		Knowledge Seeking Behavior	Proximal outcomes are the participants' behavior or reaction that occurred after the patient-provider interaction | i.e. seeking knowledge from the internet because their provider did not have asexual-specific knowledge, or they felt uncomfortable asking questions	*Johnson & Nemeth (2014)*
				Health Care Seeking Behavior	Changing their health care seeking behavior after a poor quality healthcare interaction	*Johnson & Nemeth (2014)*
				Disguise Sexual Orientation	Disguise SOGI from providers	*Johnson & Nemeth (2014)*
				Change Provider	Finding different providers	*Johnson & Nemeth (2014)*
APPLIES TO ALL POINTS IN THE HEALTHCARE JOURNEY	***PATIENTS' EXPECTATIONS***	***Seeking Healthcare***		Motivation for Seeking Healthcare	Participants discuss the reason they sought healthcare. Examples include for seeking treatment or support, for preventative healthcare, or they were taken to seek services by guardians because they were a minor at the time of the experience shared.	*Inductive Code*
				Decision for Selecting Provider	Participant discuss what lead to the decision of selecting the provider for their healthcare.	*Inductive Code*
		Healthcare Interaction | Disclos	*Provider Factors in Non-Disclosure*	Lack of Inquiry	Providers not asking about LGBTQ identity	*Rossman, Salamanca, & Macapagal (2017)*
				Provider/Patient Relationship	Factors in the patient/provider	*Rossman, Salamanca, & Macapagal (2017)*

		ure of SOGI			relationship that impact disclosure	
			Resistance to Disclosure	Discretion	Reason for non-disclosure was that LGBTQ identity was personal information	*Rossman, Salamanca, & Macapagal (2017)*
				Stigma	Reason for non-disclosure was concerns of negative reactions from providers	*Rossman, Salamanca, & Macapagal (2017)*
				Ambivalence	Patients were unsure of their reasons for not disclosing	*Rossman, Salamanca, & Macapagal (2017)*
				Conditional Disclosure	Patients indicated that they would disclose identity under certain circumstances	*Rossman, Salamanca, & Macapagal (2017)*
			Other Reasons for Non-Disclosure	Not Being Truthful About Sexuality	Participants discussed not being truthful to providers about their sexuality when prompted about their SOGI.	*Inductive Code*
				I Didn't Know I Was Ace	Participants shared that although their healthcare experience related to their ace identity, they did not identify as ace or they did not know about asexuality at the time.	*Inductive Code*
				Not Relevant	Patients indicate that their identity is not relevant to their health	*Rossman, Salamanca, & Macapagal (2017)*
			Patient Expectations of Providers	Lack of Negative Reaction	Patients reflect that providers react in a negative way to disclosure	*Rossman, Salamanca, & Macapagal (2017)*
		Outcome from Healthcare Interaction		Quality of Care	Participants described the quality of care they have received from their providers. Includes the discussion of whether participants were satisfied with their care.	*Inductive Code*
	IDEAS FOR IMPROVEMENT			Provider-Level Improvements	Participants share ideas they had about improvements about provider training that can be made in healthcare to make healthcare more welcoming to them.	*Inductive Code*

		Office-Level Improvements	Participants share ideas they had about improvements that can be made in healthcare facilities to make healthcare more welcoming to them.	*Inductive Code*
		Procedural/Practice Improvements	Participants share ideas they had about improvements that can be made to procedures and healthcare practices to make healthcare more welcoming to them.	*Inductive Code*
		Institutional/Societal-Level Improvements	Participants share ideas they had about policies and institutional-level changes that can be made in healthcare to make healthcare more welcoming to them.	*Inductive Code*
		Identity	When participants discuss the ways in which any aspect of their personal identity relates to their healthcare experience and at any point during their healthcare journey. Includes the discussion of gender, sex, sexuality, race, ethnicity, disability, and health identities.	*Inductive Code*
		Intersectionality	Any discussion of how the intersecting of identities played a role in participants' healthcare journey experience.	*Inductive Code*
	IDENTITY AND HEALTHCARE	Health Information Disclosure and Asexuality	Participants shared if their Asexual identity played a role during the disclosure of health information.	*Inductive Code*
		Negative Experience	All mention of negative experience at any point in the healthcare journey.	*Inductive Code*
		Positive Experience	All mention of positive experience at any point in the healthcare journey.	*Inductive Code*
	TYPE OF EXPERIENCE	Neutral Experience	All mention of neutral experience at	*Inductive Code*

				any point in the healthcare journey.	
			When Experience Occurred	Placement code used to describe when healthcare experience took place.	*Inductive Code*
			Visiting Provider Frequency	Placement code used to describe how often participants visit the provider described in their experience.	*Inductive Code*
		Time-Related	Visiting Provider Duration	Placement code used to describe how long participants for how long they visited the provider or obtained healthcare services from recounting their experience.	*Inductive Code*
			Locale Classification	Used to describe the type of locale participant obtained services. Divided into Urban, Suburban, and Rural classification.	*Inductive Code*
			Geographic Location	When participants identify specific geographic location (i.e. state) they obtained healthcare.	*Inductive Code*
		Location	Type of Facility	Used to describe the type of facility participant obtained services. Include hospital, clinic, or urgent care.	*Inductive Code*
			Intake	Any discussion of intake forms or intake sessions with providers.	*Inductive Code*
			Signage	Any discussion of signage around healthcare facility. This includes signs, posters, flags, etc.	*Inductive Code*
	DESCRIPTIVE CODES	***Items***	Health Education Materials	Any discussion of health education materials available in the facility. Includes discussion of brochure display or participants being explicitly given education materials by providers.	*Inductive Code*

			Procedure or Treatment	When participants discuss types of procedures or treatments they underwent. Examples include pelvic exams, hysterectomies, being screened for depression, and being prescribed medication like birth control.	*Inductive Code*
			Insurance	Any discussion of health insurance in relation to healthcare experience.	*Inductive Code*
			Type of Provider(s) Visited - Grounding Question	Used for descriptive measures to tabulate the various types of providers participants visit for their healthcare.	*Inductive Code*
			Type of Provider(s) Visited - Experience	Used for descriptive measures to tabulate the types of providers participants interacted with when recounting their healthcare experiences.	*Inductive Code*
			Demographics	Used for descriptive measures to describe participants. Race, ethnicity, gender, sexuality, level of education, employment, and additional characteristics were recorded.	*Inductive Code*
			What it Means to be Ace?	Used for descriptive measures to describe how participants defined being an ace individual.	*Inductive Code*
			Providers that Need to Know About Asexuality	Used for descriptive measures to tabulate the types of providers participants believe should be knowledgeable about asexuality.	*Inductive Code*
		Used for Descriptive Statistics	Providers that Do Not Need to Know About Asexuality	Used for descriptive measures to tabulate the types of providers participants believe do not need to be knowledgeable about asexuality.	*Inductive Code*

		Patient's Feeling/Reaction(s)	When participants described their reactions and/or feelings anytime during their healthcare journey.	*Inductive Code*
		Ideal	Any data relating to ideal condition or context. Examples include when participant describe an ideal healthcare interaction, provider attribute, intake form, etc.	*Inductive Code*
	OTHER UNCATEGORIZED CODES	Interesting Quote	Interesting quote to be used in the writing	*Inductive Code*

Appendix L: Pilot Study Interview Schedule

INTERVIEW QUESTIONS

As you know, the purpose of this study is to find out more about your healthcare experiences as an Ace-identifying individual. I wanted to start out our discussion more generally.

Can you tell me a story of a healthcare encounter you had that had an impact on you, or that stands out to you in your mind?

> **Is this provider someone you have been seeing for some time? Or was this encounter with someone you met for the first time?**
>
> Thank you for sharing your story. **It sounds like your experience was [positive/negative]. Did you ever share that you identify as Ace or under the Ace umbrella with your provider?**
>
> > *If yes:* **Can you tell me what your experience was like? How did you feel? What was your provider's reaction? How did their reaction make you feel?**
> >
> > *If no:* **Can you tell me why you did not share your identity with your provider? What prevented you from sharing your identity with your provider?**
>
> I appreciate you sharing your [positive/negative] experience. **Now I would like to know about a [opposite experience: positive/negative] healthcare encounter you had. Does a [positive/negative] experience come to mind?**
>
> > **Is this provider someone you have been seeing for some time? Or was this encounter with someone you met for the first time?**
> >
> > > Thank you for sharing your story. During this encounter, **did you ever share that you identify as Ace or under the Ace umbrella with your provider?**
> > >
> > > > *If yes:* **Can you tell me what your experience was like? How did you feel? What was your provider's reaction? How did their reaction make you feel?**
> > > >
> > > > *If no:* **Can you tell me why you did not share your identity with your provider? What prevented you from sharing your identity with your provider?**

Does identifying as Ace ever influence your decision to seek healthcare?

> *If yes:* **Can you elaborate?**

In addition to the experience you were kind enough to share, is there any aspect of the healthcare system that invalidates your experience as an Ace individual?

To follow up on that question, **is there any aspect of the healthcare system that validates your experience as an Ace individual?**

What do you wish healthcare professionals would do to make it comfortable for you to receive healthcare?

Before we wrap up our conversation, I would like to get to know a little more about you. I will be asking you a few demographic questions. This is because it would be helpful for me to know about the backgrounds of the folks who participated in the study. If you do not feel comfortable answering any of the following questions, please let me know so we can skip them.

What is your racial identity?

What is your ethnic identity?

What is your gender identity?

What is your sexual identity?

What is the highest degree or level of school you have completed?

What is your employment status?

And, that is it! Thank you so much for taking the time to speak with me today and for sharing your experience, I really appreciate it! **Is there anything else you would like to share that we have not touched on regarding your healthcare experience?**

Thank you. I will now stop the recording, but please stay on so I can verify your email address for the gift card.

Appendix M: Email Templates

Eligibility Survey Follow-Up: Eligible

SUBJECT: We look forward to your participation in the research study!

Dear [insert name],

Thank you for completing the Research Eligibility Survey for a study by Teachers College, Columbia University. You are receiving this email because you are eligible to participate in the research study.

If you still are interested in participating, I would like to arrange a time to have an interview with you. Please use your personal link [Calendly link] to schedule a 45-minute timeslot. To ensure your confidentiality, we have created this unique link specific to you, so please do not share it with others. If you do not find a convenient time available, please do not hesitate to reach out to me so we can arrange a better time.

Also, please find a link to the "Informed Consent Form" attached to this email. In this document, you will find more details about this study. Please be sure to review this document before our interview session so you are well-informed about this study before you verbally consent to participate. If you have any questions before our interview session, please do not hesitate to contact me.

I appreciate your time and consideration! Please feel free to reach out to me at any time by email at mmm2419@tc.columbia.edu.

Thank you again for your interest in the study. I look forward to speaking with you soon!

Best regards,

Mohima Meera, M.A.Ed.
Principal Investigator
mmm2419@tc.columbia.edu

Thank You for Scheduling An Interview

SUBJECT: Thank you for scheduling an interview!

Dear [insert name],

Thank you for scheduling a Zoom interview with me for a research study from Teachers College, Columbia University. Our interview session will be on [date] [time] [time zone].

Please log in using this [Zoom link] at our scheduled interview time.

Also, please find the link to an "Informed Consent Form" attached to this email for your review. As a reminder, please be sure to review this document before our interview session so you are well-informed about this study before you verbally consent to participate. If you have any questions before our interview session, please do not hesitate to contact me.

If your availability changes, you can reschedule using your personal [Calendly link]. As a reminder, to ensure your confidentiality, please do not share this link with anyone.

I appreciate your time and consideration! If you have any questions, please feel free to reach out to me at any time by email at mmm2419@tc.columbia.edu.

Thank you again for your time and consideration. I look forward to speaking with you soon!

Best regards,

Mohima Meera, M.A.Ed.
Principal Investigator
mmm2419@tc.columbia.edu

Interview Reminder Email

SUBJECT: Research Interview Reminder: Speak with you soon!

Dear [insert name],

Thank you again for scheduling a Zoom interview with me for the research study from Teachers College, Columbia University. This is a friendly reminder that our interview session will be on [date] [time] [time zone] via Zoom.

Please log in using the Zoom link, found at the bottom of this email, at our scheduled interview time.

If you need to reschedule, please use your personal Calendly link, located at the bottom of this message, for a more convenient time.

As a reminder, please be sure to review the "Informed Consent Form" [insert link] before our interview session so you are well-informed about this study before you verbally consent to participate.

I appreciate your time and consideration. After completing our interview, you will receive $50 in appreciation for your time.

Please do not hesitate to contact me if you have any questions. My email address is mmm2419@tc.columbia.edu.

I look forward to speaking with you soon!

Best regards,

Mohima Meera, M.A.Ed.
Principal Investigator
mmm2419@tc.columbia.edu

Interview Cancellation Email

SUBJECT: Sorry you had to cancel!

Dear [insert name],

I have noticed that you had to cancel our interview session for the research study from Teachers College, Columbia University, which was scheduled for [date] [time] [time zone]. I appreciate your interest in the study and I understand that schedules change. Because of your initial interest, you are still eligible to participate in this study.

You can use your personal [Calendly link] to reschedule your interview for a more convenient time. If you prefer, you are welcome to contact me directly at mmm2419@tc.columbia.edu to reschedule, or if you have any questions related to this study.

Thank you,

Best regards,

Mohima Meera, M.A.Ed.
Principal Investigator
mmm2419@tc.columbia.edu

Interview No-Show Email

SUBJECT: Sorry I missed you!

Dear [insert name],

Sorry I missed you for our interview session on [date] [time] [timezone] about the research study from Teachers College, Columbia University. I understand that last-minute conflicts can happen.

I still look forward to speaking with you. Because of your initial interest in the study, you are eligible to participate in this study. Please use your personal [Calendly link] to reschedule your interview for a more convenient time. If you prefer, you are welcome to contact me directly at mmm2419@tc.columbia.edu to reschedule, or if you have any questions related to this study.

Thank you,

Best regards,

Mohima Meera, M.A.Ed.
Principal Investigator
mmm2419@tc.columbia.edu

Post-Interview Survey

SUBJECT: Thank you for your participation! & Action Items

Dear [insert name],

Thank you for participating in the research study from Teachers College, Columbia University! It was a great pleasure speaking with you and learning about your experience.

Just so that I have correctly understood your experience, I wanted to share a few bullet points of what I gathered from our conversation. Please use this link to a secure Google Doc [insert link to Google Doc] to find the summary. **I would appreciate it if you could let me know if, 1) the summary points that I have made match your experience, 2) if there is anything you wanted to change, and 3) if there is something I missed that you would like to add.** Please use this Google Doc to add your thoughts. To ensure your confidentiality, please do not share this link with anyone else.

In addition, I would appreciate it if you could take a moment to complete a **Post-Interview Feedback Survey** [insert link to Google Forms survey]. I would like to get your honest feedback on ways I can improve the research interview.

As a token of my appreciation for your time and support, you should have received $50 via [participant's preferred method of payment, i.e. Zelle or Venmo]. **Please let me know if you have NOT received the $50.**

Once again, I sincerely appreciate your time and support. If you have any questions about this study, please feel free to contact me at my email address mmm2419@tc.columbia.edu.

Thank you,

Mohima Meera, M.A.Ed.
Principal Investigator
mmm2419@tc.columbia.edu