Understanding the Dynamics of Informal, Community-Based Care Among LGBTQ2+ Young Adults in Southwestern Ontario

by
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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Background: Historically, North American health care has been developed through predominantly a hetero- and cis-normative, and white, lens which has led to the social exclusion of LGBTQ2+ individuals through institutional heterosexism, racism, homophobia, and transphobia (Brotman, Ferrer, Sussman, Ryan, & Richard, 2015; Gahagan & Colpitts, 2017; Hudson & Romanelli, 2019; Pepper, 2015; Warner, 2002). Non-inclusive health care services have the potential to compromise the well-being LGBTQ2+ young adults and influence their willingness to seek health care services, which can lead to additional adverse health outcomes (Burch, 2008; Gahagan & Colpitts, 2017; Hudson & Romanelli, 2019; Zay Hta et al., 2021). Emerging research presents evidence that a sense of community care develops among marginalized groups struggling with similar adversities; however, there are several uncertainties surrounding the experiences of informal community-based care that LGBTQ2+ young adults provide or receive in the absence of inclusive, professional health care services (Gahagan & Colpitts, 2017; Garcia, 2010; Kleinman & Van der geest, 2009; Sturman & Matheson, 2020).

Specific aims: The goal of this research is to explore whether LGBTQ2+ young adults in Southwestern Ontario receive and provide informal community-based care for one another in the potential and/or perceived absence of sexuality-inclusive and trans/non-binary gender competent health care services. My research sought to identify which informal, community-based care practices might be enacted amongst this marginalized population, as well as determining what prompts these young adults to offer and receive this type of emergent care.

Methods: This study included qualitative semi-structured interviews with young adults in Southwestern Ontario who identify as a part of the LGBTQ2+ community. The interviews explored their experiences within the formal health care system and community-based care. Calls for the participation of LGBTQ2+ community members to were advertised via flyers (see Appendix. A) that were distributed online through LGBTQ2+ networks, social media forums, LGBTQ2+ servers (Twitter, Discord, Reddit). Zoom video conferencing software was used to conduct the interviews. Abductive reasoning was applied during the narrative analysis of the participants' responses to identify potential motivations and ways in which LGBTQ2+ young adults promote well-being amongst themselves. Autoethnographic reflection pieces were utilized throughout the study and during the analysis to provide further experiential insights as well as my own voice in the findings.

Results: Responses garnered from 10 interviews with LGBTQ2+ young adults (24-27) living in southwestern Ontario are included in the results of this study to demonstrate their experiences with formal health care services and informal community-based care. These experiences provide reasonings for the reluctance to rely on formal health care as well as impetuses for turning to informal community-based care. The most common methods of informal community-based care included forms of emotional, physical and epistemic care. Lastly, the results of this study illuminated the existence of a sense of watchfulness and social obligation to care for fellow members of the LGBTQ2+ community that transcend social, economic and geographic differences.

Conclusion: The results from the study illustrate how sex, sexuality, trans/ non-binary gender, and variation of gender identity or expression, can shape young peoples' experiences with or their willingness to seek out health care services. The findings of the study demonstrate the potential reluctance for LGBTQ2+ young adults to solely rely on mainstream health care practices by illuminating the prevalent barriers to inclusive services. This study is one of the first to identity some of the potential approaches that LGBTQ2+ young adults might employ to provide care to, or receive care from, fellow community members (alternatively to, or in tandem with, formal health care). Lastly, the study describes the possible impetuses beyond the unwillingness to pursue formalized health care services, for the utilization of informal community-based care.

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Lastly, I would like to thank by partner Michael Wong, for being by my side every step of the way and being the metaphorical and physical hand on my shoulder throughout my writing process. Thank you for listening to and bearing with my stress induced tangents and constant demands for quality assurance.

Dedication

To all the LGBTQ2+ individuals who have ever been scorned by the formal health care system and have suffered because of it.

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List of Abbreviations

LGBTQ2+ - Lesbian Gay Bisexual Transgender, Queer/Questioning, Two-Spirit, Plus

GSD – Gender and/or Sexual Diversity

HIV – Human Immunodeficiency Virus

AIDS – Acquired Immunodeficiency Syndrome

Cishet – Cisgender Heterosexual

HCPs – Health Care Providers

Chapter 1: Background

Lesbian, Gay, Bisexual, Transgender, Queer, two-spirit, (LGBTQ2+) individuals, despite progress being made in policy and laws to uphold their rights, still face discrimination, abuse, violence and even death, due to their trans/non-binary gender and/or sexual diversity, simply because they do not conform to the expectations held by cis-and heteronormative societies (Brotman et al., 2015; Fisher, 2020; Pepper, 2015).

Gender and Sexual Diversity (GSD) as a term is used to define all the possible variations in sex characteristics, sexual orientations, and trans/ non-binary gender identities and expressions without having to specify every existing identity, behaviour, or characteristic within the LGBTQ2+ community (Balswick & Balswick, 2001; Pepper, 2015). Due to the GSD present within the LGBTQ2+ community, many of these individual's identities and expressions do align with the generally accepted heteronormative expectations of mainstream, Canadian society, and as a result suffer a substantial amount of personal, social, occupational, health and socioeconomic status inequities (Brotman et al., 2015; Gahagan & Colpitts, 2017; Pepper, 2015). However, the degree to which a society might be reluctant to embrace these diverse genders and sexualities is influenced by global trends regarding the attitudes held towards LGBTQ2+ people (Fisher, 2020; Pepper, 2015; Zay Hta et al., 2021).

The hegemonic views held by the past and present biomedical community—due in large part to the pathologizing of non-hetero/cis normative sexualities and gender identities—have led to distrust in health care system from the LGBTQ2+ community (Fisher, 2020; Mayer et al., 2008; Mulé et al., 2009; Pepper, 2015). Discrimination because of one's GSD continues to create barriers to receiving inclusive and adequate health care services (Brotman et al., 2015; Gahagan & Colpitts, 2017; Röndahl, 2011). Consequently, the provision of health care services are non-inclusive, resulting in health disparities among the LGBTQ2+ community (Meyer, Ouellette, Haile, & McFarlane, 2011; Röndahl, 2011). Colonialism and the actions of religious missionaries have historically erased the GSD from non-white populations, most notably the Indigenous third gender, and continue to suppress non-hetero- and cis- normative identities (Native Women's Association of, 2010). The structural violence propagated from these institutional powers embedded itself into systematic administration of a myriad of public services, including the health care system (Native Women's Association of, 2010; Röndahl, 2011).

The social suffering of the marginalized groups affected by the hegemonic views of a predominantly white and heteronormative society was especially pervasive during the AIDs epidemic. HIV was a new illness that many individuals in the health care system did not know how to treat and, once it was considered “the gay sickness” their willingness to treat gay patients or researching a cure diminished due to prejudice (Röndahl, 2011; Stulberg & Smith, 1988; Warner, 2002). Numerous LGBTQ2+ leaders lost their lives from inadequate medical interventions, or the refusal of providing treatment by prejudice health care providers (HCPs) and the unwillingness of gay patients to access treatment due to issues with trusting the health care system or denial that they were sick (Röndahl, 2011; Stulberg & Smith, 1988; Warner, 2002). The horrendous treatment of people living with HIV/AIDs in the 1980s led to a loss of a large portion of a generation, which deepened an already low faith and trust these communities had regarding medicine and formal health care services

(Richards, Wrubel, & Folkman, 2000; Stulberg & Smith, 1988; Warner, 2002). The gap left by the deaths of gay leaders, role models, and elders meant that there was a dwindled generation which could form a dialogue with younger LGBTQ2+ individuals or advocate for gay rights in medicine (Richards et al., 2000; Stulberg & Smith, 1988). During the epidemic, the community largely rallied within itself with lesbians and survivors leading a types of informal community-based care (Warner, 2002). One of the reasons to have the "L" standing for Lesbian placed first in every widely-used version of the LGBTQ2+ acronym was to appreciate the support of and advocacy for better medical treatment for gay men, and is a reminder of the informal community-based care that emerged in a crisis (Warner, 2002). Informal care stemming from within the community only increased throughout the 90's, seeing 67% of HIV/AIDS-related deaths occurring at home rather than in a hospital, with 71% of these instances having an informal caregiving partner present (Richards et al., 2000). The existence of this informal community-based care among marginalized groups provides a foundation for the assumption made in this thesis that individuals who experience discrimination within the formal health care system due to their GSD continue to carry out similar emergent care practices to this day (Brotman et al., 2015; Gahagan & Colpitts, 2017; Röndahl, 2011).

Iatrogenic harm and discrimination have led to a culture of LGBTQ2+ individuals delaying or avoiding health care for fear of institutional heterosexism, homophobia, and transphobia, and/or receiving inappropriate or inferior care (Meyer et al., 2011; Röndahl, 2011). LGBTQ2+ individuals have been seen to have poorer health due to inadequate services that can create iatrogenic harm or deter them from seeking health care services (Herek & Garnets, 2007; McLaughlin, Hatzenbuehler, & Keyes, 2010). LGBTQ2+ young adults have reported that their negative perception of mental health services is one of the major barriers that compromise health-seeking behaviours, and that they need to see improvement in the requirement of gender competent practices and LGBT-affirmative policies (Zay Hta et al., 2021). Studies show that HCPs who are aware of their lack of LGBTQ2+ health knowledge do not feel confident treating LGBTQ2+ individuals competently and would prefer to rectify this (Dill, Chuang, & Morgan, 2014; Gunderman, 2006; King et al., 2018). It has been reported that practicing health care professionals lack the gender competence and/or sexual diversity training needed to adequately treat LGBTQ2+ communities (Bonvicini & Perlin, 2003; Burch, 2008; Röndahl, 2011).

Gender competence refers to the ability to recognize gender-based discrimination in one's occupation, research, learning environments and clinical practice and, using these understandings, to improve equality of opportunities and outcomes (Fisher, 2020; Pepper, 2015). In addition to being aware of potential gender-based discriminatory attitudes and behaviours towards non-binary/transgender folks, it is essential for affirming practitioners of gender competence to counteract gender-based stereotypes that may limit the rights and reinforce disparities among these gender and sexually diverse individuals (Balswick & Balswick, 2001; Fisher, 2020). The notion of gender competence is especially important in health care for it is vital to promote equal access, as well as equity in health outcomes (Balswick & Balswick, 2001; Fisher, 2020). Furthermore, being accepting and knowledgeable of sexual diversity is essential for the provision of care strategies regarding stressors unique to sexual minorities in order to ameliorate the experience of the health care, but also to improve LGBTQ2+ health outcomes (Fisher, 2020; Gahagan & Subirana-Malaret, 2018; Herek & Garnets, 2007; McLaughlin et al., 2010). It has been demonstrated that HCPs have a dedication to upholding best practice when treating patients, with many pursuing continuing education and career advancement to achieve this goal (Dill et al., 2014; Gunderman, 2006). Gender competency and sexual diversity training enables HCPs to treat LGBTQ2+ individuals by offering high-quality, inclusive care, thus improving the likelihood of LGBTQ2+ individuals pursuing health care services, which improves the overall well-being of the LGBTQ2+ community (Bonvicini & Perlin, 2003; Brotman et al., 2015).

In this study, I explore the informal community-based care experiences that occur between LGBTQ2+ young adults living in southwestern Ontario, either supplementary to or in tandem with formal health care services. The circumstances of individuals aged 24-27 were of specific interest because the administration of poor health care services to LGBTQ2+ young adults has the potential to compromise their wellbeing continuously into older adulthood and throughout their life course (Burch, 2008; Gahagan & Subirana-Malaret, 2018; Mayer et al., 2008). Despite the AIDS epidemic occurring in the 80's and the survivors belonging to older generations, the mistrust of the formal healthcare system still permeates within the younger age groups (Fisher, 2020; Mayer et al., 2008; Mulé et al., 2009; Pepper, 2015). Any additional restrictions to the delivery of health care will only foster further distrust and may influence young adults' health-seeking behaviours and future interactions with health care that may deter them from using these services (Gahagan & Colpitts, 2017; Mayer et al., 2008). Some of the major facilitators that have been seen to improve health-seeking behaviours among LGBTQ2+ individuals are self-awareness of HCPs (being aware that they have or have not received adequate GSD training to provide inclusive service), accessibility or availability of mental health services, and positive attitudes and beliefs about health care services in general (Burch, 2008; Zay Hta et al., 2021). Health care services that possess the aforementioned facilitators, as well as appropriate GSD training, are more likely to lead to better health-seeking behaviours and the improvement of wellbeing for LGBTQ2+ individuals (Fisher, 2020; Zay Hta et al., 2021).

While it is known that there is a lack of access to inclusive health care services, there is also a gap in research pertaining to LGBTQ2+ care experiences as well as the emergent care networks that LGBTQ2+ young adults have created as a response to this inequitable provision of formal heath care. Kleinman's "The Illness Narratives" provides interesting insight into how to interpret an individual's encounter with illness, not just as a biological condition, but as a human experience (Kleinman, 1988). This study utilized Kleinman's findings, which were originally intended to bridge the gap between patient and practitioner, in order to better understand the narrative-based care experiences of LGBTQ2+ individuals who rely on informal care networks (Kleinman, 1988). Narrative-based care experiences refer to the stories that individuals share to make sense of their encounters with the health care system (Zaharias, 2018). Similar to narrative-based medicine, which sees the application of personal accounts in care practices, incorporating narrative-based care experiences can compensate for the inadequacies of capturing health care encounters using more biomedical approaches (Zaharias, 2018).

Kleinman's study described 'care' as comprised of two components, technical and emotional. Technical care refers to the act of carrying out activities for others who may not be able to do so themselves, and emotional care is the act of care for someone with an implied 'special devotion' motivated by concern, dedication, or attachment (Kleinman & Van der geest, 2009). This dichotomous model of care is quite interesting in the context of this thesis for my hypothesis hinges on both these forms of care existing and interacting with each other. According to Kleinman the technical or emotional constituents of care, "depending on [their] context, one aspect may dominate, indeed overrule, the other" (Kleinman & Van der geest, 2009). This approach to the understanding of what "care" is or can be, informed this study's examination of the informal community-based care, as a model of care that demonstrates a community's initiative and willingness to assist individuals that they consider "one of their own" (Kleinman & Van der geest, 2009; Sturman & Matheson, 2020). These forms of care seem to present themselves usually through culturally-based tactics or 'emotional care' methods, supplementary to, or in the absence of the inclusive health care, the technical aspects of care, that are supposed to be offered from formal services (Kleinman & Van der geest, 2009; Sturman & Matheson, 2020).

In the past, some informal community-based care networks have emerged when individuals had reported reluctance to engage with HCPs, if they were not currently in a perceived health crisis, and/or if they had experienced stigmatization or discrimination while pursuing health care (Sturman & Matheson, 2020). For example, informal community-based care has provided benefits to individuals dealing with heroin addiction in New Mexico (Garcia, 2010). The Pastoral Clinic by Angela Garcia showcased the efforts of one of Garcia's research participants, who used her experience as a midwife to provide informal care (in the form of pain relief, and harm reduction) to those suffering from heroin addiction in her community (Garcia, 2010). Garcia also describes the notion of "watchfulness" – a form of care in which a community remains watchful with one another in the presence of mutually antagonistic circumstances – which helped to demonstrate how alienated groups take accountability for their own (Garcia, 2010:182). The LGBTQ2+ community may also execute a level of watchfulness, monitoring each other's physical and mental wellbeing, since it has long experienced marginalization and exclusion from access to health care services.

The motivation for this watchfulness within the LGBTQ2+ community is further demonstrated through another concept purported by Garcia, commensurability. Commensurability is defined as "remaining in the face of one another's unshared vulnerabilities" and was used to describe the circumstances of those caring for heroin addicts (Garcia, 2010: 68). In the case of this research, vulnerabilities that commensurability described are vehemently shared within the LGBTQ2+ community for the experience of societal marginalization because of one's GSD is pervasive across the lives of all community members. Likewise, the concern expressed by remaining present during adverse circumstances could also be described as *Phroureō* (Ancient Greek) which translates to "protect by guarding", or "to preserve oneself (or others) for the attainment of something" (Silva 2007: 806). *Phroureō* can also mean to protect from "hostile invasion", which sparked my interest in exploring informal community-based care within the LGBTQ2+ community (Silva, 2007). I can foresee the protection of health and dignity in the face of incomplete medicalization of LGBTQ2+ bodies perpetuated by lack of gender competence (‘hostile invasion’) becoming a potential motivator to guard one’s own kin from harm fostered by the heteronormative health care system.

Chapter 2: Goals & Specific Aims

Goals: The overall goals of this thesis are to (1) identify the existence of informal, community-based care that LGBTQ2+ young adults may implement alternatively to, or in tandem with, mainstream formal care, and (2) investigate the motivation for this emerging form care.

Specific Aims:

1. This study examines if one's sex, sexuality, trans/ non-binary gender, and variation of gender identity or expression, can shape their experiences with or their willingness to seek out health care services.
2. This study also seeks to explore the potential approaches that individuals of non-cis-gender identities and/or non-hetero-normative sexualities might provide, or receive from others, in order to care for one another (alternatively to, or in tandem with, formal health care).
3. This study hopes to identify the possible impetuses for the utilization of informal community-based care and investigate the potential reluctance for LGBT2Q+ individuals to solely rely on mainstream health care practices.

Chapter 3: Methods

3.1 Theoretical orientation

As a non-binary gay man from a multidisciplinary health background heavily influenced by critical medical anthropology, I intended to infuse the culmination of my perspectives into the theory and methodology of this research. The theoretical approaches that I drew upon whilst completing this study included the intersection of critical feminist and queer perspectives, which was influenced by a postmodernist Butlerian perspective (Butler, 2003). Personally, I agree with Butler's stance on queer theory, which conveys that defining or conceptualizing this theory as an academic field with rigid praxis might inevitably lead to misinterpretation or cause it to counterproductively become an academic domain itself (Butler, 2003). The use of a Butlerian inspired queer theory coincided well with my study's participants for it possesses a flexibility that allows for the constant readjustment of reasonings and conclusions. This analytical fluidity was necessary to accommodate for the complexity of experiences regarding informal community-based care stemming from the unique social relations of individuals under the GSD umbrella (Butler, 2003; Compton, Meadow, & Schilt, 2018; Eng, Halberstam, & Muñoz, 2005). Queering this study's epistemology enabled me to pay particular consideration to those who may embrace these critical forms of thought, while still remaining mindful to the populations involved that should have legitimate access to the understandings being uncovered (Compton et al., 2018; Eng et al., 2005).

I utilized Butler's perspective on sex and gender during the analysis to highlight the western biomedical treatment of LGBTQ2+ bodies, as well as demonstrate how the enforcement of socially constructed ideologies like binary gender and heterosexuality are harmful to the well-being of the LGBTQ2+ community (Butler, 2004). The compulsory heterosexuality that is purported through the biomedical distinction of sex and gender incites a structural violence against anybody that may not conform to the pre-established dichotomous notions of sex and gender (Butler, 2004). The social suffering experienced by the LGBTQ2+ community because of the hegemonic biomedical rhetoric surrounding sex and gender was of particular importance to me and my research, for I have dedicated my academic career to researching the health and well-being of marginalized populations. Thus, I applied a queer lens to shape my methods in such a way that actively critiqued traditional heteronormative assumptions to avoid inciting further structural violence towards the study's participants.

3.2 Research Design

When designing this research, I was interested in exploring the intricacies of the human experience and how belonging to certain communities can influence one's well-being over their life course. This study employed a qualitative methodological approach using semi-structured interviews and a queer abductive analysis to examine narratives-based care experiences shared by the study's participants. Autoethnographic aspects were used throughout the study and during the analysis to provide further experiential insights. As a member of the LGBTQ2+ community, I have first-hand experiences as a member of the LGBTQ2+ community that I felt should not be absent from this study's findings, for my own personal insights were heavily entangled with the concepts and themes that this work produced.

3.3 Recruitment Plan and Participants

For this study, I sought to recruit LGBTQ2+ young adults (ages 18-30) who reside in southwestern Ontario and self-identify as LGBTQ2+, Gender and Sexually Diverse, and/or non-heteronormative. Participants were recruited via research flyers that were posted on social media platforms and LGBTQ2+ digital networks. Snowball sampling was also used to spread the word of this study from previous participants to their peers to bolster the amount of eligible and willing participants. Once participants expressed interest in the study, they were e-mailed an information letter that provided the details of their roles if they were to agree to be a participant. Should they wish to join the study, they were asked to sign the consent form or provide verbal consent (which was recorded) at the beginning of the interview. The study used non-gendered and inclusive language during the writing process; however, during recruitment I used the term LGBTQ2+ when sending out calls for participants.

I recruited 10 LGBTQ2+ young adults between the ages of 24-27. Despite recommendations from fellow queer researchers, I refrained from using the word *queer* to identify myself or the participants (unless they explicitly stated that this is how they identify), for I have personally not reclaimed the term's usage as a descriptor for LGBTQ2+ persons (Levy & Johnson, 2011; Valocchi, 2005). Nevertheless, I still wished to foster fluidity and mutability regarding the identity of the participants, and did so by allowing them to discern for themselves if they are eligible to join this research based on the language used while recruiting (Levy & Johnson, 2011). During the study, I was mindful of the GSD of the participants by asking them to detail their own descriptors, identities, and pseudonyms as well as being receptive to their conceptualizations of self that are constantly changing, multi-dimensional, and fluid (Valocchi, 2005)

3.4 Data collection and management

Semi-structured interviews were conducted remotely via video conferencing software (e.g., Zoom). The interview guide had open-ended questions and aimed to elicit narrative-based experiences regarding the health care system and provision of community care (See Appendix A.). The open-ended questions allowed participants to freely share their narratives, whilst the semi-structured nature of the interview provided guidance to the conversation and the opportunity for prompt inquiry and further clarification. Malinowski's phatic expressions (statements or questions used solely for social interaction) were implemented to maximize the establishment of positive relational rapport with the participant before proceeding with more personal inquiries regarding factuality (Rygg, 2016). Additionally, Ellis' approach to "compassionate interviewing" was used in order to listen actively, engage, and provide an opportunity for future follow up questions to prove commitment and willingness to continually listen (Ellis & Patti, 2014).

The 10 interviews were conducted between November 2021 and March 2022. The individual interviews were expected to be one hour in length, however they varied with some lasting approximately 40 minutes and others extending to two hours. During the interviews, necessary demographic questions were asked before starting the two-part interview; the first section consisting of questions about the participant's current access and opinions on the formal health care system, and second portion covering their potential insights on informal care experiences within the LGBTQ2+ community. I also wrote field notes and observations throughout the interviews, documenting participant's emotion and body language to provide further context regarding a participant's response, when I performed the analysis. The interviews were transcribed and stored on a secure password-protected laptop accessible only by me. Data was de-identified and participant-selected pseudonyms were used for the transcripts.

3.5 Data analysis

Abductive reasoning was applied during the narrative analysis of the participants' responses to uncover the underlying ideologies embedded in LGBTQ2+ stories. The use of abductive reasoning aimed to develop theory from 'surprising' facts as well as regularities present in the shared narratives generate and test logical arguments about the care experiences of LGBTQ2+ individuals. The analysis of personal narratives, ascertained from a long and open-ended interview, allowed for an extended account of participant experiences that could be used to explore, and attempt to understand, the nuances of informal community care amongst LGBTQ2+ young adults. The themes and explanations derived from multiple participant accounts that were shared during the semi-structure interviews were compared to the current literature and my own experiences in order to ensure rigor and trustworthiness among the abductive conclusions (Green & Thorogood, 2018). The abstractions from previous literature on informal care within marginalized communities would account for the potential transferability of the analytical insights produced in this work. My experiential contributions to the work also provided a level of credibility to the analysis of the participants' narratives, for they heavily aligned with lived and observed experiences among LGBTQ2+ young adults in southwestern Ontario. I extracted representative quotes of participant experiences to demonstrate the common and emergent themes but, whilst coinciding with this study's queer theory perspective, only offer a singular explanation that still possesses a remnant of uncertainty or doubt (Green & Thorogood, 2018). Additionally, the analysis included autoethnographic aspects tying in my personal experience on the topic to reveal important insights into the experience of oppression and discrimination of LGBTQ2+ individuals within the health care system, in tandem with the semi-structured interview responses (Cook, 2014; Ellis, Adams, & Bochner, 2011; Reed-Danahay, 2017).

The autoethnographic nature of my research consisted of post-experience recollections and my personal thoughts that I have named "Research Diaries," interwoven throughout the research design, findings and discussion, regarding my own care narratives as a practice utilized to incite reflexive thinking. I ensured to consider reflexivity here to evaluate my own position as a gay researcher, as well as situate the research itself within a broader socio-political context, to check my assumptions as a member of the LGBTQ2+ community. The analysis involved highlighting the transcribed interviews with similarities between the participants narratives and my own recollections of discrimination faced while pursuing health care, as well as personal experiences with the provision and reception of informal community-based care. This type of reflective analysis was done to promote cultural self-awareness while generating self-cultural understandings (an individual's metacognitive understanding of culture's influence on the self) (Lu & Wan, 2018). I used the reflection sparked from this process as a writing tool to illustrate the experiences that are congruent with existing communal thought, research and literature, whilst adhering to the description that previously characterize evocative autoethnography (ethnography that employs forms of discourse to evoke multiple images, ideas, memories, and emotions) (Boluk, Muldoon, & Johnson, 2019; Gergen, 2018).

The formation of abductive conclusions pulled from the interview responses mixed with autoethnographic insights provided another dimension of interpretation and representation regarding the potential for informal community-based care practices among the LGBTQ2+ community.

Chapter 4: Findings

The findings presented in this section are derived from 10 semi structured interviews with member of the LGBTQ2+ community as well as my own personal experience and understandings. The participants had varying self-described GSD, including a Lesbian Woman, a Gay Non-Binary Trans Person, two Gay Transgender Men, a Bisexual Woman, a Bisexual/Lesbian Woman, a Queer/Bisexual Plus Woman, a Pansexual Non-Binary Person, a Homosexual Trans-Femme Genderqueer Person, and a Bisexual Transgender Person. It is important to note these were how the participants were identifying themselves at the time of the interviews and that many participants described their identities as being fluid or in flux, so these descriptors may no longer be accurate. I felt that by introducing participants alongside their age and GSD for their initial quote was important when discussing their care narratives in section '4.1 Formal Health Care,' to emphasize how LGBTQ2+ individuals with intersectional identities experience formalized health care services. When providing quotes in later sections the emphasis was on injecting community voice and opinions, thus the quotes there are instead seamlessly sewn between paragraphs to emulate a conversation as well as provide a sense of narrative flow to the findings. I intend for the personal reflections that I have incorporated throughout to act as guidance to the flow of our community's narrative as well as amplify the voices of the participants as ambassadors, advocates and my peers.

4.1 Formal Health Care

Research Diary 1: My Personal Experience with Formal Health Care

I personally avoid and delay seeking formal health care services due to past negative experiences with health care professionals, which I believe to be based on the heteronormative assumptions that they have enacted upon me and my peers. The fact that there are essentially no guidelines or policies put into place to protect us against indirect iatrogenic harm caused by discrimination or prejudice in the health care setting has contributed to my lack of medical check-ups and unwillingness to pursue formal health care services. I have been assumed heterosexual and have been asked about "what my girlfriend thinks" when discussing erectile dysfunction caused by anti-depressants. Putting aside a consideration of how necessary this question is, even if the patient is straight, this incorrect perception that the doctor had of myself engaging in heterosexual practices was obviously affecting my care and influencing the treatments he was going to recommend. For me, a rainbow flag on the door on a health care institution is a great first step for signaling a safer space, however, many times this symbol is more of a blanket statement and does not necessarily represent the thoughts or beliefs of the individual HCPs within an organization.

In my experience, when HCPs offer sexual health related services for non-heterosexual practices, they are often surprised or confused, not knowing where to start, what to ask, or what treatments or screenings to recommend. Simply put, if they don't know what I need, and if I didn't know what I needed, then I would not receive adequate care. I am in the fortunate position of possessing the unique intersection of being a homosexual man *who is also a health student. My knowledge of sexual health and STIs has spared me from a great deal of medical speculation and scrutinization due to being aware of specific treatments and the ability to use medical related language to explain LGBTQ2+ health issues. However, the process of educating a health care provider is taxing and does not always end amicable when trying to confront someone who is a licensed physician. I have been asked by doctors, "do you think you need an anal swab?" after I have told them nothing other than the fact that I am Gay. That question immediately made me wonder, "I don't know? You are supposed to be the doctor?" and if I did not have a health background, would I have received inadequate care during that interaction? These unpleasant exchanges often lead me to delay seeking care due to a fear of judgement, awkward prying, answering questions about private things without the assurance that volunteering this information will result in a solution, or the worry that it would turn me into some sort of spectacle.*

My generally negative experiences of the encounters with HCPs were echoed by most of the study participants. When asked about their experience with formal health care, Bella, a 26-year-old Homosexual Trans-Femme Genderqueer person, shared their disdain of being subjected to the medical gaze.

"*Yeah, like I'm just like a kind of object that is being examined … to put it in like boiled down terms is like, I guess … [what] extends to a lot of marginalized folks is like being stripped of like subjectivity.*" – Bella

The synonymous experience of this study's respondents regrading health care utilization was negative. Comparisons drawn from these participants' care narratives revealed that there are still inequities and barriers to accessing formal health care services that prevent this form of care from being a viable option for LGBTQ2+ individuals. The quote from Bella illustrates the genuine concern that comes with receiving health care that is heavily entrenched in the biomedical gaze, as a LGBTQ2+ person. Based on the apprehensions shared by the participants, sexuality, sex and gender seemingly do affect one's interactions with HCPs and, as a result, willingness to pursue formal health care services. Most of the LGBTQ2+ individuals that I spoke to said they often delayed or avoided seeking formal health care services due to the fear of being discriminated against, based on their assumptions of the heteronormative views perpetuated by the structure of health care system or their own experiences that have confirmed such opinions.

For example, Jane, a 25-year-old Gay Transgender Man, said that he is extremely apprehensive of seeking formal medical care.

"*Oh, all the time! Even when I'm like, clearly like dying on the floor sick, I'm normally not going to call the doctor.*" – Jane

Jane aptly states that he has seen himself struggling with immense pain and suffering due to a malady while continuing the refusal to contact a medical professional about it. This seemingly stubborn response to symptoms is, in his reality, an act of self-preservation and is not an isolated incident, or an uncommon notion within the community. Another similar account to Jane's experience was provided by Math, a 25-year-old Bisexual Woman expressing that she is aware of the discrimination actively contributing to an avoidance of health care services in LGBTQ2+ circles.

"I think when you know people or live in a circle, whether that be in person or online, where people have negative experiences in the similar help that you're trying to seek, that it can bar you from even wanting to try in the first place." – Math

These statements illustrate justifications of avoidant behaviour when it comes to pursuing services for the betterment of one's health and rang true to my own experiences. It was gleaned from participant responses that, these apprehensions are due to the fear of judgement, perception of potential or previously experienced indirect or direct discrimination due to lack of knowledge, ignorance, or blatant homophobia, transphobia, and heterosexism. It is important to note that these negative feelings are based on the communal perception of these services based on past experiences that are shared by fellow community members. The commonality between participants' perceptions is that formal health care services in their current state are not primed to deal with LGBTQ2+ community's specific health needs or, more abrasively, common health concerns if possessed by a queer person.

Furthermore, it was stated that a lack of confidence in their HCP's competency was a major deterrent from seeking further services with them or other providers in the future. Several participants expressed that the LGBTQ2+ participants would not want to enter themselves into a situation where they would have to educate the health care provider before they were capable of providing adequate services, especially if they were not confident about certain LGBTQ2+ concepts themselves. For example, Kermit, a 26-year-old Gay Transgender man, expressed his dissatisfaction with the current medical practices and lack of knowledge that HCPs are exemplifying.

“It's the fact that the lack of knowledge makes it- me wonder if I know more than the doctor anyways in half of these situations, like if I have like half an idea of what's going on, I usually don't go in because they're not going to know any more than I am.” – Kermit

The experience of doctors not understanding seemingly straightforward transgender health issues leads Kermit to wonder if he knows more about LGBTQ2+ health than a licensed medical professional simply by being a part of the community. Other participants shared this sentiment and furthered it by stating that doctors who are LGBTQ2+ are capable of providing more holistic care to GSD aligned individuals simply because they possess insider knowledge of the community that was not covered in their formal education or training. The negative perceptions of doctors’ lack of training regarding LGBTQ2+ health issues were echoed by Ezra, a 24-year-old Transgender man.

“I was seeing a- another doctor in Toronto, and she- she identified as a lesbian… so she, number one, she was a lot easier to talk to, and I just felt like she had more of an understanding in general … So, I just felt a lot more connected to her, but she, she wouldn't have to outsource anything… she would immediately know what I was talking about. Whereas talking to this doctor, it's almost like I have to educate her, instead of like her providing me like support.” – Ezra

Listening to Ezra speak, I felt the same way. Explaining and defending what LGBTQ2+ identities mean to health care professionals and what these translate to, in terms of our health needs, can sometimes feel like an exhausting and fruitless endeavor, especially when considering that some HCPs would not be able properly perform care with that information anyways. It is a very valid reason to not want to waste time on a service that these participants or someone else around them can perform better, without the added fear of being judged or discriminated against. An example of the fear of discrimination preventing someone from comfortably and easily deciding to rely on formal health care services was provided by Lauren, a 24-year-old Bisexual/Lesbian Woman.

"I just don't want to exp- I don't think rationally that I'll experience any judgment, but I don't want that to happen, like if I'm- if I'm incorrect, I don't want to get judged or have like a lower degree of care." – Lauren

Lauren's sentiments expose that realistically she does not truly believe that all health care professionals are going to be automatically discriminatory, but she is aware of the very real possibility and does not want to risk it and be proven wrong. Lauren's apprehensions were also exacerbated due to the intersectionality of also being a Black Woman, and the potential racial discrimination that she also could had to deal with from the medical community because of this.

"Yeah. I mean, I'm already dealing with being a woman, being black, like I don't want to add like lesbian on top of it." – Lauren

Pursuing health care for these LGBTQ2+ participants can become an anxiety ridden experience where they are on edge the entire time, which causes them to purposefully withhold information about one's GSD that could be imperative to their care. We as LGBTQ2+ young adults are often not well versed in explaining/ knowing what vocabulary to use when conversing with cishet HCPs for them to understand gender and sexually diverse identities. The community understands the vernacular so we do not train or practice how to advocate or explain ourselves to those who do not know even the basics, nor should the onus be on us to do so. The concerns of being able to properly advocate for oneself were mirrored by Pollux, a 26-year-old Pansexual Non-Binary Person.

"Oh, yeah, I would say that I am currently avoiding seeking out medical care and attention, because I don't want to position myself in a way that my safety is compromised. I'm not in a place where I feel like I can advocate for myself. And I'm really worried about coming across like gatekeeping or like something like, like, what's the word I'm looking for? Like institutional transphobia and things like that." – Pollux

Pollux expressed that they do not want their gender identity or sexuality to be a reason for HCPs to diagnose them with something like depression for falsified or assumed reasonings. The participants in the study reported that HCPs would often jump to conclusions stating that the LGBTQ2+ participants would have worse health because they are gay. These accounts, which are prevalent in western biomedicine, demonstrate the presence of the remnants of the pathologizing of "deviant" sexual identities/ "sexual deviance". Intersectionality plays a role here as well, for the participants who are a part of multiple marginalized groups do not want to provide additional reasons for doctors to make assumptions about their health based on unchangeable social determinants. The solutions and treatments in this regard are offered with broad strokes that heavily adhere to the standards of a heteronormative and Western-European body. Participants described having to suppress their LGBTQ2+ identity because they knew they were going to enter a medical situation where they would be evaluated by a biomedical gaze.

"Yeah. Yeah. It's cause like, it's not worth it. And then at the- and then at the same time, it's also like, if I need something like, I don't want this to be a like barrier to anything, or to come into play, because it shouldn't. Yeah." – Pollux

Presenting and being perceived as queer is important for visibility and identity affirmation, however during these health care scenarios we conform/ concede our identities because we do not want to be treated differently, nor do we want to have our quality of care lessened. Administratively, the forms we are required to fill out, when setting up appointments or taking questionnaires, are still not progressive or inclusive and, more often than not, the participants and myself will choose the options that match what the doctor will assume based on our external appearance. Limiting or concealing your own identity as an LGBTQ2+ individual is a source of medical anguish which can prove to be emotionally painful and providing another reason to avoid or delay formal health care to prevent such a negative experience. Yet in some cases, it may be necessary to receive care that is not skewed by being non-heteronormative.

"*No, it's true! It's like, there are real consequences, because the medical system functions in this way that's not safe. Yeah."* – Pollux

Based on participants' experiences, the heteronormative standards that are often perpetuated by HCPs are more often a result of the current system that enables ignorance, more than their own internal biases or prejudice. The system does not promote or reward education regarding the best practices for LGBTQ2+, nor does it provide avenues that foster updating treatments and methods to be more inclusive. Thus, the possibility of discrimination is resulting in a negative perception of the services, sometimes before these LGBTQ2+ young adults have ever used them.

Not every participant in the study would avoid seeking health care based on their GSD; however, they were still able to recognize that this struggle does exist for their fellow community members. The participants who did not actively avoid health care stated that, aside from being fortunate in their situations, they were only able to circumvent potential adverse health care experiences because they were assertive or possessed the appropriate vernacular. Such a stance was garnered through having relatives working as health care professionals, or by being a part of health care administration themselves. Hope, a 24-year-old Lesbian woman, stated that she did not have issue with pursuing healthcare, either due to the fact that she had her mother's aid as a liaison to set up appointments, her nursing knowledge to guide her, or having a familiarly with a family doctor.

"Honestly, probably not for me. And I feel like I don't access it as much as other people. I mostly only go to my family doctor, except for that one specialist. So, I feel like she knows me pretty well and I'm pretty comfortable with her." – Hope

Emily, a 26-year-old, Bisexual Trans Person agreed that the LGBTQ2+ community struggled with ascertaining health care services even if that was not synonymous with their own experience.

"I know from just being aware that like the LGBTQ community struggles with health care, and like finding people who can actually support them and finding like, people who respect them. And meanwhile, I'm like, basically ever since I came out as trans, I've been completely supported… but again, um, I learned how to speak to them and that's also a lot to do with it." – Emily

Emily continued later, saying:

"It reflects mostly on society in general, but yes for the current health care, because it's like, it's only the people who are with privileged knowledge that are getting the help that they need, where that's not really fair." – Emily

Similarly, Cavendish, a 27-year-old Bisexual/Queer Plus Woman, said that she had to take matters into her own hands and adapt herself to the system in order to utilize it without issues.

"Yeah, like obviously it's a tough situation, but it's like I had to learn to adapt, you know? And it's maybe not as ideal because like I shouldn't have learned to adapt, like I should have already been receiving this, like I already should have been treated equally and I should have, you know, not have been assumed to be straight. I already should have just, you know, had my care and my needs met, but they weren't. So that's why I had to mold myself to be this way, just to get health care." – Cavendish

For me and the participants, it felt like simply pursuing formal health care services had the potential to pose a threat to our well-being. Regardless of if this is the convergent reality, the fear of this reality is the very real perception that most of the participants possessed. Not taking advantage of the formal health care opportunities presented to us, especially in times of crisis, can also pose serious threats to our well-being. However, there is potential of placing ourselves in an adverse circumstance that may end up being just as or more harmful than our current ailments. Thus, this reluctance to use formal health care due to the barriers of access is the main motivator that either directly or indirectly drives these LGBTQ2+ individuals to rely on informal care within their community.

Research Diary 2: My Thoughts on Formal Health Care After the Interviews

So, myself and several of the participants have expressed that we possess subpar health seeking behaviors, and for the most part, not at a fault of our own. It is not a stretch of the imagination to believe that our health is being negatively affected by these avoidant patterns, but also that it may not even be any better if we did use formal services. LGBTQ2+ individuals are statistically presented to have worse health outcomes and it's not because we're predisposed or biologically more receptive to illness. It's the system and the fact that we're marginalized in society that has led to myriads of mental health issues and the potential for unmonitored chronic illnesses because we're not being treated adequately.

Thus, the pervasive prejudice and discrimination are leading us to take it into our own hands, which may or may not be the best care that we can be provided. Even still, I will consult the advice of another gay person in order to vet if my issue is something that we can handle ourselves or if it is something that requires medical attention. Even if the health issue doesn’t directly involve being LGBTQ2+, the ways that GSD intersect with my wellbeing *cannot be separated from myself and indirectly affect all facets of my health, especially emotional, social and mental wellness.*

4.2 Informal Community-Based Care

"I think community care exists separate from formal care and could never be replaced by it." – Jane

<u>Research Diary 3: My Personal Experience with Informal Community-Based Care</u>

As an active member of the LGBTQ2+ community I have been a recipient, provider and observer of various levels of informal community-based care on multiple occasions. Helping other LGBTQ2+ individuals with a myriad of GSD related health issues, physical or mental, as well as emotional and social support, came as second nature to me, maybe even first nature. It was an intrinsic inclination to help those who I see myself in or who have had struggles due to the same adverse circumstances (marginalized or oppressed by society at large, raised in a homophobic or transphobic environment, identity crises, threats of homelessness, etc.). As a health student my care was also usually able to extend to providing advice on, and even treatment of, physical symptoms, often as a substitute to formal health care. I think I enjoy that aspect of being a health student as well, I like being able to help those around me with quick health recommendations. Maybe it's in my nature as someone who has chosen health research as my life path, or maybe my altruistic nature plays some role here, but I do have to wonder how things would differ if I had a different personality or career path.

That being said, I do feel that the levels of care or interest I apply when providing care do differ regarding who the recipient is. I do find myself constantly putting other LGBTQ2+ individual's troubles before those who are not a part of the community. Reflecting on why I put those in the LGBTQ2+ community first, I realize that it is not out of malice or because I dislike cishet people more. It is because I assume that their troubles could be ameliorated through already accessible channels, and the care that I could provide would be suboptimal in comparison. The opposite applies to the care that I know I can provide to those within the community. I am aware of many of the complexities involved with existing as an LGBTQ2+ individual and the unique physical and emotional qualms that are accompanied by this. Personally, I seek to receive advice and care from other LGBTQ2+ young adults for the same reason, the level of empathy that they are capable of providing when employing care methods. I find myself less likely to jeopardize my own comfortability, safety, schedule or responsibility for someone who could potentially ascertain help elsewhere, whereas with those within the LGBTQ2+ community, especially younger members, I am much more willing to drop everything to help and mentor them. I think it's what I would have crucially appreciated at their age and would have prevented an insurmountable amount of turmoil on my end.

From my personal reflection and confirmation during the conversations about informal care narratives, there seems to be an innate kinship between LGBTQ2+ community members that is expressed through an inclination and in some cases a feeling of obligation, to help and look after one another. All the participants agreed that this ineffable phenomenon--

where we provide and receive care from one another before seeking formal services-- exists to at least some extent among community members.

"I'm trying to think if there's like a root to it, like in the community, or if like because I saw it in other people and therefore I did it." – Emily

The feeling of being compelled to help those who possess synonymous attributes to yourself can stem from many positions, in this case, an empathetic one. Empathetically, LGBTQ2+ individuals seem to recognize what their health concerns or general struggles feel like and can surmise what we would want or need in that situation to ameliorate the condition of fellow community members. Simplistically, it is the desire to provide a type of care that one would have appreciated if and/or when they were previously in similar adverse circumstances. Furthermore, it is the urge to provide a care for someone because these participants possess the ability to do so and are aware that others may not be able to. Some participants went farther by saying that it was an obvious or mostly subconscious decision to help and care for other LGBTQ2+ people.

"We all have this shared experience, whether it be, you know, coming out or like exploring gender identity, or you know, whatever it may be. Yeah, I think we all have this kind of, you know, connection and we have, yeah, shared experience." – Ezra

One's health problems may differ from another, but the focus on the shared experience of coming out, affirming one's identity, and navigating societal discrimination is something that is binding and cannot be found elsewhere. The formative experiences of the participants existing as LGBTQ2+ individuals in a heteronormative society are not a familiar scenario for a majority of society and, as such, fosters bonds between those who can relate to such struggles.

"I think I feel a degree of camaraderie with other queer people. There's this idea that like, oh, I already know some of the odds stacked against you. And I'll never know your experience, of course, but like, I can see where this might be coming from. And I feel like I should do the best I can." – Jane

Members of the community are aware of the societal marginalization experienced by LGBTQ2+ individuals and are willing to do commit a decent amount of effort to ameliorate the conditions, or at the very least not worsen their situations, through the provision of care. This care phenomenon heavily involved the notion of intersectionality, as oppressed people are familiar with having mass societal opinion working against them, and the struggle of navigating institutions founded on standards that exclude them. As reaction to this, there seems to be an informal system that has developed in order to mitigate the potential damage from avoiding or receiving inadequate formal health care and supplement missing inclusive services.

"*Ah... I think for me... I think I'm a little more inclined to like, jump to the help of like, another queer person. Sometimes, especially if they're impacted by intersectionality. Yeah, that's a big one, because a lot of my queer friends are also intersectional in some other aspect…So I will be definitely trying to help more."* – Pollux

Presenting and being perceived as queer is important for the reciprocal relation of these forms of care and can even contribute to one's motivation to provide care. The general sentiment is that a cishet person would most likely not understand the nuances of queer issues, and that people in the LGBTQ2+ simply understand each other more. For the informal care to be readily accepted, there must be some point of relation or frame of reference for the provision of care in order to establish trust. Having this common thread acts as an automatic check and balance that allows for the removal of at least one layer of guarding or reluctance. We are more willing to receive or provide care to fellow gay persons because they are more likely to understand and less likely to harm me. As it stands, we cannot automatically surrender ourselves with complete confidence to the care at the hands of a cishet person, and we would also not immediately go out of our way to reciprocate.

"I gravitate towards queer people, in like a friendly way, more than straight people. So yeah, it's hard to- it's hard to think of a situation where I've like really confided in someone who's not a part of the community, and they felt that inclination to also confide in me." – Ezra

Additionally, there also seems to be a parental connotation towards this imposed obligation to take care of each other, specifically from the standpoint of an intergenerational mentorship. Due to the missing generation, this notion of helping those who will succeed us is even more desired/present, we were lost, and we do not want that to happen again. Advocating for others but also teaching them how to advocate for themselves, felt an obligation because it is what they would have wanted/ they do not want others to struggle the way they did.

"Yeah, yeah, I would have wanted that, like if there was somebody who could have like led me through that process, like I would have appreciated that more than anything. So, now I just felt like I had to, because it's just such a tough process doing it on your own with like clueless professionals in your own life." – Kermit

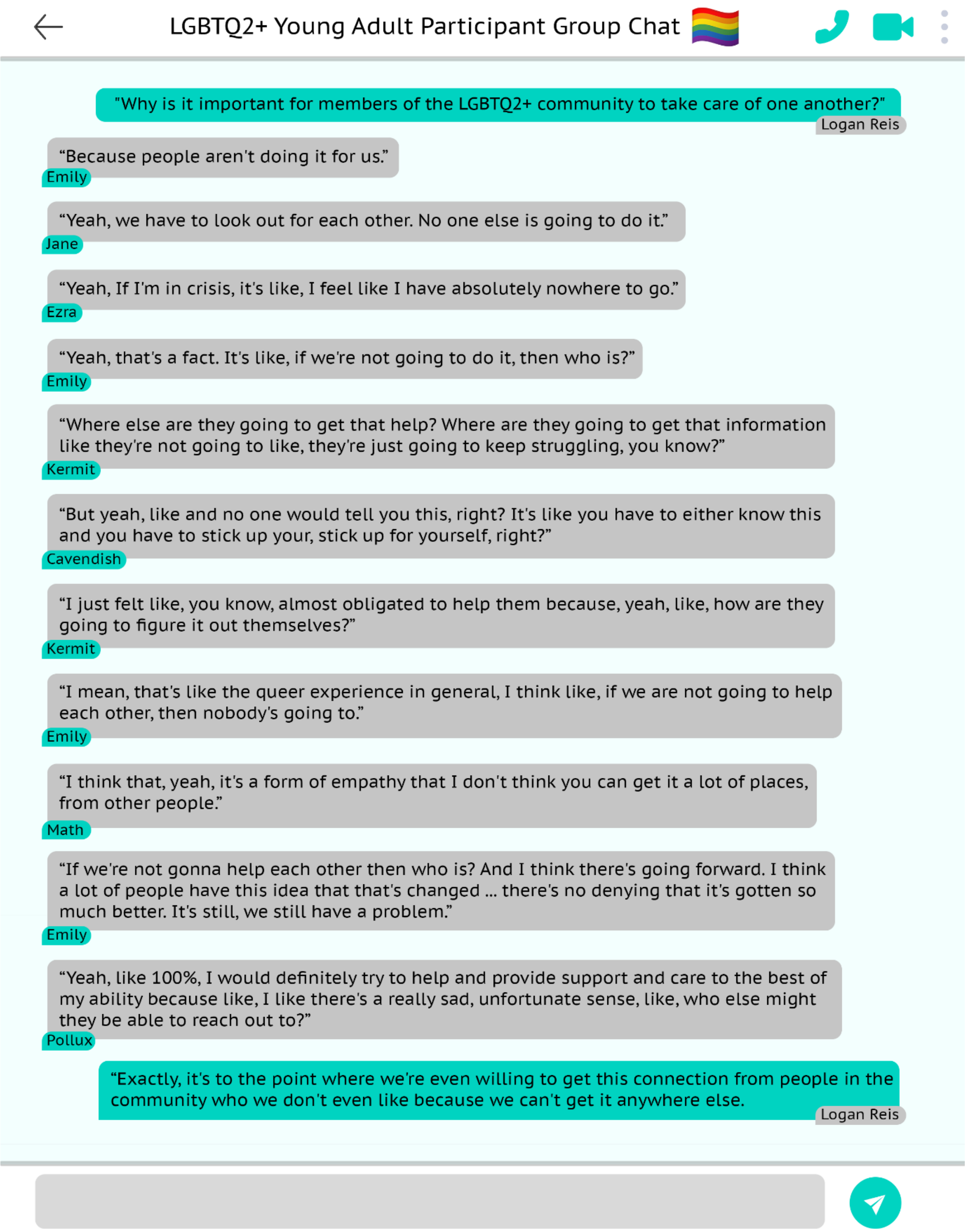
Many participants noted that they have not only observed that the LGBTQ2+ community takes care of our own, but that other marginalized groups do as well, however they also perceived that groups of cishets individuals do not behave as such. They surmise that cishet people do not perform these care actions for each other nor do they need to do so, on the basis that both parties are heteronormative. The participants and I speculate that, by default, cishet individuals are just strangers with a common heteronormative sexuality and binary gender identities, and, as such, do not share a foundation of societal oppression to bind them to each other.

"I don't think straight people have the same, you know, the same inclination to help, you know, no straight person would be like, I'm helping this person because they're straight, you know?" – Ezra

The participants observed that this care phenomenon surpasses familiarity in a way that they would still be willing to provide care for someone, that they would normally consider to be a stranger, solely because they regard them as one of their own. Furthermore, this inclination to provide care even transcends the standard requirement of amicability towards the other LGBTQ2+ individual as a person, which is a unique interaction that I have not observed between people who share heteronormative identities.

"The few queer people that we did have, even if you didn't like each other, you had to, like sit around with each other, just cause just to make sure, you know? We all knew each other and we all like, even if we didn't like each other, it would be like, if one of us like needed aid, I feel like even if I fucking hated them, I'd still probably help." – Jane

Helping our own community members that we may not have a good relationship with was described as a tactic to not increase the oppression in a society that is built against them; we do not need or desire to promote in-fighting. In my experience, this unique interaction of "caring for" but not "caring about" an individual as a person presents itself within the LGBT community and not in other groups, seemingly due to the lack of breadth to explore in Gender and Sexually diverse populations. The general conclusion among participants therefore is that they are the first line of defense by choice and the last line by circumstance. Thus, the LGBTQ2+ community needs to stand in solidarity to survive. Turning away from a member in need could produce amplified negative ramifications as they may already be struggling to navigate heteronormative institutions; and they may internalize this lack of care, turn away from the community, and refuse to provide or receive care from fellow LGBTQ2+ individuals. It is important to be compassionate and lead by example so that they will carry that forward, because the stakes are too high if we as the LGBTQ2+ community do not care for each other, as reflected in Figure 1.


LGBTQ2+ Young Adult Participant Group Chat 🏳️‍🌈

"Why is it important for members of the LGBTQ2+ community to take care of one another?"
Logan Reis

“Because people aren't doing it for us.”
Emily

“Yeah, we have to look out for each other. No one else is going to do it.”
Jane

“Yeah, If I'm in crisis, it's like, I feel like I have absolutely nowhere to go.”
Ezra

“Yeah, that's a fact. It's like, if we're not going to do it, then who is?”
Emily

“Where else are they going to get that help? Where are they going to get that information like they're not going to like, they're just going to keep struggling, you know?”
Kermit

“But yeah, like and no one would tell you this, right? It's like you have to either know this and you have to stick up your, stick up for yourself, right?”
Cavendish

“I just felt like, you know, almost obligated to help them because, yeah, like, how are they going to figure it out themselves?”
Kermit

“I mean, that's like the queer experience in general, I think like, if we are not going to help each other, then nobody's going to.”
Emily

“I think that, yeah, it's a form of empathy that I don't think you can get it a lot of places, from other people.”
Math

“If we're not gonna help each other then who is? And I think there's going forward. I think a lot of people have this idea that that's changed ... there's no denying that it's gotten so much better. It's still, we still have a problem.”
Emily

“Yeah, like 100%, I would definitely try to help and provide support and care to the best of my ability because like, I like there's a really sad, unfortunate sense, like, who else might they be able to reach out to?”
Pollux

“Exactly, it's to the point where we're even willing to get this connection from people in the community who we don't even like because we can't get it anywhere else.
Logan Reis

Figure 1. Graphic of a Simulated Group Chat Created with Similar Participant Quotes

A large portion of the provision of informal community-based care hinges on the genuine and perceived failures of the current formal health care system. The LGBTQ2+ participants and I understand the formal and informal access is sparse, so we are not in a position to deny providing care when we are able. Since the health care system is built on heteronormative ideologies, the marginalization is ever-present leading to the continual need for informal care actions. The participants noted that they care for other community members because they are marginalized, and through that care they become closer, which also increases the motivation behind providing that care; however, we also would not need to provide that care, if we were not marginalized to being with. A sense of watchfulness or communal guarding is fostered in order to sustain ourselves, prevent harm and survive. Watchfulness appears during the existence of shared adversities, which in this case would be society's foundation that implicitly perpetuates this oppressive biopower continually through heteronormative institutions. As mentioned previously, not all aspects of community-based care stemmed from the lack of formal care, but many health seeking behaviours, whether avoidant or supplementary, were motivated by previous negative experiences with formal care. I truly believe that there would still be some sort of bond, simply due to the sameness of identity, that is now being unfortunately exacerbated by strenuous and inequitable circumstances.

"Institutional transphobia just like threatens the lives of queer people like way too much to like even consider not helping." – Pollux

Research Diary 4: My Thoughts About Informal Community-Based Care After the Interviews

I have provided care without a second thought to LGBTQ2+ community members that I had the ability to help because I would have liked to receive the same from them if I were in need. So, for me, my care obligations are heavily entrenched in reciprocity, but the interesting thing within this exchange of care is that it transcends familiarity and amicability. I relate heavily to the parental connotations of informal community-care, I find myself adopting a parental role, almost animalistic to where a mother cares for her offspring, when confronted with younger LGBTQ2 + individuals' issues. I have in the past become verbally aggressive when I see some form of discrimination being enacted towards community members, more so than I would do for myself. For most of the participants the impetus for this innate sense of caring was the desire to guard those we consider our own. I myself find it difficult to describe at times, but from the findings collated in this section I now have several plausible reasonings that coincide with other community members' experiences.

This collection of narratives is the main reason that I wanted to do this research, because if I can start putting words to these feelings that we share, shine light on these experiences, then there will be something tangible that can explain why they may feel this way. Coincidentally, this is my way of caring for the community informally, or rather indirectly, because I'm sure there is a high degree of confusion regarding community-based care, and I would love if this research could be used as a resource for explanation and awareness.

4.2.1 Types of Informal Community-Based Care

The informal care practices employed by the participants within the LGBTQ2+ community offer more than just supplementing a lack of inclusive formal services. Whether or not the impetus of the community-based care stems from the barriers to access, the paucity of adequate or inclusive services, or the desire to care for one’s own kin, the participants of this study described approaches to care that went beyond a simple replacement or substitution of services. The methods of informal community-based care received or provided by the participants that emerged from this study can be categorised into three types: (1) emotional and social, (2) physical and instrumental, and (3) knowledge sharing or what I call “epistemic care”.

4.2.1.1 Emotional and Social Care

A large portion of the care that participants described that LGBTQ2+ individuals were capable of providing was heavily attuned to an emotional support level. Simply existing as a member of the LGBTQ2+ community gave participants the lived experience as someone who is marginalized for being for their GSD and commences care interactions with a shared understanding. The ability to intrinsically relate to one’s qualms on a personal level enables them to provide a type of empathetic resonance with care recipients and automatically establishes a rapport consisting of trust and security. Preemptively understanding that an individual, who is assisting someone during an emotionally turbulent situation, is coming from a place of social commensurability allows one to be more receptive and accepting of the sentiments.

"I would say even the emotional aspect, I think that a lot of people within the LGBTQ+ community can experience a lot of trauma through health care professionals, and I've seen a lot of people use each other as like, like to emotionally just unpack that and share those experiences, even just verbally. Like it doesn't have to come to any like, solution to what happened, but just like to feel represented that they weren't alone within those experiences. And I think I've seen a lot of people just share that trauma too, for the sake of unloading that." – Math

Empathy is a powerful tool in scenarios where the provision of emotional care is being expressed through a recognition of fellow community members. Being considered as a member of the community by fellow LGBTQ2+ individuals is validating and affirming to one's GSD, which is beneficial to our social and mental well-being. Being present and identifying as queer is enough to increase feelings of safety or security in one's own life and identity. Several participants noted that in some cases simply existing as LGBTQ2+ in the same space helped calm anxiety and allowed them to comfortably decompress.

"I guess the kind of care that I gave was like just being there for a friend within the community who was, yeah just like, not sure of herself and just talking, just talking through- talking through gender expression, because it is really hard to do on your own, especially when you don't have like- especially when you don't have someone in your life who is like- who does identify as the identity that you think you are or that you're trying to like- or that you're questioning that you are." – Bella

Research Diary 5: A Personal Provision of Emotional Informal Community-Based Care

In my experience, provision of emotional care requires a certain level of understanding. The importance of emotional forms of care between members of the community is exemplified by the shared understanding we have regarding the experiences of emotions filtered through a heteronormative society. It was tough for me to realize that people do not experience emotions inside a vacuum and that actions and reactions are inseparable from the reaches of societal factors and norms. Members of the community are capable of experiencing all the stressors and anxieties as the rest of the human population in tandem with the negative societal reception to their identity. Simply put, our existential crises are a little bit more existential than most. Thus, one cannot simply evocate to someone how to navigate a certain emotion if they have never felt the same way before. The empathetic pathways available to other members of the LGBTQ2+ community are seemingly handed down to us because of the nature of society. It is because societal institutions are founded on heteronormative ideals, that we have endured the experience of existing in spaces that were not built for us, and as a result we are able to provide a level of empathy to fellow marginalized individuals that others cannot.

This was the case with myself and Lauren, a participant of this study with whom I had shared an extremely vulnerable emotional care moment. Lauren and I were roommates during the first year of my master's program. Amongst the good times that we shared together there were also instances where the stressors of life (school, dating, family or past trauma) had taken a toll on our mental well-being. In those instances of emotional turmoil, we were experts at not asking for help and leaving things to bottle up until we found *ourselves in borderline panic scenarios. One situation expressed itself as me walking into the kitchen to get water at around 1 in the morning and discovering Lauren sitting in the middle of the kitchen floor having a panic attack. I immediately sat with her without saying much and just existed with her in that space, for I knew that my presence of shared understanding would help her feel slightly better at the bare minimum. Eventually, we had a conversation about what was plaguing her, a topic that neither of us can remember to this day, and I was able to alleviate her turmoil enough to get her off the floor and onto the couch. This research has presented us the opportunity to discuss that experience and the conversation went as follows:*

Lauren: Yeah, literally when I was having an anxiety attack and you sat with me on the floor of the kitchen and we're just like, “I'm here, I don't know what you need and this is kind of weird, but I'm not going to leave”, and like, yeah, and like [redacted] will do similar things where she'll know I'm feeling anxious and sort of be like, “you want a coffee?”. Like, yanno, anyway.

Logan: No, that's perfect. And how did you feel during that event? When I- when I sat with you?

Lauren: Just like really like heard, if that makes sense because, you know, my mom or whoever else could do things and I will still feel supported to some level like, I don't always feel heard, like, really listened to and seen in that moment. So yeah.

Logan: Well, would you have felt just as comfortable if I was a straight male and I sat down with you?

Lauren: Nooo, I don't know if this counts, but no, because I would try to feel like- I would feel like they were trying to make a move. And then I would feel even more uncomfortable because not only am I not really attracted to straight men sooo,

Logan: I mean, exactly.

Lauren: Its weird in general.

Logan: … Like, there's this level of informal care that can only be provided by other people in the community and that you would only want from other people in the community.

Lauren: Yeah, it's yeah, there's like that solidarity there that I think is just, I don't know. Like, I think sometimes with like this, it's like very specific to straight men, but I just don't trust them (Laughs).

Lauren was able to feel comfortable with my presence as a gay man because she knew that I did not have any ulterior motives behind my desire to help her when she was struggling emotionally. As a fellow member of the community, she recognized my motivation to help was simply because I saw another LGBTQ2+ person in crisis and immediately felt comforted.

In addition to providing emotional care through a LGBTQ2+ presence, recognizing each other as a part of the same community fosters positive affirmation and identity validation amongst members. The feelings of being present and recognized are important to the mental well-being of the LGBTQ2+ participants due to the continuous direct and indirect attempts made by heteronormative institutions to silence and ignore this community or discredit the existence of diverse gender and sexual identities. Thus, being told that one's

GSD is validated by fellow community members is a form of care that cannot be provided from outside the community.

“*The internal validation, though, is always a much better feeling for me, because it is just the people that let me be me, and then they can love me for whatever reason. But it always feels that there is a different, it's euphoria. It's- or it's like euphoric to just like be in a room and just be treated as normal.”* – Emily

Furthermore, openly portraying one’s GSD demonstrates that it is possible for someone who is a part of the LGBTQ2+ community to not only live happily and healthily, but also thrive. The LGBTQ2+ participants that spoke of steeping up and helping younger LGBTQ2+ individuals truly lead by example in this regard and placed a lot of importance on this mentorship. Having the emotional guidance of other LGBTQ2+ people who have been in similar adverse scenarios, enables us to not repeat the same mistakes and avoid suffering in the same way they might have.

“*It felt good, it was like, especially when it relates to as we mentioned before those stigmatized illnesses or disorders, that you already feel apprehensive about reaching out to professional care in the first place. Hearing someone who either is like ‘yo, I see you and like I also experienced this,’ for starters is already enough. But then also for them to be like, ‘this is how I went around it. You might be better if you do this way. This is like a place I would go to’ and then it's more reassuring and it allows you to take that first step because it's a less scary step, now knowing that someone you are close to has experienced that themselves.”* – Math

The notion of wanting to support fellow community members by being visible bleeds into advocacy and political awareness. Visibility and representation are very important tools that are being utilized to increase rights, prevent harmful bills or laws from being passed, raise awareness of GSD health concerns, and generally ameliorate the societal perception of the LGBTQ2+ community. Advocating for each other, especially those who experience more intersectional marginality, BIPOC and Transgender individuals, is a care action that is motivated by the urge to increase community wellness by taking advantage of their privilege (white, cis-gender, or heterosexual members) and utilizing heteronormative channels/ appealing to the masses.

"*Yeah. Yeah. cause it's like- it's, I think, like advocating for the people around you is- provides more care than we're willing to admit*? -Emily

In similar fashion to Emily, Bella explains:

"*Like I have like one like nonbinary coworker and we both actually- that's what we both do like for each other, like we like, we'll have like when someone like would misgender us… the other person would like just would like have a private conversation with that person who gendered the conversation and then say like, 'hey, I don't know if you knew this or not, and but like so and so like uses, they/them pronouns and like they're like, this is like they identify as like this' and Yeah, so like we show up for each other, but like we don't show up for ourselves, but like we show up for each other*!" -Bella

Following suit with Emily and Bella, Hope echoed:

"*I don't know if this is like a type of caring, but I remember a while back there was the protests, and then a trans woman got arrested, and then we went and we protested that, and I think a majority of us were probably a part of the community that was there*." -Hope

4.2.1.2 Physical Care

The physical aspects of care presented by the participants of this study mostly include the provision of instrumental and or daily tasks that a fellow community member could not perform themselves due to varying adverse circumstances. Some methods of physical care described by participants included cleaning a fellow LGBTQ2+ persons apartment while they were depressed, taking care of one's pet when on vacation, and helping one change clothes when sick.

"*Like, you know, he's having a really hard time with his depression, and, you know, yesterday, I, you know, cleaned his house for him and did his laundry and yeah, so like, you know, I think I'm supporting him in that way*." – Ezra

Other instrumental informal community-based care actions included completing errands for those who were either sick or just not mentally primed to deal with social institutions. Picking up and delivering items such as food or medicine when one was sick or immunocompromised is something that I have observed often, especially during the height of the COVID-19 pandemic. On the surface these practices do not seem like endeavors that are exclusive to LGBTQ2+ folk, however, the participants noted that they would not trust someone who was not a part of the community with the completion of these tasks for them. Many of these favours would involve someone entering their living space and handling their possessions, which could allude to LGBTQ2+ nuances that could compromise their relationship or safety if handled or observed by someone ignorant.

In general, having another community member, particularly if they better appeal to heteronormative institutions, retrieve necessary items is a common protective practice to circumvent adverse social interactions due to someone's visible GSD. However, in some cases a LGBTQ2+ person may simply wish to avoid situations that could provide an unpleasant situation such as prejudice, discrimination, misgendering, or other heterosexist practices, so they will ask another community member to go in their stead regardless. The care action of being a messenger or a delivery person is vital, because it could mean the difference between getting and not getting something crucial for one's health and/or GSD wellbeing, such as antibiotics, antidepressants, and hormones.

"I did not go outside because… I could have died, right? So, my not immunocompromised partner walked over groceries for me every two weeks, and I needed that. I wouldn't have eaten. Yeah, they also picked up my medication for me." – Jane

The handing down of clothes and the gifting of other physical resources like gender affirming tools or transition related items is a well-respected care practice that I have observed within the community. LGBTQ2+ clothing swaps have become a popular method to pass down clothing items to individuals with diverse gender expressions giving them wardrobe options that are difficult or impossible to acquire from mainstream retailers. Beyond just articles of clothing, gender affirming tools such as chest binders, are commonly handed down from transgender men who have received Top surgery (gender confirming double mastectomy) to other transgender men or non-binary individuals. Furthermore, transition related care items such as spare needles, hormones and blockers are distributed to transgender individuals who either do not have or cannot refill prescriptions due to money issues or medical transphobia.

"*You know, I see that all the time, like trans people- like they never really sell their used binders or their used old clothes and stuff like that. They usually just give them away because they know that there's another trans person out there who could use it. Yeah, and what they know, they understand what they're going through. You know, it's that empathy that we just can all have for each other because we all know."* – Kermit

Another example of sharing physical health resources is through the collection and handing out of safe-sex materials like condoms and dental dams. The stigmatization of sexual activities within the LGBTQ2+ community makes members wary when asking for safe-sex resources. Some members of the community are more comfortable than others in this regard and often act as collectors who will then distribute these items amongst their peers.

"*Yeah. And then another, smaller like more like, this is kind of community care kind of thing is, so, me and my partner, our doctor's office has dental dams, we have a friend- we have two friends who like to use dental dams and cannot figure out for the love of God where to buy the ones they like, and their doctor's office does not have dental dams. So, we have regularly just taken the free dental dams and pass them over. That's really useful, you know? Like a dental dam has a literal sexual purpose that's safety regulated.*" – Jane

The necessity of informal community-based care is exemplified with this exchange of physical resources because things like chest binders that could help with gender dysphoria, syringes and hormones for medical transition, or condoms and dental dam to prevent the spread of STIs, are not covered or widely administered by formal services. The proper use of any gender affirming and transition related materials is important so that the user does not harm themselves, and as such the handing down of these supplies, as well as the safety instructions, that they have tested themselves is crucial to maintaining physical health. Since these resources and the knowledge of how to use them are not easily accessible through the formal health care system, the concern and monitoring of physical health is another form of care that the LGBTQ2+ community engages in.

"*But, you know, there's this kind of internal monitoring of this community that I don't think I've experienced in communities with people of more mixed [hetero and non-hetero] sexualities, like, with those kinds of groups, like there's always like, we're gonna keep tabs on each other's mental health, and we'll visit you if you go to the hospital, but there's not keeping an eye on that physical health that same way*." – Jane

Research Diary 6: A Personal Provision of Physical Informal Community-Based Care

An example of physical informal community-based care that is prominent in my mind was during my undergraduate studies when I was living with several roommates while actively taking health studies courses. My roommate's boyfriend had just received top surgery and was staying with us so my roommate could take care of him. The circumstances around the intention to willingly stay in a student housing with 3 other LGBTQ2+

individuals after having surgery, instead of with family or in a recovery ward, already speaks volumes to the necessity of and desire for familiarity of LGBTQ2+ health issues and comfortability in identity. One evening, my roommate was at work, and I was home alone with the boyfriend recovering from surgery. Essentially, the night progressed, and he needed to change his bandages, but he was too weak to do it himself and did not want to raise his arms, so he just asked me to help him. At this point, I've only known him for about four months, and we have talked about this situation since, and he said he wouldn't have asked me to do something so sensitive and related to his chest area if I wasn't part of the LGBTQ2+ community. If I was a cishet man who did not understand transness at all, he wouldn't even have bothered to ask; However, he asked me because he assumed that since I was a part of the community, we had a shared understanding that I knew more about transness than a cishet man. Even if that perception of me being more knowledgeable was based purely on an assumption, we bonded over the level of trust that he placed in me regardless. To me, that was just a very clear-cut example of him not wanting to go to a walk-in clinic because he desired the security of someone in the community. He knew I was a health student, so I don't know if that influenced it, but regardless it was a very intimate moment and uncontestably informal community-based care. I had the opportunity to include this person as a part of my research, the following conversation about this care event was recorded during our interview together:

Ezra: I don't remember that super well, but yeah, I think just yeah, somebody- member of the queer community doing that, like you doing that as opposed to like, you know, my stepdad or my mom you know, really helped me feel comfortable and you know Yeah, yeah, … cared for! Yes, made me feel cared for and made me feel well supported, and yeah,

Logan Reis: Would you have asked me to do that if I wasn't queer?

Ezra: Probably not. … um, Yeah, I think um, you know, to, yeah, asking somebody who isn't queer, like, you know, I don't know how they would feel about the surgery or, you know- you know, you just see a lot, a lot of negative stuff about, like gender affirming surgeries online and stuff like that, like people saying, like, why would you do that to your body? It's so extreme, like seeing it as more of a body modification, rather than, like a necessary surgery. So, yeah, definitely having somebody who like, understands why I had the surgery, and you know, you know, who I am and, and everything.

Logan Reis: Definitely, yeah, because I remember at the time that, like, we knew each other, but I don't think it was for that long at the time, and that's like, a very vulnerable thing, like showing me your top surgery scars and also your bare chest after having female breasts.

Ezra: Yeah, totally!

Logan: …So yeah, that was, I mean, that made me feel very good. Like, it made me feel trusted, and also made me feel a different identity as someone who was part of the community, because I also felt that you wouldn't ask me to do so unless you recognized me as someone from the community.

Ezra: Yeah, definitely. Yeah.

Logan Reis: So, it was good to both of us, it was a- it was a very reciprocal kind of thing, but I was happy to provide the care.

Demonstrated by the Research Diary, in more extraneous situations, the informal physical care of community members can become more medical and will take on the treatment of symptoms or ailments to the best of their abilities. This form of care harbours a much higher risk and has the potential to take an emotional toll on the recipient and the provider due to the potential to cause harm. Beyond the amount of trust and comfort required to engage in a physical care situation, there is also the possibility that the provision of care may be suboptimal in actual medical treatment, however pleasant in practice. Several of the participants and I agree that sometimes it is worth the risk to perform or receive these informal physical treating of sickness, due to the potential harm we could face from the formal services being less desirable. The general sentiment of the participants' accounts was that the LGBTQ2+ young adults, including myself, would rather have a pleasant care interaction that ends in unintentional harm, rather than an unpleasant medical interaction that ends in iatrogenic harm or discrimination.

"I also feel validated because then it's affirmed. Yeah, because like these types of informal care are gender affirming care and trans informed care, even though they're not formal at all, because then- because a priority becomes like my safety as like, and my experiences as like a trans person and a non-binary person feels considered. My body autonomy feels considered as well, and I feel like a lot of respect in these conversations. Yeah, and then I'm not worried about like, this bigger or institution of authority impacting or

gatekeeping the way that I see myself, and what I desire and want to pursue in my body.” – Pollux

The transgender individuals in this study spoke of their bodies in a vulnerable way that emphasizes the importance of reservation and personal privacy. It would be difficult to openly share their bodies, needs and vulnerabilities with another person, particularly those outside of the community. The potentially tumultuous nature of external interactions with transgender bodies are only exacerbated in a biomedical context, where the body becomes a subject of examination and medical scrutiny.

“*Gender and sexuality have a lot to do with the body, and therefore, the body has become like this place of like, glory and hatred.*” – Jane

The notion of protection over one’s LGBTQ2+ body extends to physical intimacy as a form of care. Several participants in this study emphasized that they truly would only be interested in physical touch as a form of care, providing comfort and acceptance, from another member of the LGBTQ2+ community. Physical touch was noted as an important form of care for some participants and myself, for it is an aspect of holistic wellness that we had not encountered often or safely elsewhere.

“*If I'm seeking touches, like as a form of like comfort or like- like if I'm anxious, like, I only want it from some people, and those people are not straight, and they're not Cis. Also, like again the violation of the queer body.*” – Jane

Overall, the administration of physical health care tactics is limited within informal care settings due to the risk they could pose if performed incorrectly or without proper training. The benefits of physical touch are uncontestable. Thus, the passing down of resources and information as a form of care is much more preferred and is more common among the LGBTQ2+ individuals, for it allows the community to be the tether point of vital knowledge and empowers us.

4.2.1.3 Epistemic Care

"Yeah, yeah. But like, you experience it so much as you're coming out and like- like growing up like in that community that you just want to do it for others, because that's what you've already been experiencing. Like, so many people have like passed on their knowledge to you or help you through these situations, you just do it yourself because that's what everybody else has been doing for years, and it's been happening like this forever." – Kermit

Another form of care that the participants described, named here as epistemic care, was the sharing of knowledge to prevent harm, circumvent adverse situations, and improve the complicated experience of navigating social institutions as a member of the LGBTQ2+ community. Sharing advice amongst peers due to common circumstances is not an uncommon occurrence, however the GSD within the LGBTQ2+ community provides a connection that surpasses the standard demographic similarities. Thus, the exchange of LGBTQ2+ knowledge provided a shared existence that other community members can translate into their own lives, which allows for the possibility to explore how to proceed carefully and knowledgably in various social, medical, or sexual situations.

"*Yeah, it's more so just advice like what has your experiences been with so and so like, have you found that this happens to you like, you know, it's just kind of like sharing and* *comparing what our experiences are like? You know, sometimes I'll ask them like, 'Oh, like, I'm interested in this thing, have you ever tried this before?' Like, 'Oh, let's have you ever heard of this thing before?' Yeah, that kind of thing."* – Cavendish

The oral passing down of lived experience and dissemination of homemade documentation of LGBTQ2+ information, usurps a simple sharing of advice or recommendations. Within the LGBTQ2+ community, there is a shared facet of GSD within the foundations of our existence that entangles itself with every societal interaction, that enables the information to be accepted and applied with a higher degree of confidence and assurance.

"I think sometimes people need more than just advice, then again, that's something that's like you have to work out in that specific instance. But yeah, I mean like, I'm always open to sharing my experiences and I think like I do have a- maybe not unique experience, but I have a lot of shit that I've learned from, that I can pass on." – Lauren

Kermit furthered this point by stating:

"I guess, too like, when [redacted]'s weird friend wanted to talk to me about being trans, and I sat with them for like three hours and explained like literally everything, like how to start the process and stuff like that for transition, and everything, and answer all these invasive questions about that. I gave him binders too." – Kermit

One of the main institutions that the LGBTQ2+ participants noted that they need assistance in navigating is the health care system. For the amount of people within the LGBTQ2+ community that are avoidant of formal health care services, there remain those who are persistent in improving their care experience, are proactive with their vetting of these services and assertive with their HCPs. These individuals will disseminate their findings through LGBTQ2+ channels in order to improve their ability to comfortably engage in formal health care services.

"I've done these preliminary research things for like, say, like, like top surgery, and I'm like, I know these sort of things, and then through their experiences, they talk about like, their process or like, for example, like, if you go through like, like, OHIP versus like, like a private institution, what that might look like their processes on like paperwork and bloodwork sort of things, and how they've maneuvered around sort of tough conversations in a way where like, by gaining this knowledge, access to, like care is like less gatekept, in a way. Yeah, so I would say that was one of the biggest ones." – Pollux

Pollux continued later, saying:

"*I feel like I've participated in like, discussions and conversations on what it means to navigate medical care as, like nonbinary person, and that way, I can speak to like, maybe a little bit of like, what has worked for me or like, what hasn't worked and things like that*?" – Pollux

Referrals and recommendations of which services to pursue, from what providers to receive care, and which clinics to attend, are a common practice performed within the LGBTQ2+ community to encourage one another to seek formal health care services and generally improve health seeking behaviours. Having a fellow community member act as a check and balance in order to vet certain services, helps eliminate the fear of discrimination they may have regarding the formal service, which is a primary barrier to access.

"*What good doctors that are good to go to, like, that's actually- that's a huge one. Um, like, basically talking about like, oh, I have this doctor, I finally found one I trust, here's their information, because, like, you can trust them to do this test and be discreet about it, or you can trust them to do this test. Like, and not be judgmental, or whatever.*" – Emily

Inquiries about sexual health, sex life and dating are necessarily and exclusively exchanged between members of the community. The unique nuances of LGBTQ2+ sexual relations are not broadcasted often in mainstream media and as such have to be acquired and learned, either through word of mouth or experience. Additionally, knowledge about LGBTQ2+ sexual activities, the potential STIs and associated tests are not readily accessible in most formal health care repertoires. Furthermore, engaging in dating as an LGBTQ2+ person bring forth a myriad of specific challenges that are not easily transferable without insider knowledge. Vernacular and terminology that are not necessarily unique to the community will often be utilized to describe the types of relations or sexual activities that LGBTQ2+ individuals may be seeking and would only be understood given the appropriate context. This makes it incredibly difficult to discuss these facets of our lives with those not participating in the LGBTQ2+ dating or hookup scene.

"*Yeah, like we'll talk more about like, you know, like our queer- like sexual encounters or like, you know, dating other queer people and like relationships and how that* *like, the dating world is like. But yeah, I'll only talk about that with my other like, queer friends. I won't talk about that with my straight friends.*" – Cavendish

Furthermore, there are certain gender affirming practices present with the LGBTQ2+ community that additionally would not fall under the standard comprehension of cishet individuals, and as such lack formal resources. As mentioned previously, gender affirming or transition related actions such as chest binding and the administration of hormone therapy require proper knowledge and instruction in order to prevent the users from causing undesired harm to themselves. Additionally, actions such as wearing a packer or tucking one's genitalia do not have a lot of written resources on how to perform them or where to acquire the necessary materials. The spread of this information alongside with the materials is an unvaluable resource to allow for the successful performing of these actions that can only be easily ascertained from within the community.

"*So, for me, I think that's a major one that I see, I also have engaged in a lot of, like care towards like binders, safety, and like accountability of what it means to like, find a good binder, how to bind safely and things like that. So those are sort of the two big sort of things I like, these are things I would like, reach out to my doctor about because like I don't just for- it feels like a spiral of a conversation that I don't really want to talk about, or like, explain, like, does my like- am I the first person coming into my doctor talking about binders?"* – Pollux

Kermit provided another, more specific, example, stating:

"*I mean, yeah, like when I called [redacted] or when he called me and told me all about that, like when I- I've been seeking out, like tattoo nipple artists, you know, like because that's not something you can just Google like you can't just Google 'Toronto nipple artists' like it's not like 'tattoo artists' like that's not a thing. Like*." –Kermit

The access to online communication has been a huge facilitator towards the access to LGBTQ2+ specific information and has allowed for the dissemination and collection of knowledge and resources. Social media forums have become the primary location to discover share and receive advice on various LGBTQ2+ challenges. They also provide the opportunity to, generally discuss one another's experiences living as LGBTQ2+ individuals. Not only does access to the internet's wealth of knowledge provide a seemingly endless stream of information regarding the lives of LGBTQ2+ individuals, it also provides an anonymous means to spread and receive these experiences.

"*Yeah, well, so I would say that, like, other examples are what- kind of what we talked about with the like whole online, the ones that I consider both like very helpful, but it's like the- like the social media care, where people are providing like symptom lists and tips as to like, how to cope and, like, what, what's different between like, like dating scenes, and like things you should know when talking to people of like, gender diverse gender identities. And like, basically, like how to interact- like a 'how-to guide' to interacting with the world is like a huge a huge thing."* – Emily

Research Diary 7: My Experiences and Opinions with Online Care Communities

Growing up in a small town where most people knew each other, it was difficult to talk about LGBTQ2+ topics without outing yourself, and it was difficult to find or connect to other LGBTQ2+ individuals without talking about being gay. Eventually, I found myself participating in online LGBTQ2+ group chats and forums, usually tethered together by common interested beyond sexuality, like comics, gaming and other shared media. Personally, my online relationships with fellow community members have only grown and strengthened over the past 2 years during the pandemic. I frequently engage in group chats and voice/video calls with other LGBTQ2+ gamers and artists in order to stay connected. It feels nice and, in a sense, healing to be able to completely be myself around these friends and safely discuss our LGBTQ2+ related issues in our pocket of the internet. I just think that it is incredible that most recently I was in a call with LGBTQ2+ people from 5 different continents bonding over the same video games. It makes me feel like I am not alone in this world, it made me feel care for and cared about, and that even if being LGBTQ2+ marginalizes me , that we are still all over the globe trying to live our authentic lives.

As vast as the internet can feel at times, it has been an incredibly formative tool in my journey of self-discovery. Being able to ask the void, also known as a google search in a private tab, "am I gay?" as a teen is an invaluable experience that most young people who question their sexuality go through. Of course, the results were always inconclusive with most telling you "Well, if you have to ask, chances are yes". Being able to safely explore one's sexuality in an online space became a common occurrence for the LGBTQ2+ youth in *my circles, and by doing so led us to discover these online communities of other LGBTQ2+ individuals looking for their people also. I owe a lot of my knowledge on LGBTQ2+ topics to those on these forums, whom most likely learned what they know from other forums of the same nature. The passing down of knowledge through a widely accessible platform to this scale was previously not available and it only continues to grow.*

A large portion of the advice on these forums surrounds the topic of navigating health care and or how to proceed with taking care of your health or transition without interacting with a medical professional. Reading about someone else going through a similar medical scenario provides an abundant amount of information that can often spare LGBTQ2+ individuals a trip to a clinic where they would have felt uncomfortable sharing their circumstances.

"*I do know that, so, within the online sphere of social media, I know that people will surround themselves in their accounts with person- like similar aligning views and people. So online on certain social medias, a lot of the circles that I would be in would be LGBTQ plus, and you would see a lot of people try and share tips and resources for LGBTQ plus care or like their knowledge on certain things, because they knew that the like, access to professional medicine and professional health care is more difficult. Like It's difficult in general, so, I've seen a lot of care through those circles*".—Math

Kermit and Emily shared their thoughts about the specific LGBTQ2+ Reddit threads:

"So, like I had to go online and seek out like Reddit communities and like online communities and stop and ask people for resources."– Kermit

"Oh, my god, yeah, um, it's like Reddit. I like, again, I'm new to this or new to this platform, but Reddit's just like this smorgasbord of people help trying to help others and like providing Community Care." – Emily

The self-care information being provided through these online channels are insurmountably valuable to members of the community who are avoidant of formal health care services. However, this behaviour also comes with its own sets of risk, especially in cases of those who are transitioning without going to medical professionals.

"I mean, like, it's just especially being in the trans community that is such an informal based health care. Or just care system that like we have like together, like it's so, you know, like a lot of people will DIY their own hormones, you know, they go online. There's whole like- there's like subreddits dedicated to it and stuff like that of just people telling each other how to purposefully go throughout their transition without having to see a doctor." – Kermit

The risks involved have led the participants of this study to have mixed opinions about the use of online forums to receive health information because anyone can say anything on the internet, and some people may be spreading misinformation with the intention to harm LGBTQ2+ groups. While I am grateful that this trans sensitive information is being distributed, there is still a level of threat to one's health being presented through homebrewed hormones or other medical procedures. The real issues stem from the fact that these unmonitored and unregulated actions that are potentially harmful are taking place due to barriers preventing trans people from confidently seeking formal services.

Furthermore, a few participants discussed that sometimes LGBTQ2+ individuals feel that they must be the one to be the saviour of all those who are struggling with their identity and may place an unnecessary amount of pressure on those questioning their gender and sexuality. I feel similarly in this regard, more so pertaining to the fact that most strangers on the internet are not professionally trained to handle sensitive and personal qualms of this nature, and that their only expertise comes from being LGBTQ2+.

"*Yeah, I have a very negative view of… um, it's- it's not healthy because this is actually something very important that a lot of us are not professionally like capable of addressing, you should like talk to the therapist that you mentioned in your like- in your post or like you should, right?*" — Emily

Math echoed the point made by Emily, noting:

"*I find that I'll probably- a lot of online resources don't like share or show that experience, and that you need to, you know, hear from someone who's done it because you're not going to find the most accurate information online.*" – Math

Epistemic exchange within the LGBTQ2+ community enables its marginalized members to become the owners of useful knowledge. It is empowering to be the owners of this knowledge, especially since we literally cannot find it elsewhere. Thus, we must use these knowledge exchanges as not necessarily voluntarily but rather as the only resources widely and quickly available to us, just insofar as they equip us with the means to navigate potentially harmful heteronormative assumptions.

"I feel like I really supporting like, the other person I'm speaking with. But at the same token, like, I'm always unsure of like, how like, and like, and also this happens on the flip side, where like, were this advice worked out in reality, sort of thing because the medical system is not great for queer people. yeah. So, but it's become really useful because you develop and like learn ways to like mitigate situations and whatnot." – Pollux

Research Diary 8: My Thoughts on Informal Community-Based Care After the Interviews

Becoming aware of the phenomenon of informal community-based care practices was not as if I was discovering something new, it was more akin to a process of waking up from a trance. I was on autopilot performing these care actions for fellow LGBTQ2+ community members, and never once did I question why I was providing this care or if I should have been or not. The informal community-based care experiences I have engaged in as a provider or recipient have only strengthened my bonds with other LGBTQ2+ individuals and has made me feel that I have cemented my place as a helpful community member that others rely on. It just feels good to provide help and be helped, especially for and by people you can trust. I do feel a certain sense of pride when I am able to successfully provide a level of care that I know formal health care services would have not been able to. On the other hand, mostly when providing physical forms of informal community-based care, I do worry that there is a chance that I could also cause harm to my peers.

Being in health studies and learning about the history of the way the LGBTQ2+ community has been treated by the medical system, ignited within me a drive and a need to *spread this knowledge to prevent horrendous medical discrimination from ever happening again, whether they directly affected me or not. In a way I do feel like these care actions are simultaneously influenced by the notions of what we as LGBTQ2+ individuals would want to receive and would have benefitted from in our times of need, as well as the desire to guard our own and watch them prosper. Sometimes it can feel like the burden of our community's health is far too great, and the risk outweighs the benefits. It is nice to lean on fellow community members, but it is not great that that we feel that we must rely on them. In a perfect world there would be a blended model of care where we help each other because it feels good to relate to those you are providing care to or receiving care form, while simultaneously having the option to safely and confidently pursue formal health care services for treatment, medication and proper diagnosis.*

Chapter 5: Discussion

The purpose of this study was to explore the motivations that lead LGBTQ2+ young adults to avoid formal health care services and examine if and how they employ their own informal community-based care. As a gay health student, it was simple to decide on a topic for my thesis. I wanted to somehow incorporate my identity into my work while also using my platform as a white male researcher to amplify the voices of the LGBTQ2+ community. It is important to note that the responses gathered through this research cannot provide a definitive view of informal care actions that are taking place within the entire community, particularly in other age brackets. As with most anthropological and ethnographic works, this research provides a snapshot of the lives of 10 LGBTQ2+ young adults living in urban/rural/mixed areas in southwestern Ontario. An interesting observation that I made during the interviews was that the participants often spoke on behalf of the community, acting as a representative of their peers. I believe it is because of the shared experiences that is present within the community that the individual accounts of the participants in this study were able to channel the voices of other community member (or at least the members from their subsections) relaying their peer's issues while conversing about their own.

The LGBTQ2+ community is not a static entity conceptually or physically and exists as an amorphous network of connections that are not concretely tangible. It also seems that this community transcends most institutional boundaries. There is not a definitive central hub, or physical catchment area for all LGBTQ2+ community members, as it would be impossible and potentially harmful to localize the sprawl of GSD to a singular location. A striking parallel to the nature of the LGBTQ2+ community as described by the participants can be seen through the concept of ‘imagined communities’ as introduced by Benedict Anderson (1983). Originally used to describe the political community of nations as both limited and sovereign, Anderson describes these communities as being ‘imagined’ because “the members of even the smallest nation will never know most of their fellow members, meet them, or even hear of them, yet in the minds of each lives an image of their communion” (Anderson, 1983: 6). The idea that community bonds can exist in one’s perception of others hold true within the LGBTQ2+ community, for the participants and I all alluded to the fact that we would have some sort of intrinsic amicability towards other LGBTQ2+ individuals, even if they were essentially strangers. Anderson furthers this observation through his explanation of why nations are imagined as communities, stating, “it is imagined as a community, because, regardless of the actual inequality and exploitation that may prevail in each, the nation is always conceived as a deep, horizontal, comradeship” (Anderson, 1983: 7). The nation, in this case the LGBTQ2+ community, being conceived as a comradeship was remarkably relatable for camaraderie was a reoccurring theme among the participants when discussing the motivation behind providing and receiving informal community-based care.

The amorphous nature of the community is reflected in the most progressive forms of thought among members, wherefore younger generations reclaim and prefer the word ‘queer’ as a self-descriptor (Levy & Johnson, 2011; Pepper, 2015). Even though I personally have not reclaimed this term and have refrained incorporating it in this research, the reclamation of the word ‘queer’ has become popularized because as a label it is less rigid and restrictive and allows for fluidity and open-endedness (Levy & Johnson, 2011). Any individual regardless of race, sex, religion, geographic location, economic status, could potentially be a part of this group so long as their identity has some form of GSD (Pepper, 2015). Thus, the widely available potentiality of inclusion allows for a possibility of community that would previously go unseen through a heteronormative lens. As it stands, for young LGBTQ2+ adults there is no physical area where we can really feel completely at home and safe, because we are always going to be a part of a larger system that is heteronormative.

My research brought me to the realization that there are underlying and unseen connections that are present between the members of the LBGTQ2+ community. This takes form in a way of ‘watchfulness’, where the participants described looking out for each other in the presence of adverse circumstances that alienated them from the rest of society (Garcia, 2010). The societal oppression of the LGBTQ2+ community imposed by heteronormative norms ranging from the seemingly mundane absence of diverse gender options on medical forms to the active and direct discrimination against LGBTQ2+ individuals; heterosexism runs deep within the roots of every system in this country (Gahagan & Subirana-Malaret, 2018; Meyer et al., 2011). For a group whose oppression is interwoven throughout the entirety of every societal institution, these circumstances are, in a way, ever-present and I believe that this inclination to provide care partially stems from that.

The findings from this research confirm those stating that discrimination and stigmatization continue to plague the experiences of LGBTQ2+ individuals seeking medical care (Brotman et al., 2015; Zay Hta et al., 2021). The engrained heterosexism within the health care system ensures that formal health services are the hardest institutions to navigate for the LGBTQ2+ community (Gahagan & Subirana-Malaret, 2018). The participants of this study echoed these sentiments noting that the lack of the inclusive provision of services creates massive barriers to the accessibility of the current health care system for LGBTQ2+ individuals. The LGBTQ2+ individuals that I interviewed are finding it incredibly difficult to utilize these services for the betterment of their health, and in some instances this perilous journey has instead proven to be a detriment to their overall wellness. Most of the LGBTQ2+ participants noted that the medical, administrative, and political sectors of health care as a social institution do not have adequate gender competency and, as a result, their specific GSD needs are going uncared for. The participants' experiences are congruent with the limited documentation in literature, demonstrating that formal health care services being founded on the heteronormative standards of the western biomedical gaze incites discrimination and prejudice that continues to foster a deep mistrust for the health care system by LGBTQ2+ young adults in southwestern Ontario (Gahagan & Subirana-Malaret, 2018; Warner, 2002; Zay Hta et al., 2021).

The participants and I agreed that the threat of institutional discrimination leads us to carefully curate the identity and information that we share with HCPs. The notions of withholding information and presenting as cishet during medical encounters can be considered a form of code-switching, the process of altering language, style of speech, appearance, behaviours, and expression in order to optimize comfort of others (Peek et al., 2016). Whilst this is a necessary survival tactic that the community has had to hone for centuries, this can cause mental anguish and be harmful to one's sense of identity or well-being. Watering down one's GSD for the sake of appeasing the masses was not an uncommon occurrence among the LGBTQ2+ young adults in this study, however this becomes a greater concern when one's GSD is inscribed upon their physical body.

The emphasis placed on the body within the formal health care system, and the struggles faced by transgender individuals can be shown through the concept of "three bodies" presented by Scheper-Hughes and Lock in "The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology" (1987). The three bodies are described as the individual (referred to as the physical or biological), socio-symbolic body and the body politic, and their delineations in this context provide the source of institutionalized transphobia as well the explanation of the current treatment of transgender bodies (Scheper-Hughes & Lock, 1987). The western biomedical gaze focuses on treating physical and diseased bodies, abnormalities in structure or function, without the consideration of a patient's illness narrative and is not congruent with the gender and sexual fluidity present within the LGBTQ2+ community (Fisher, 2020; Mayer et al., 2008; Scheper-Hughes & Lock, 1987). The way the biomedical gaze treats bodies is a particularly volatile problem for the LGBTQ2+ community, especially for transgender individuals, because their health issues are often harbored within the body; as a physical entity, and the body as a social concept. Allowing already vulnerable LGBTQ2+ bodies to be observed, diagnosed, and treated through a heteronormative lens is in itself an othering experience that is only exacerbated when the biomedical perception of the body is enforced upon the bodies of individuals whose social identities may not reflect the normative perception of the individual body. The pathologizing of transgender bodies, requiring a diagnosis of gender dysphoria for the acquisition of most gender-affirming treatments such as hormone therapy, invokes institutionalized heterosexism that has traumatized many transgender individuals from pursuing medical transition. Therefore, an apparent medical indignity stems from the recognition that the standard of a healthy body has been created by heteronormative baselines, and HCPs that attempt to diagnose, treat, or provide care within these parameters can worsen the health of a transgender care-recipient.

The informal care experiences from my LGBTQ2+ peers continually occurred in times of crises and need, which alerted me to the existence of this happenstance. Over the course of this study, there were many informal community-based care practices that the LGBTQ2+ young adults and myself had previously observed, but also newly discovered forms of care. The emotional and physical well-being support actions were fairly obvious to most participants. Being able to provide guidance for unique emotional turmoil as well as navigation through social institutions as a LGBTQ2+ individual, is an invaluable act of care that can only be provided by those who can empathetically understand the complexities of these situations. Physically, LGBTQ2+ bodies are a site of great sensitivity, and the young adults of this study find themselves more likely to trust someone in their own community to treat their physical ailments over someone with formal medical training. Providing care is also a vulnerable experience; one must put themselves in situations that are potentially volatile depending on the condition of the person in need of care, as well as taking responsibility for any negative health outcome that may occur from the provision of informal care. The innate safety provided from informal community-based care is essential for when one needs care, they are usually in a vulnerable position and would not want to risk the chance of being near harmful agents when expecting the provision of care.

A more intersubjective form of care among the LGBTQ2+ young adults presented itself through the dissemination of community knowledge. The sharing of resources, and information curated through centuries of LGBTQ2+ experience demonstrates, in a philosophical sense, a rhizomatic system. Rhizome as a philosophical term, was introduced by Deleuze and Guattari (1988) in “A thousand plateaus” to demonstrate a non-hierarchical dissemination of information that allows for multiple exit and entry points, similar to the botanical definition referring to how a ‘mass of roots’ spreads water and nutrients. The spread of information horizontally through a system of roots, here accurately describes the flow of epistemic exchange within the ‘rhizome’ of the LGBTQ2+ community. According to Deleuze and Guattari , a "rhizome has no beginning or end; it is always in the middle, between things, interbeing” and as such presents the propagation of history and culture without a singular point of reference (1988:25). A rhizomatic form of knowledge transfer directly opposes the hierarchical way through which information and knowledge are curated and spread within the formal medical system, where health care providers tend to be the sole propagator of information. The current method of resource sharing bypasses the potential of gatekept knowledge, while enabling community members to be the owners of their health information and as such empowering them to informally employ gender-informed care tactics.

The main impetus for the emergence of informal care practices among the LGBTQ2+ participants and myself is a reaction to how society views and treats people in this community, which constricts our ability to pursue any services that are provided by institutions built on hegemonic heteronormative views. In lieu of access to such services we rely on each other’s knowledge, experience, aide, care, assistance, resources, and advice. The reliance on community care comes naturally for there is already the common groundwork and implied or fictive kinship between the LGBTQ2+ community that allows them to understand each other’s plights. The empathic axis provided by this intrinsic connection dissolves any apprehensions that these LGBTQ2+ young adults may have for it is just innately assumed that other community members will be there for support regardless of their relationship beforehand. The participants and I have observed that cishet individuals are not a community under the same pretenses as the LGBTQ2+ community, as there is no assumed pre-existing connection or intrinsic empathetic understanding between cishet individuals. I had originally wondered if the LGBTQ2+ community would not be able to develop this bond without the societal oppression that creates the context for the necessity of informal community-based care. However, it has become apparent through the findings of this study that LGBTQ2+ community members’ amicable actions towards each other are not solely dictated by the societal marginalization of their GSD, for there are other relational factors that go beyond compensating for institutionalized heterosexism.

The philosophical concept of 'I and Thou', introduced by Martin Buber, can provide some insight towards the relational essence of informal community-based care (Buber, 1958). According to Buber, The I-thou type of relation is built from a natural association, and uniquely establishes a new entity known as 'We'(1958). Relating to observations garnered from the LGBTQ2+ young adults in this study, there does prove to be a form of natural association among members of the community based on recognition of identity. In this study, the concept of 'I' is representing an LGBTQ2+ young adults own GSD and 'Thou' is indicative of other individuals who identify as a part of the LGBTQ2+ community . The 'We' that stems from the I-Thou relations, as summarized by Michael Gardiner (1996:125) in his work Alterity and Ethics: A Dialogical Perspective, can "denote a subjective and highly personalistic relation between two flesh-and-blood human being located firmly in actual time and space". In this case, the 'We' is presented in the form of the LGBTQ2+ community as a whole and the nuances for how this community functions mesh well with this concept. Gardiner (1996:125-6) states that the "I-thou encounter 'surpasses understanding" and that it "is not amenable to abstraction or theoretical reduction". The seeming elusiveness of concrete motivations for the strong relations between LGBTQ2+ young adults is again explained well through the notion of I-Thou, for it is a form of contact that goes beyond simple explanation and is not available for scientific examination.

The parallels between these relational concepts and the nature of the LGBTQ2+ community are further exemplified through Gardiner's work that summarized that I-Thou was a "relation of pure reciprocity, of mutuality", formed from the drive for contact and tenderness that “requires a particular type of community” (1996:126-8). The type of community the Gardiner refers to here is a ‘dialogical’ one, which is described as encounters that “requires the participation of ‘one’s whole being’” or “co-presence” during the “enactment of an essential deed” that “does not involve the exercise of conceptual logical thought” (1996:126). Therefore, the necessity to spontaneously and physically be involved in essential deeds, in this case informal community-based care, without any forethought demonstrates the co-presence, or reciprocal caregiving, that is being observed in the participants of this study (Gardiner, 1996). Thus, the carrying out of informal care actions between young adults in the LGBTQ2+ community agreeably overlaps with the I-Thou relational encounter intrinsic to a dialogical community.

The solidarity present within a group of diverse individuals demonstrates the existence of an underlying mechanism that binds this community together. After completing this research, I believe that this ineffable connection is the source of the possibility of a community that allows the LGBTQ2+ community to be categorized as an imagined or dialogical community. A potentiality for the formation of camaraderie through shared experience and identity enables individuals to perceive each other as a collective, one that does not exist by default but materializes due to a desire for belonging and acceptance that may exist separately from, or be exacerbated by, societal marginality. Regardless of the motivation, there is an evident phenomenon of those identifying as LGBTQ2+ openly providing and receiving informal care for one another based on a mutual recognition of community.

: Conclusions

The goal of this study was to demonstrate the existence of informal community-based care among LGBTQ2+ young adults in southern Ontario, identity the potential approaches that these LGBTQ2+ young adults might employ to provide care to, or receive care from, fellow community members, as well as investigate the motivations for these emerging forms of informal care. I found that there is an underlying network of informal caregiving present among these LGBTQ2+ young adults where they provide emotional, physical and epistemic care to one another. The motivation behind the emergence of these informal community-based care practices was demonstrated to be due to an innate kinship they these LGBTQ2+ young adults had with their fellow community members. Furthermore, the need for these forms of informal care was exacerbated by a reluctance to solely rely on formal health care fostered by inequitable access to inclusive services that can provide inadequate or discriminatory treatment.

There is a dearth of research on the informal, community-based care practices present amongst this marginalized population, especially regarding the ways in which wellbeing is being promoted in the LGBTQ2+ community in Southwestern Ontario. My research identified such practices and their importance in understanding ways through which LGBTQ2+ young adults might provide informal care for each other. Ascertaining these understandings will hopefully allow for improvements to the current facilitation of healthcare services by increasing the awareness and visibility of LGBTQ2+ health disparities that the informal community-based care is attempted to compensate for. Enhancing comprehensive formal health care that is perceived as inclusive could address unique health disparities and improve LGBTQ2+ communities' overall health and opinions regarding healthcare services. Thus, the findings of this study can be used towards improving the inclusivity of care being provided by healthcare providers bettering the health seeking behaviours and ultimately the health outcomes of LGBTQ2+ young adults.

Future research on informal care within the LGBTQ2+ community may investigate if informal care practices are widespread across the LGBTQ2+ community in varying demographics (age, ethnicity, income level) and locations, explore if informal community-based care emerges in similarly marginalized groups and the motivations behind those actions, as well as assist in the formation of educational materials aimed at improving the legitimacy and rigor of informal community-based care. The limitation of this studies small sample size of 10 individuals presents challenges with generalizability, and can be improved upon with more wide-scale ethnographic endeavors. Based on the importance of access to informal community-based care by the LGBTQ2+ young adults in southwestern Ontario, my recommendations for implementation would include developing blended models of health care administration that involve inclusive formal health care services working in tandem with the informal community-based practices to provide a more holistic approach to LGBTQ2+ well-being.

Chapter 6: Closing Reflection

If we as LGBTQ2+ young adults are taking matters into our own hands, I do not want that to stop. I don't want to discourage people from doing informal care. I have seen many sources take that kind of spin when researching communities involved in unregulated behaviours. I absolutely agree that we shouldn't be performing our own medical treatments , but in some cases, we must assess the situation we are in and conclude that the benefits of informal care outweigh the risks present with formal services. Regardless of the potential harm, it's like a call to action for us to just pick up the slack to take care of each other. On the other hand, if members of the community are persistent, and continue to pursue formal health care, there is a chance that they could be directly discriminated against or not receive the appropriate care for their situation, especially trans individuals, and that could harm their health anyways. So, there's not much "winning" here, we are damned if we do and damned if we don't, but that's why this concept of informal community care is so interesting and important to me. I feel that as a health student, I obviously still advocate for using health care services when you are sick beyond the means of home remedy and whatnot. However, I would love to see a blended model, similar to how complementary and alternative medicine (CAM) practices can co-exist and work in tandem with the formal health care system. The general recommendation is that CAM is also use simultaneously with formal health care services that are regulated and licensed. In my mind the informal side of the model would function mostly through the epistemic side; getting referrals and recommendations from people we trust in the community, sharing resources, and discussing health information. The *formal side of the model being more physical and medicinal, but the current health care system would have to make several updates and accommodations to be comfortably approachable by LGBTQ2+ individuals. If there was some sort of pamphlet or resource for me as an informal care provider to be able to, like do it at home, safely , that would be novel, and that it would save a lot of hurt and pain in those situations.*

In my ideal world, the formal services would have information and resources on common informal care tactics and how to provide that community-based care. I feel like the informal community-based care can and should act as a first line of defense for LGBTQ2+ well-being, at least until the formalized health care system can make the appropriate changes There are pros and cons within these blended models, but the institutional homophobia and transphobia is pervasive still to this day. Thus, at the moment I think it would be best to encourage autonomy, letting those seeking care to decide what is best for their own well-being. Progress is happening, and I am very happy with a lot of services that have acclimatized to a more progressive society. There are still a lot of improvements to be made. I mean, besides the highly optimistic notion of training medical professionals with gender competency, personally I would like to just find a doctor who is a part of the LGBTQ2+ community themselves. This would make me feel much comfortable. Booking an appointment with a LGBTQ2+ health care provider is the opposite experience of pursuing formal services because instead of the presumed discrimination and barriers, there will be an assumed understanding. Not having to explain the basic attributes of my identity and how that interacts with my physical, mental and sexual health, immediately enables access by *removing the barriers of fear of discrimination, or doubt of professional capability, while increasing the willingness to comfortably share information due to familiarity.*

In the end, this research has provided me with invaluable knowledge about myself and my peers within the LGBTQ2+ community. I have confirmed that this feeling of camaraderie and care for others with shared identities-- that I have felt and observed all my life-- is also the experience of other young adults in the LGBTQ2+ community. The conversations I had during the interviews with LGBTQ2+ young adults were just as therapeutic to me as they were enlightening. It generally just felt really good to talk to other LGBTQ2+ young adults about a topic that was somewhat saddening, but at the same time empowering and inspiring. Our conversations ended with an appreciation for the resilience of the community and optimism about the future of LGBTQ2+ health.

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Appendices

Appendix A: Recruitment Materials

CALL FOR LGBTQ2+ PARTICIPANTS

EXPLORING COMMUNITY-BASED CARE AMONG LGBTQ2+ YOUNG ADULTS IN SOUTHWESTERN ONTARIO

RESEARCH QUESTION

In the absence of sexuality-inclusive and gender competent healthcare, do LGBTQ2+ young adults seek out and/or provide informal community-based care for one another?

ELIGIBILITY

- Ages 18-30
- Identify as LGBTQ2+
- Reside in Southwestern Ontario

PARTICIPATION

- Join a 1-2 hour zoom session for a semi-structured interview
- sharing opinions on the current healthcare system
- Sharing potential experiences with informal community-based care.

RESEARCHER

Logan Reis,
Msc Candidate

For more information about this study, or to volunteer as a participant, contact:
Logan Reis at
[redacted]

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Email response to respondents interested in the study from other recruitment methods

Hello *[Respondent's Name],*

Thank you for your interest in this research study!

At this stage, I will be interviewing LGBTQ2+ young adults to identify in what ways they might provide informal care for each other to further understand the dynamics of this practice. Your involvement in this thesis research will include a semi-structured interview, in which you will be asked about your opinions on the current health care system as well as your potential experiences with informal community-based care. The session will take approximately 1 to 2 hours and it will be from the comfort of your home over video conferencing software, Zoom, or via telephone.

I have attached an information letter that contains more information. if you are still interested in participating after reading the information letter, please sign and return the attached consent form **OR** you will be asked to give verbal consent at the start of the interview session.

Please let me know if you have any questions.

Thank you for your time and consideration.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board.

Best regards,

Logan Reis, BSc
Msc Candidate

<u>If participant agrees to take part in the study, follow-up to email recruitment:</u>

Hello [*Respondent's name*]:

I'm glad to hear that you are interested this research and sharing your experiences with me.

Here are a few things I need you to do before we can conduct this interview.

1) Please read through the attached information letter and consent form. This will give you an overview of the study and inform you on what your role will be in this process
2) Please check to see if you have an up-to-date version of Zoom on your computer. (Please visit https://zoom.us/ to download if you have not already)
3) please sign and return the attached consent form **<u>OR</u>** you will be asked to give verbal consent at the start of the interview session.

Please feel free to email me any questions you have in regard to the study information or consent form, I would be happy to assist you.

After you have read the information and consent form, we will set up the interview at a time most convenient for you.

Thank you for your time and consideration.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board.

Best regards,

Logan Reis, BSc
Msc Candidate

If participant does not agree to take part in the study, follow-up email:

Hello [respondent's name]:

Good to hear back from you. Thank you for letting me know that you are not interested (or unable to) participate in this research.

If you change your mind (or if your plans change), please feel to email me at:

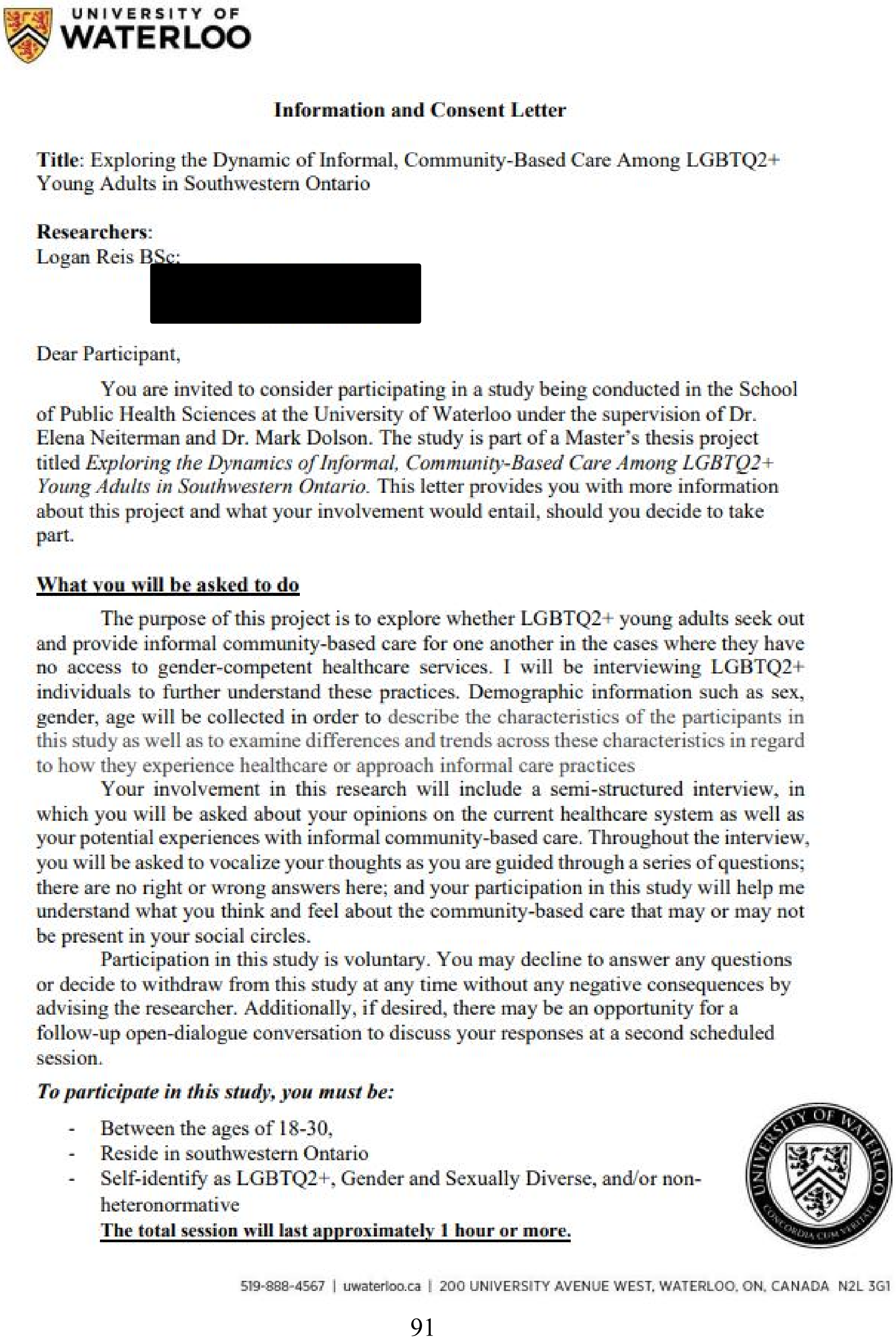
Thank you for your time and consideration.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board.

Best regards,

Logan Reis, BSc
Msc Candidate

Appendix B: Information Letter and Consent Form



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Information and Consent Letter

Title: Exploring the Dynamic of Informal, Community-Based Care Among LGBTQ2+ Young Adults in Southwestern Ontario

Researchers:
Logan Reis BSc;
[redacted]

Dear Participant,

You are invited to consider participating in a study being conducted in the School of Public Health Sciences at the University of Waterloo under the supervision of Dr. Elena Neiterman and Dr. Mark Dolson. The study is part of a Master's thesis project titled *Exploring the Dynamics of Informal, Community-Based Care Among LGBTQ2+ Young Adults in Southwestern Ontario.* This letter provides you with more information about this project and what your involvement would entail, should you decide to take part.

What you will be asked to do

The purpose of this project is to explore whether LGBTQ2+ young adults seek out and provide informal community-based care for one another in the cases where they have no access to gender-competent healthcare services. I will be interviewing LGBTQ2+ individuals to further understand these practices. Demographic information such as sex, gender, age will be collected in order to describe the characteristics of the participants in this study as well as to examine differences and trends across these characteristics in regard to how they experience healthcare or approach informal care practices

Your involvement in this research will include a semi-structured interview, in which you will be asked about your opinions on the current healthcare system as well as your potential experiences with informal community-based care. Throughout the interview, you will be asked to vocalize your thoughts as you are guided through a series of questions; there are no right or wrong answers here; and your participation in this study will help me understand what you think and feel about the community-based care that may or may not be present in your social circles.

Participation in this study is voluntary. You may decline to answer any questions or decide to withdraw from this study at any time without any negative consequences by advising the researcher. Additionally, if desired, there may be an opportunity for a follow-up open-dialogue conversation to discuss your responses at a second scheduled session.

To participate in this study, you must be:

- Between the ages of 18-30,
- Reside in southwestern Ontario
- Self-identify as LGBTQ2+, Gender and Sexually Diverse, and/or non-heteronormative

The total session will last approximately 1 hour or more.

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Collecting and storing data

The interview will be done remotely using video calling software (Zoom, Microsoft Teams, etc) or via telephone. You will be provided with a link to the meeting before the start of the interview session and supported on using the video calling software, should you need help. The session will be audio recorded by the video calling software or via a voice recorder for interviews held over the telephone The participant may choose to either keep their video on and be included in the recording or to interview with no camera. The researcher will download the video and audio files, create a verbatim transcript, and then delete the video files from their records, as they will contain identifiable features. Researchers will retain the audio file and transcript for analysis. The interview recordings, until they are deleted, and subsequential transcripts will be stored on a secure password-protected laptop with access only to myself.

Your rights as a participant

Your participation in this study is purely voluntary. You can choose to not answer any question(s) during the interviews, or the study and you are free to withdraw your participation at any time. If for any reason you feel uncomfortable taking part, please let myself, Logan Reis, know and I will attempt to discuss and address your concerns. You can request your data be removed from the study, all files relating to you will be deleted, up , until results are published as it is not possible to withdraw data once publications have been submitted to publishers (approximately summer 2022).

Risks and Benefits

There are minimal risks to you as a participant in this study. There is potential for a participant to feel upset/distress when recounting a negative experience with the healthcare system. In the event that you become overwhelmed, you will be reassured that the interview or recording can be paused or end at any time throughout the session, that you are allowed to skip any questions, and that your willingness and consent to collaborate can change at your discretion.

You will not benefit directly from participation in this study, but your participation can be a useful contribution for the identification of situations that LGBTQ2+ young adults have faced that pushed them to take their care into their own hands, the ways in which they provide care for one another, and the potential health effects of these phenomena. A goal of this project is to allow for improvements to the current facilitation of healthcare services by increasing the awareness and visibility of LGBTQ2+ health disparities, as well as assist in the formation of educational materials aimed at improving the legitimacy and rigor of informal community-based care. Furthermore, results from this study may be presented at professional conferences and used in articles in professional journals. If the results of the study are published, your name will not be used.

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Confidentiality

The data captured will be stored on a secure password-protected lab server with access only to the researchers. A participant code (not your name) will be used with your data to protect your identity. Electronic files will be kept for a minimum of 1 years, and only the researchers associated with this project will have access to it. Your name will not appear in any report, presentation or publication resulting from this research. Data will be de-identified (i.e., data such as names and non-relevant demographic information will be removed) prior to dissemination. University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information that could link your participation to your computer or electronic device.

Limitations to data privacy

The interview will be conducted over an online platform, Zoom. Zoom has implemented technical, administrative, and physical safeguards to protect the information provided via the Services from loss, misuse, and unauthorized access, disclosure, alteration, or destruction. However, no Internet transmission is ever fully secure or error free.

The password to join the interview will be e-mailed prior and data recorded over the video call will only be stored on a password-protected laptop.

Obtaining the results

You will be provided with a feedback letter upon the completion of your participation. If you are interested and provide your contact information by email, you will also be provided with a copy of any scientific articles prepared for presentation or publication based on this study.

If you would like to receive a copy of any potential study results, please contact [redacted]

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #43739). If you have questions for the Board contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or reb@uwaterloo.ca We very much look forward to speaking with you and thank you in advance for your assistance in this project.

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

please read the following consent form, signing at this moment is not necessary if you would like to provide verbal consent on the items presented below during the interview

I have read the information presented in the information letter about a study being conducted under the supervision of Dr. Elena Neiterman and Dr. Mark Dolson of the School of Public Health Sciences at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that my interview will be audio recorded

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time up until the publication of results without penalty by advising the researcher. After the publication of results, I am aware that researchers will not retract publications on the basis of my withdrawn consent.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #43739). If you have questions for the Board contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or reb@uwaterloo.ca
For all other questions contact Logan Reis [redacted]

With full knowledge of all foregoing (**on the interview day, you will be providing a verbal consent to the following**):

1. I agree, of my own free will, to participate in this study: **YES NO**

2. I agree to audio recording the entire session: **YES NO**

3. I agree to the use of anonymous quotations in theses or publications that come of this research: **YES NO**

4. I would like my contact information to be retained so that I may be contacted with follow-up questions about my responses (secondary scheduled online open-dialogue conversation): **YES NO**

Signature: ________________________ Date: _____________________

Appendix C: Interview Guide

Script: Hello, I hope your day is going well, how is it going? Before I start interviews, I usually just like to get to know each other a bit! My name is Logan, and I am a Homosexual Non-Binary man, and my Pronouns are (he/they). I am currently living in Toronto with my boyfriend and 2 cats (etc.).

What is today's vibe? Can you tell me a little bit about yourself, or if you feel comfortable could you tell me something you are passionate about or some things you like to do for fun?

Do you have any questions for me before we get started? About the interview, or anything (within reason) you'd like to know about me to make you comfortable having this interview with me?

Interview Guide

I'm going to start with some demographic questions, you absolutely don't have to answer any you don't feel comfortable with, just let me know

1. What are your pronouns?
2. If you don't mind me asking, how old are you?
3. Where are you currently living?
4. Would you mind describing how you would identify yourself –your gender identify/expression, sexuality?

Now I'm going to start the interview itself. Remember you can not answer anything, or we can come back to it, and take all the time you need to answer – and your answers can be as long or as short as you would like! The first set of questions are going to be about receiving care from health care professionals. These can be physicians, pharmacists, nurses – any licensed clinician. For this interview I won't be asking about naturopaths, homeopaths, or any alternative care you may receive, though we know how meaningful that care can be.

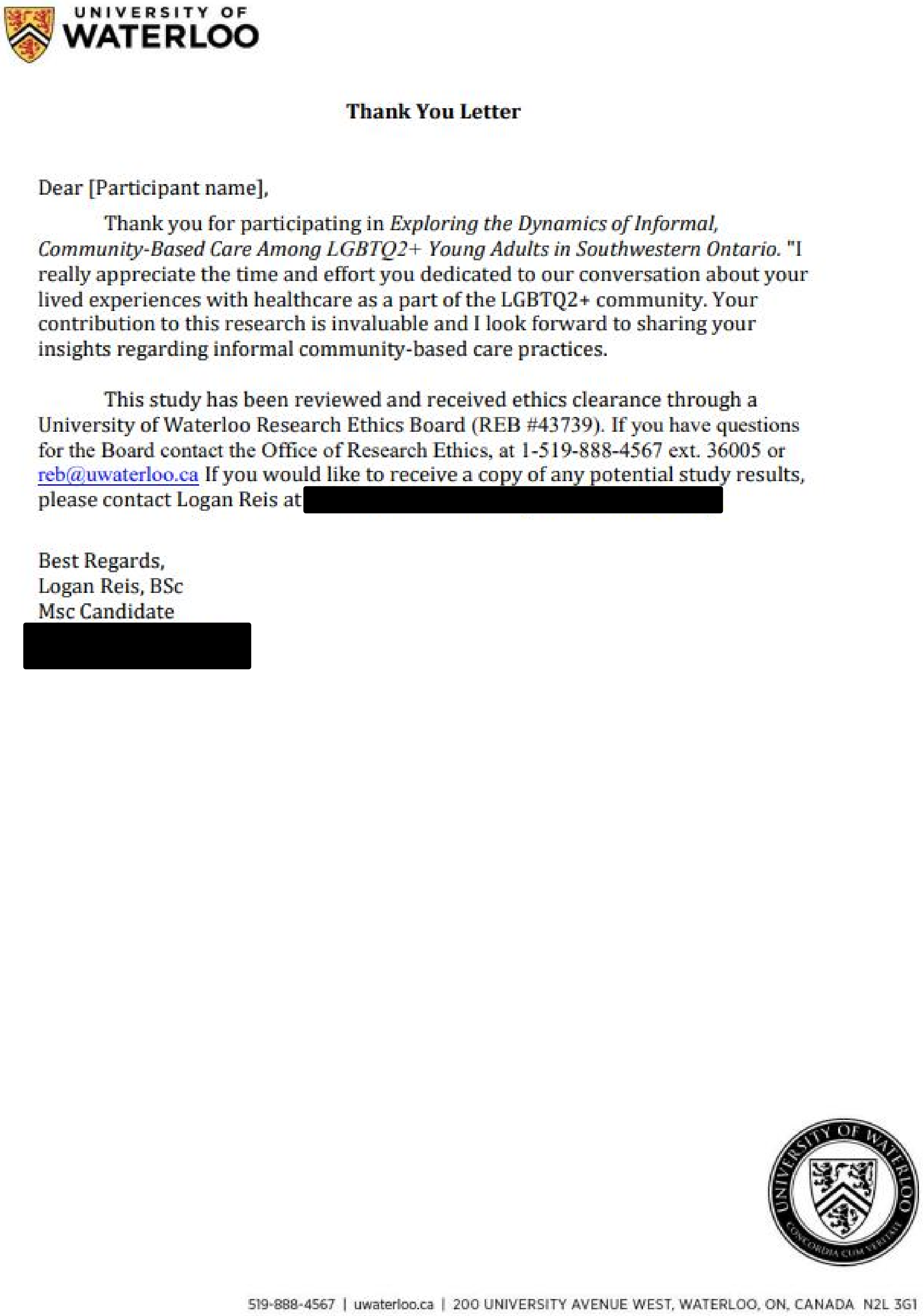
1. How would you describe your experience with the current access you have and quality of health care services?
    a. Can you recall your first medical encounter? What do you remember about it? What had you liked/disliked?
2. Are there any areas of health care that you feel might be impacted by your sexuality and gender identity?
    a. When was the last time you sought out health care services?
3. Have you ever made choices regarding health care based on your sexual identity?

    a. Have you ever felt uncomfortable going to the doctor because of your sexuality or gender?
    b. Have you ever gone to a clinician who you know identified as a member of the LGBTQ+ community? How was that experience?
4. Have you felt directly or indirectly discriminated against in a health care setting?
    a. Can you tell me more about this situation(s)?
    b. On the other hand, can you tell me about any positive experiences you've had with health care?
5. Have you intentionally avoided or delayed seeking health care services? why or why not?

I'm next going to talk about care within the LGBTQ+ community, talking about informal care given within the community. When I say community care, I mean carrying out activities for others who may not be able to do so on their own, demonstrating willingness to assist individuals that they consider one of their own.

6. Have you ever paid attention if members of LGBTQ+ community care for one another? In what way?
7. Has there ever been a time where a fellow member of the LGBTQ2+ community has provided any level of informal care towards you? (i.e., aide to a physical ailment, comforting during a panic attack, advice) Either to aide your mental health, physical health, emotional or social health?
    a. Without giving me any confidential health information, would you mind letting me know what type of care this was (i.e. were you in danger/sick/needed comfort?)
    b. Can you describe how you felt during this event?
    c. Have you ever received care from a friend or other community member who was not part of the LGBTQ+ community, and was that experience different?
8. Have you ever informally cared for the health needs of a fellow LGBTQ2+ community member? maybe a time when someone was sick or needed comfort?
9. If you were in a situation where a friend asked you for help, what are some forms of care that you might provide to fellow LGBTQ2+ community members, if at all?
    a. Would you feel inclined to aide in this situation, why?
    b. Do you think this would be different that you would provide to another friend?
10. If you asked an LGBTQ2+ friend for help, what are some forms of care that you might to provide to fellow community members?
    a. How have you felt supported by fellow community members, if at all?
11. Do you believe there are unspoken ways of caring regarding how LGBTQ2+ individuals look after members of their community?
    a. If so, how would you describe this?
    b. Why do you think this is or is not the case?
12. As our final question, would you like to add something that we didn't have a chance to discuss?

Appendix D: Feedback Letter



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Thank You Letter

Dear [Participant name],

Thank you for participating in *Exploring the Dynamics of Informal, Community-Based Care Among LGBTQ2+ Young Adults in Southwestern Ontario.* "I really appreciate the time and effort you dedicated to our conversation about your lived experiences with healthcare as a part of the LGBTQ2+ community. Your contribution to this research is invaluable and I look forward to sharing your insights regarding informal community-based care practices.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB #43739). If you have questions for the Board contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or reb@uwaterloo.ca If you would like to receive a copy of any potential study results, please contact Logan Reis at [redacted]

Best Regards,
Logan Reis, BSc
Msc Candidate
[redacted]

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