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Medicine, access, spirit, and survival: An intersectional look at concepts of health among a diverse sample of LGBTQ adults

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ABSTRACT

Research on lesbian, gay, bisexual, transgender/gender expansive, and queer (LGBTQ) health is dominated by disparities in disease, access, and risk behaviors. Such research is critical for examining the myriad factors that limit the lives of gender and sexual minorities. Few studies, however, have explored LGBTQ people's concepts of health. People's accounts of health are important, as they reveal insights into a person's relationship to the social world and are fundamental to accessing care. Semi-structured, in-depth individual interviews were conducted with a diverse sample of 40 LGBTQ-identified adults living in New York City, aiming to explore (a) how LGBTQ people conceptualize health, and (b) how participant constructions of health reflect personal, social, cultural, and political subjectivities as well as institutionalized discourses of health and illness. Through framework analysis, four primary themes were identified: (1) health as medicine; (2) health as mind-body-spirit; (3) health as survival; and (4) health as access. Implications for the health professions, including patient-centered care, shared decision-making, and provider training, are discussed.

1. Background

Concepts of health are distinctive and integral sites for understanding how individuals ascribe meaning and value to health, two key catalysts of health care access (Amzat & Razum, 2014; Furnham & Kirkcaldy, 2015). Concepts of health often reflect institutionalized discourses of health, including dominant narratives of health and systems of socialization and education that represent models of health. Lay accounts of health (aka "people's concepts") understand health as a personal, social, and cultural phenomenon (Furnham & Kirkcaldy, 2015). Lesbian, gay, bisexual, transgender/gender expansive, and queer (LGBTQ) people's concepts of health, however, have been historically excluded from broader health research, and health research that does include LGBTQ people often focuses on sexual health – with disparities and risk-based perspectives at the fore. While the number of LGBTQ health studies has grown in recent years, HIV/AIDS and sexual health research still dominate the field. An analysis of all NIH-funded studies, for example, found that 0.1% (n = 113) examined LGBTQ health domains outside of HIV/AIDS and sexual health (Coulter et al., 2014). Acknowledging these gaps, the NIH implemented a strategic plan to advance LGBTQ-specific research (NIH Sexual and Gender Minority Research Office, 2021). While these efforts resulted in both an increase in LGBTQ health projects overall and non-HIV/AIDS projects, HIV/AIDS LGBTQ research still encompasses 56% of the NIH sexual and gender minority health portfolio, while the remaining 44% is split among all other health domains (NIH Sexual and Gender Minority Research Office, 2021). This is integral to consider, as health scholarship grounded in institutionalized, top-down models of health exclude perspectives of LGBTQ communities, generally, and further invisibilize the experiences of those additionally marginalized (e.g., LGBTQ people of color; disabled LGBTQ individuals, poor LGBTQ individuals) by assuming homogeneous understandings of health.

1.1. Institutionalized models of health

Health scholarship, inclusive and exclusive of LGBTQ perspectives, is often informed by a number of dominant frameworks and health models. The biomedical model, however, has prevailed as the predominant framework for Western health care practice and research. This model is based in rationalism, positivism, structural-functionalism, and the belief that human problems can be solved through science (Hardey, 1998). There are several primary tenants upon which the model rests: (1) a

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divide between the mind and body (dualism); 2) the separation of psychological and social processes from the body; (3) the idea that every disease has a pathogenic origin, the causes of which can and should be controlled or removed through intervention. Several alternatives to the biomedical model have been utilized within research, serving as substitutes to the wellness "ease/dis-ease" continuum inherent to biomedical frameworks (Mittelmark & Bull, 2013).

One example of such is the salutogenic (adaptive) model (Antonovsky, 1996), which focuses on health promotion rather than disease prevention and incorporates considerations of adaptation and equilibrium (Mittelmark & Bull, 2013). The salutogenic model presents an alternative perspective to the conventional pathogenic (disease-oriented) model within the realm of health, introducing the concept of health as a "sense of coherence (Mittelmark & Bull, 2013)." The model goes on to explore mechanisms by which individuals maintain their well-being through effective coping with stressors, and places a primary focus on health promotion – it directs attention toward the processes of adaptation and equilibrium, offering a viable alternative to the traditional risk factor model (Mittelmark & Bull, 2013).

Other models consider health more expansively, e.g., the social model of health, which has three main components: (1) social determinants of health (e.g., housing, employment, poverty); (2) rehabilitation, social management of illness, and prevention; (3) policy, societal organization, and economics (Adibi et al., 2014; Broom, 1991). In consideration of these three factors, the social model posits that illness results as an interaction between individuals and their environments/social contexts (Broom, 1991), understanding that structural factors play a role in the interplay between individual experience and societal influence.

Because alternative models are less utilized, health scholarship, policies, and practices continue to be shaped by institutional models. In turn, individual health concepts are influenced by this dominant perspective. Institutionalized discourses have power and influence to shape social discourses via the messaging of a variety of socializing forces (e.g., educational materials and media); as such, pervasive top-down messaging throughout various public and private mediums and socializing forces presents, too, in people's perspectives (Nettleton, 2020). People's perspectives allow for insight into wider meanings of health and illness held by a broader system of knowledge (Moscovici, 1984). As such, dominant approaches to health have often reflected stigma against and stereotyping of LGBTQ people present in broader society/culture – something especially true for representation of LGBTQ Black, Indigenous, and other People of Color (BIPOC) in research (Bowleg et al., 2003; Cyrus, 2017; Elm et al., 2016; Fattoracci et al., 2021).

1.2. People's concepts and LGBTQ concepts of health

People's concepts of health, also referred to as lay accounts, ideas, and beliefs about health, are a significant part of how health is experienced both by LGBTQ and non-LGBTQ people. Several studies have examined what it means to measure and operationalize people's concepts of health more broadly – for example, Mildred Blaxter's (1990, 2010) work has integrated several conceptualizations of health, defining health as: (1) the absence of illness; (2) "function" and "ability" connected to increased physical fitness/vitality; (3) social relationships, as psychosocial well-being, and as behavior. Here, different concepts of health varied in importance for different subgroups: e.g., health as "function" was seen as most important to those with low socioeconomic status (Blaxter, 1990).

Additional studies have reported people's concepts of health as a balance, or as homeostasis (Amzat & Razum, 2014): these conceptualizations have included considerations of internal equilibrium, mind and body, responses to changing environments, and personal comparisons to others. Some reports in research operationalize people's concepts of health as a state or status or as an asset or reserve, e.g., strength and the capacity to resist illness, health as something that can be spent or renewed (Herzlich, 1973).

Few studies have explicitly focused on LGBTQ people's concepts of health. One study (Adams et al., 2013) conducted focus groups with 45 gay men that reported individual explanations of health as both an achievement and a responsibility. However, few participants in the study had social explanations for health, and the study sample was predominately white. A second study (Fogel et al., 2012) surveyed 182 sexual minority women regarding their definitions of health. This study focused on what participants wished to achieve versus behavior modification (e.g., spiritual fulfillment, vitality, absence of stress, focus on a healthy body, eating well, and exercise); despite wider-ranging conceptualizations of health, however, Fogel et al.'s (2012) participants were also predominantly white (80%). As such, neither study was able to report in-depth findings regarding the experiences of LGBTQ people of color. Furthermore, neither study incorporated transgender/gender expansive perspectives, and all participants in both studies were coded as cisgender. Consequently, minimal research examines racially and (trans)gender-diverse LGBTQ concepts of health – two perspectives often overlooked in research on LGBTQ health. Finally, while there are significantly more studies on the illness experience as compared to more holistic research on LGBTQ concepts of health (outside of an exclusive focus on illness or disease), studies on illness are outside the scope of this paper.

1.3. Why LGBTQ concepts of health matter

Measuring people's concepts of health is significant for LGBTQ populations. Perceptions of health and one's body, specifically as one engages with and situates their body within health care settings, is precarious for LGBTQ individuals who are stigmatized by the very systems they are interacting with to seek care. Historically, health care and medical systems have viewed transgender bodies, gender nonconformity, and LGBTQ "behavior" more broadly as deviant, disorderly, risky, and in need of "correcting" (Best, 2012; Bilodeau & Renn, 2005). As such, institutionally-sanctioned stigmatization of difference may lead health professionals to interpret neutral or adaptive behaviors from LGBTQ patients as pathological (Lucksted, 2004).

This directly influences how LGBTQ people consider and understand their own health. Patients' views of health are imbued with medicalized discourses that may or may not align with their actual perceptions and goals related to health and what it means to be healthy (Chapple et al., 2002). Various groups may construct ideas of health alongside or in resistance to these dominant discourses (e.g., George & Rail, 2005), which informs LGBTQ people's access to and engagement with healthcare. As such, health beliefs are fundamental to accessing care (e.g., influencing when and why individuals seek help) and inform health behaviors (Lyons & Chamberlain, 2006).

Furthermore, people's concepts of health likely determine one's ability to perceive the need for care, which is a primary dimension of healthcare access (Levesque et al., 2013). LGBTQ people experience vast disparities in illness, disease burden, and health care access; however, further insight into these disparities relies on LGBTQ people seeking health care services in the first place. This is often not the case due to a number of societal and structural barriers LGBTQ people face across myriad dimensions of health care. For example: a national survey of 27,715 transgender people indicated that nearly one-quarter (23%) of respondents reported that they avoided seeking health care they needed in the past year due to fear of being mistreated as a transgender person (James et al., 2016). When examined in tandem with race/ethnicity, "American Indian (37%) and Middle Eastern (34%) respondents were more likely to not have gone to a doctor or other health care provider due to fear of being disrespected or mistreated as a transgender person (p.98)."

Finally, this must be considered in the context of health constructed as a moral discourse (Herzlich, 1973). The presence of health reflects

correct behavior, self-discipline, willpower, and virtue; how people think about health, theirs, and others', varies with their place in society. This is informed by (A) concepts, behaviors, and experiences of health that vary by social location and (B) the positionality of persons across a spectrum of privilege and marginalization informed by multiplicative social identities and intersecting systems of oppression (Amzat & Razum, 2014; Broom, 1991; Fogel et al., 2012, Adams et al., 2013). This ties to the myriad stigmas LGBTQ people have faced throughout history, ranging from perceptions of LGBTQ bodies and behaviors as deviant, to the challenges faced by multiplicatively marginalized people within LGBTQ communities who navigate compound stigmas that often go unacknowledged within research (Bilodeau & Renn, 2005; Elm et al., 2016; Fattoracci et al., 2021; Lucksted, 2004)

1.4. Theoretical framework

Intersectionality (Crenshaw, 1989) will serve as the guiding theoretical framework for this study. Intersectionality theory has been used by numerous scholars both in and out of health research to conceptualize how compounded axes of oppression and domination intersect to uniquely impact [multiplicatively] marginalized populations (Abrams et al., 2020; Bowleg, 2008, 2013; Hancock, 2007). Having emerged from the foundational work of Black feminist scholars, the theory posits that (a) intersecting, identity-based oppressions are not experienced additively but multiplicatively, and (b) homogenizing broader group identities without examining intersections therein actively exacerbates the challenges faced by those at the distinct crossroads of compounded, interlocking oppression(s) (Bowleg, 2008, 2013; Collins, 1990, 2000; Collins & Bilge, 2016; Crenshaw, 1989; Hancock, 2007; Davis, 1983; hooks 1984, 1981).

As such, integrating intersectionality theory in the interest of nuanced, in-depth research on LGBTQ populations is critical, and becomes all the more salient when conducting research specific to health. Applications of intersectionality not only bring multiplicatively-marginalized LGBTQ people to the fore, but also present a contrasting framework and epistemological paradigm to the biomedical model. Utilizing intersectionality in health scholarship offers researchers an alternative to dominant Western epistemological paradigms around health – the latter of which Indigenous scholars (Dhar, 2019, pp. 1–9; Smith, 1999) have indicated as positioning researchers/practitioners as experts over the experiences of participants/clients, rather than individuals having the agency to define health for themselves, as they experience it. Applications of intersectionality theory that consider multilayered, interlocking systems of oppression and marginalization have the potential to foster agency and autonomy over one's own health narrative and mitigate barriers to accessing culturally appropriate health and social care and (Kapilashrami & Hankivsky, 2018). By adopting this approach and utilizing intersectionality as a grounding theoretical framework, this study aims to prioritize LGBTQ people's health concepts within broader constructions of health and demonstrate how holistic and self-determined LGBTQ health is an integral part of overall health and wellbeing.

1.5. Current study

To address myriad gaps in the literature regarding LGBTQ health, this qualitative study explores people's concepts of health as defined by a diverse sample of LGBTQ adults utilizing intersectionality as a grounding theoretical framework for analysis. This study aims to: (1) explore themes in participants' concepts of health, (2) examine how participants' concepts of health draw upon (or not) institutional and/or people's discourses of health, and (3) draw implications for the health professions. In examining such, this study serves to broaden the scope of LGBTQ research by looking beyond risk, disease, and sexual health – modeling a radical rejection of pathology. Finally, this study contributes to the existing body of knowledge by introducing a diverse sample whose experiences, as reported in findings, will be analyzed utilizing an intersectional lens.

2. Materials and methods

The current study explored how LGBTQ people conceptualize health through semi-structured, in-depth interviews with a diverse sample of 40 LGBTQ adults living in New York City (NYC). Findings of this study are grounded in intersectionality theory, which served as the foundational framework for analysis. This methodological choice was driven by increasing attention to intersectionality within both social work and health scholarship. Centering research and analysis that critically examines and incorporates understandings of compounded oppression has been illustrated by notable intersectionality scholars (e.g Lisa Bowleg, Ange-Marie Hancock) across various disciplines. As such, this study builds upon the work of scholars who have made significant contributions to the integration of intersectionality theory in research. Furthermore, qualitative data collection is uniquely situated to capture interlocking experiences of oppression that influence participant health (Abrams et al., 2020). This was critical to acquiring and understanding findings specific to this study's diverse sample: grounding qualitative work in intersectionality theory allowed researchers the opportunity to gather and interpret findings specific to health concepts for LGBTQ individuals whose identities lie at intersecting axes of oppression or domination.

This study also utilizes a phenomenological, social constructionist, feminist approach to community health psychology (Adibi, 2014) – one that assumes power and oppression are already in play. This approach was utilized as interview data are considered to be discursive reconstructions reflecting personal, social, cultural, and political subjectivities shaped by institutionalized discourses, past experiences, and the research/interview process. As is central to qualitative research in general, inductive reasoning helps us begin to understand how participants make meaning/re-construct their concept of health through dialogue. Finally, scholarship on intersectionality as an emerging research paradigm (Hancock, 2007) indicates that critical theories and constructivist approaches are concordant with intersectionality, as the collective use of these approaches broadens our understanding of how power relations throughout history have shaped today's representation of multiplicatively marginalized experiences.

2.1. Sample

Forty participants were identified and purposively sampled through twelve LGBTQ organizations in NYC. Flyers with information about the study, eligibility requirements, compensation details, and researcher contact information were posted at numerous LGBTQ-specific health and social service agencies across NYC. To promote diversification and broad representation in the sampling process, researchers were mindful of including organizations that supported a wide range of LGBTQ individuals at different intersections (e.g., age, gender, disability). Eligibility for participation included identification as LGBTQ (or another identification outside of cisgender and/or heterosexual) and being at least 18 years old with the ability to give consent.

Sociodemographic information was gathered during interviews following participant completion of a written questionnaire containing open-ended questions specific to demographics. Participants were between 21 and 68 years old ($M = 45$; $SD = 14$), with the majority identifying as African American or Black, poor, and bisexual. Nearly half of participants identified as living with a disability. Regarding gender, ten

participants in the sample identified as transgender/gender expansive, and approximately half of the broader sample identified as cisgender female.[1] The majority of participants (60%) reported past utilization of LGBTQ-specific health services. Table 1 (see A.1) displays sample characteristics by race/ethnicity, gender, sexual identity, socioeconomic status, ability, and age.Table 1 is provided to visually pattern identity intersections across the sample, offering additional context for the preceding report of the distribution of single identity characteristics.

2.2. Interview Procedure

In this phenomenological study, semi-structured, one-on-one in-depth interviews were used to explore the subjective experiences and meaning-making of health among a diverse sample of LGBTQ community members. Individual interviews were conducted with participants from August 2016 through October 2016, and were approximately 60–90 min long. The interview guide was composed by the primary investigator (second author), a researcher with extensive clinical experience working with LGBTQ populations in NYC; the primary investigator subsequently provided focused training in interviewing techniques to the interviewer (third author), who holds a background in both doctoral-level research methods and clinical social work.

Interviewers utilized open-ended questions to conceptualize health with participants, characterizing domains such as perceptions of health, structural barriers, and the role of LGBTQ-specific services when speaking with participants. This consisted of questions such as: "I am trying to understand more about different perceptions or ideas people have about health. Can you talk a little about what it means to you, generally?" Follow-up questions were also utilized in interviews where appropriate, including but not limited to questions such as: "What does health mean to you?" and "How, when, where did you learn about what health is?" This open-ended approach allowed for participants to shape their conceptualization of health in dialogue with the interviewer, rather than respond to a pre-established definition.

The Human Subjects division at [blinded for peer review] provided ethical approval for this study (IRB-FY2016-581, Health Reimagined: Making Meaning of Health in LGBTQ Communities) and involved informed consent. Participants were compensated with $40. Interviews were audio-recorded and transcribed verbatim. Following completion of the interviews, researchers prepared debriefing memos to document emergent themes and observations of both verbal and nonverbal participant cues (Padgett, 2006).

2.3. Data analysis

Data were examined using framework analysis techniques (Ritchie & Spencer, 1994; Ward et al., 2013). Inductive, open-coding was used to identify patterns, and initial codes were organized into a framework of categories and themes. This framework was then applied deductively to the data and further refined. This method involved a five-step process that began with familiarization with the data, during which phase authors reviewed the interview transcripts and key study materials, such as the study description and interview guide. The second step involved coding and identifying themes; two authors led this process of applying codes to key words, phrases, and excerpts of the interview transcript, and then identifying patterns in those codes, and grouping them into themes. The authors then engaged in the third step, bringing those themes back to data, determining the extent to which data converge or diverge with those themes, refining the themes in the process. The final two steps of data analysis involved charting, summarizing interview excerpts within the emergent thematic framework and mapping relationships across themes where they might exist. All analysis included the use of memos to track insights and communicate across the research team. Analysis was done "by hand" with the support of Word and Excel documents.

Several strategies were used to enhance the quality and credibility of this study. Consistent with an intersectional theory and approach to methodology, authors engaged in critical reflexivity practices about how our positionings, points of privilege and disadvantage, and biases influenced the research process. The lead author is a licensed clinician, also a PhD student at the time of writing, whose research examines the criminalization of survival strategies employed by BIPOC women and LGBTQ people experiencing intimate partner violence. The research team consisted of two additional scholars with PhDs in social welfare and social work. Our positionalities included: a (gender)queer, disabled Latine femme of color; a white queer non-binary scholar; a queer-mixed femme who benefits from White privilege. Given our scholarly interests and varying intersectional positionalities of privilege and marginalization relative to the research topic and process, we engaged in reflexive discussion about how our personal, academic and professional backgrounds might impact our framing of the research questions, our grounding of the study in theory, interpersonal dynamics with participants, and analysis. To document and reflect on this, we maintained an audit trail through memos and used peer debriefings to check for researcher biases and how they might be showing up in the research process (Davies & Dodd, 2002).

3. Results

Participants discussed their individual concepts of health in a variety of ways – aligning with and diverging from dominant biomedical models of health – as well as the ways in which they came to internalize these conceptualizations. Four primary themes were identified: 1) health as medicine; 2) health as access; 3) health as mind-body-spirit; and 4) health as survival.

3.1. Health as medicine

Traditional perceptions of health, associated with the biomedical model, were described by the majority of participants. Just as these conceptualizations align with the dominant perspective, generally, understanding health as related to factors such as risk, diagnosis, disease, and physical health prevention and treatment prevailed as one of the most common ways that LGBTQ participants understood health (n = 16).

LGBTQ communities' histories are inextricably linked to the HIV/AIDS epidemic. The lasting impact of this link was apparent as participants detailed their concepts of health. For some participants, HIV and AIDS were central to LGBTQ health. HIV, for example, was described as coming "to mind first" and as "more important to me than […] someone that's not in the community" (N004). Despite improving prognosis for individuals diagnosed with HIV and evolving attitudes, many participants still conceptualized health as an absence of HIV or AIDS describing that "good health" was being "… HIV negative, AIDS negative" (N010). Others verbalized the lingering stigma that the community still faces even if you are in "good health," "A lot of people stigmatize you when you're in a certain community […] they think automatically HIV and AIDS" (N007). One participant who disclosed their HIV status, indicated that this diagnosis was a catalyst for understanding health:

> *I'm HIV positive[…]So when that entered my life that was a whole realm, a whole new world of health, particularly for someone that for the most part learned the hard way on how to manage himself. There's a lot of different tendrils to that, between self-care and then various needs I have just with my own medical issues.* (N035)

Participants who described their health within the dominant medical

[1] Language of "female" or "male" is utilized throughout the paper to reflect participant responses on gender, and is not intended to perpetuate practice in research that conflates gender and sex through interchangeable use of the words male and man, female and woman, etcetera.

model continued to focus on health as the absence of certain conditions (e.g., "diabetes," "high blood pressure," "cancer") and the shape of their "internal physical state" (N021). LGBTQ communities, often surrounded by conversations related to health disparities rather than thriving and health equity and promotion, may come to understand their health as related to deficits rather than holistic wellness. With this perspective, participants only discussed prevention and treatment in relation to physical health needs:

> *"[…]it's like taking care, going to your doctor regularly and getting checked out. Making sure everything is running the way it's supposed to be running. That's what I think health means to me. Basically, being on top of everything and make sure your body's doing what it needs to do"* (N023).

Several participants whose responses fell within the traditional medical model perspective confirmed that health and health care was addressing physical health. These participants listed the types of monitoring medical tests ("mammogram," "pap smear," "EKG,"), health behaviors ("self-care," "exercise," "nutrition," "sleep,"), or interventions ("medications," "chemotherapy") one might engage with to facilitate "good" physical health or mitigate health risks. One participant described health as "Getting regular checkups. Getting tested for STDs. HIV. Hep C. Good eating" (N020), another as "taking care of your body as far as GYN, your heart, your EKG, and anything else that might be wrong with you" (N010). To this group of participants, "Health means when someone is feeling good, they don't have any health issues in their lives" and to do this, "One would have to make sure that they go to the doctor, make sure everything is ok with their health. Check up on what needs to be checked up on" (N027). Responses within this theme may suggest that despite divergence from some societal norms, LGBTQ communities are still impacted by dominant perspectives of health.

3.1.1. Health as access

Health as access (to formal care systems) surfaced as an additional theme, and was described by the fewest number of participants (n = 6). While some participants detailed particular services that facilitated health, others assigned distinct qualities to these services that were necessary to promote access and subsequently, health. One participant indicated that physical and emotional health are the result of "… a doctor that's just open to listening to you" (N014). Another described that health means having access to information and services in different languages (N030). Beyond direct health and mental health services, participants also described health as synonymous with access to other resources that determine health, such as insurance (N009; N014 N034) and healthful foods (N014; N033; N035). Limited findings within this theme may point to barriers to care that restrict participants' beliefs that formal health services can support the health and fortify the health concepts of LGBTQ communities; this said, it is worth noting that among the six participants, five indicated their socioeconomic status as falling within the categories of poor or low income, while the remaining participant identified as homeless. This additional context for findings may indicate access as health concept that carries heightened significance for individuals navigating poverty and homelessness.

3.2. Health as mind, body, spirit

Unlike participants who subscribed to the traditional medical model and provided restricted descriptions of physical health, a second set of participants took a more holistic approach to health, conceptualizing it as the mind-body-spirit (and beyond) connection. Nearly one-third of participants (n = 13) remained grounded in this biopsychosocial-spiritual perspective. The depiction of health among this group was more homogenous than among those who shared different facets of physical health as essential characteristics of their health concepts. They described health as "a combination of components" (N003):

> *"[…]health is basically a mixture of physical, spiritual, emotional, mental, and environmental contributions to the individual […]"* (N003)

The idea of health as the holistic picture of multiple domains was agreed upon by this groups of participants, describing health as "being good physically, emotionally, mentally, spiritually and socially" (n036), "both physical and mental" (N008), and "keeping up a good conscience, a good state of mind, and also physically as well" (N038). Along with these descriptive explanations of holistic health, participants defined *how* they stay well, "I'm gonna treat my body right […] but also, I'm gonna treat my brain right" (N016). Another participant expanded on the nexus of mind, body, and spirit:

> *"What I mean physical is that making sure my body, and I'm taking my medications, that I'm going to the gym, that my body's well fed, that I'm getting my eight hours sleep. When I mean mentally, that I'm doing the right thing, that I'm following my goals, that I'm keeping track of the things that I need to do. And spiritually, making sure that I'm nurturing myself by going to a place where I feel more spiritual, and get connected with a higher power."* (N022)

Among participants, a central tenant for maintaining optimal health was achieving "balance" or "equilibrium" of the physical, mental, emotional, spiritual, and social/environmental dimensions of life, describing that:

> *[…]all of those things are really pertinent if you wanna be healthy all around. Everything has to have an equilibrium to it. One can't be here, and the other one is up here. All of them have to be equal, and you have to deal with each of them individually as well as collectively."* (N018)

Some participants described that they might start to feel negative effects without this balance:

> *I can go about my own day, and physically I could feel that I'm on top of the world, mentally I'm trying to get a point A to point B, but spiritually there might be some little prick in the back of somewhere, I hear a voice or something comes to my ear, and it can damage me spiritually and things. And then that's when depression kicks in […]"* N029

These findings suggest that integrated components share value in promoting wellness among LGBTQ communities and contribute to more holistic conceptualizations of health.

3.3. Health as survival

Structural, interpersonal, and individual/internalized stigma may make it difficult for LGBTQ communities to achieve the balance and equilibrium described as central to health. With this perspective, some participants (n = 17) described health as a more elemental concept, health as survival. Survival, for many participants, meant staying alive and wanting to live. Several participants equated health and life itself, stating "Health is my life. Without health, I have no life" (N002), "Health, to me, is the length of time I'm gonna be on this Earth" (N024),. and "[…] if you don't have health, you don't have nothing" (N006).

Within this theme, participants further explicated the link between health and survival. Threads of self-preservation, self-regulation, simply being able to function and live independently were expressed by participants. These participants both reflected on the current situations contributing to their conceptualization of health as survival and approached their health concepts through a developmental perspective. One participant described, *"Health means living life to the fullest, staying alive, able to function independently, regardless of your disability. The ability to get up in the morning. The ability to rise above the stigma of LGBT […]" (*N019)

While this participant displayed resistance to identity-based stigma, its impact on health concepts may contribute to the unfolding course of other's health concepts. This may be especially true for participants who

described perseverance and their health concepts as evolving over time:

> *"From my past experience when I was not taking care of myself, I didn't care, but once you wanna live and be healthy and just try to live in a world and pursue your career, you wanna take care of yourself, so I think that health is a very important factor in your life because you're not giving up on life, 'cause for a while, I almost gave up."* (N032)

Personal life-experiences helped participants define health as survival within the individual context, for example, through reducing risks, being cautious, exercising self-control. One participant described that they "[…] learned the hard way how to manage" (N035) while another reflected on their trajectory, "Health is very important because when I was younger, I took myself through a lot of—I took a lot of chances when I was younger" (N011). Members of LGBTQ communities have also relied on each other for health and survival because of histories of exclusion. For participants with this standpoint, survival extended beyond the individual to mean community survival. One participant described their own work:

> *"I like to go out and educate people in the community, LGBT community, that health is important to us. In order for us to function on a day-to-day basis, we have to be healthy, we have to stay healthy in order to work and help others to learn how to stay healthy. And that's why I work with LGBT men and women, to let them understand that without us being healthy today, we wouldn't be able to function on a daily basis. I'm grateful that I wake up every morning to do the work that I do, and to go out and educate my clients."* (N040)

Within this community-based context, health began with participants' own survival and wellness in order to provide outreach, education, and support to others. Participants described growing into a shared reliance on each other for health promotion, potentially in response to the community's restricted access to formal care systems. Furthermore, as with access, findings were notable specific to socioeconomic status: of the seventeen participants, fifteen identified as poor/low income and working class, with the remaining two identifying their socioeconomic status as "retired" and "other," respectively.

4. Discussion

This study examines how LGBTQ people conceptualize health, uncovering the extent to which LGBTQ participants'narrative accounts of health reflect broader institutional health paradigms and/or people's discourses of health. Participants demonstrated a range of concepts – individual, relational, and social – in their conceptualizations of health, with a flow between both people's concepts (bottom-up) and institutional concepts (top-down) reflected in their narratives. These findings reflect literature (e.g., Nettleton, 2020) that indicates the continuous interaction of bottom-up and top-down discourses, wherein dominant Western and biomedical concepts filter into people's perspectives throughout various public and private mediums and socializing forces.

The nature of this study's diverse sample richly informed findings and laid the groundwork for advancing intersectional analysis related to concepts of health. The broad range of identities and experiences held by each participant not only allowed for more nuanced considerations of LGBTQ concepts of health, but provided health perspectives of multiplicatively marginalized LGBTQ people that (a) have historically been invisibilized in research, and (b) are most disproportionately impacted by compounding experiences of violence. As such, utilizing an intersectional framework facilitated analysis of how intersecting axes of oppression within LGBTQ communities influence each person's experiences and conceptualizations of health. This is significant in light of dominant institutional paradigms and broader societal norms that frame health in white, cisheteronormative terms and directly influence how multiplicatively marginalized LGBTQ people understand and conceptualize health.

One significant example and consideration of such that came from findings is around disability. Notably, a majority of our disabled participants — 13 out of 18 —identify as bisexual, with 11 of 18 participants identifying bisexual and female. Furthermore, 8 out of 18 bisexual participants are Black/African American, while approximately one-third (6 out of 18) identified as bisexual, female, and Black/African American. These findings underscore the importance of understanding the health beliefs within these intersectional identities and the broader dynamics of invisibility within society.

4.1. How constructions of survival shape LGBTQ concepts of health

Despite sample diversity, dominant institutional constructions of health and survival still played a crucial role in shaping participant conceptualizations of health. Among participants, health was consistently intertwined with messaging from dominant paradigms that stigmatizes LGBTQ people and constructs survival as "independent functioning," despite systemic barriers that LGBTQ people face when attempting to access health care. Patterns arose for participants of color wherein compounded stigmatization directly informed how participants conceptualized health as survival: LGBTQ- and disability-based stigmas compounded to create a distinctive form of marginalization experienced within white, cisheteronormative, ableist constructions of what it means to be healthy and to survive. This is paramount when understanding how LGBTQ concepts of health are influenced by dominant discourse that reifies stigma and marginalization. While dominant constructions of health emerged among participant narratives, the modes of survival connected to such may not actually align with the needs of or serve LGBTQ communities. Furthermore, attempts to uphold biomedical paradigms present in dominant perspectives may harm LGBTQ individuals: participants reported having to overcome significant challenges present within the dominant, medicalized healthcare system to even begin to consider how they personally conceptualized health.

These considerations gain heightened significance when applying both historical and intersectional frameworks to our understandings of health. When integrating experiences of stigmatization at interlocking intersections, we must also consider the role of race, gender, disability, class, and more in the historical policing of gender and sexuality presentations within LGBTQ communities. Inclusive health research and practice necessitates adequately contextualizing things such as the targeted policing of Black LGBTQ people, stigma present in what is considered "legitimate" in the context of healing for disabled LGBTQ people, and more.

For LGBTQ communities, survival has been utilized at the grassroots level as a unifying and mobilizing call against anti-LGBTQ rhetoric and violence, and has permeated cultural symbols for decades (e.g., the Stonewall Uprisings of 1969 against police violence targeting LGBTQ people) (Duberman, 2019). Survival holds specific and important symbolic meaning to LGBTQ communities, particularly for LGBTQ BIPOC and disabled LGBTQ communities; this is evident in "health as survival" findings that (A) conceptualize health as intra-community support, and (B) discuss how historical anti-LGBTQ rhetoric informs conceptualizations of health.

4.2. Problematizing Hyper-focus on LGBTQ disease and disparities

Dominating approaches to the study of LGBTQ health have predominately centered sexual health, focusing on disparities and risk in the context of sexual health rather than understanding sexual health as one component of a broader experience of health. Broader hegemonic social forces shape prevailing biomedical discourses of health, which, in turn, extend to influence how LGBTQ people view their own health, who, often surrounded by conversations on health disparities and pathology rather than health equity and empowerment, may perceive their health in terms of deficits rather than overall well-being. This can be seen reflected in findings that indicated that participants conceptualize health through the lens of risk, diagnosis, disease, health treatment, and

prevention. However, interpretation of the presence of strong biomedical narratives must distinguish between (a) the institutionally sanctioned and perpetuated notion that risk and disease is sole and predominant lens through which LGBTQ people conceptualize health, and (b) the role of historical stigmatization and pathology that has inextricably linked LGBTQ communities to disease and broader epidemics such as HIV/AIDS.

Despite reflections of biomedical paradigms in many participant narratives, when examining subgroups within participant findings, a more holistic conceptualization of health can be discerned. Findings suggest that LGBTQ BIPOC participants may be more resistant to accepting dominant, Western biomedical paradigms, understanding concepts of health largely in the realm of mind, body, and spirit. This is imperative to consider in light of research examining health for white, cisgender, heterosexual samples, which often reduces experiences and conceptualizations of health down to risk, disease, and sexual health (Bailey, 2019). Cisgender and heterosexual individuals also experience health in relation to (a) sexual health and (b) distinct gender and sexuality experiences; yet, cisgender heterosexual people are often considered the unspoken default when sexualities and (non-TGNC) genders go unmentioned, and there is a more comprehensive and holistic focus on health afforded to these populations. These considerations are key in moving toward more comprehensive, inclusive approaches to health research and practice.

4.3. Language's impact on health care access and considerations of cultural and linguistic Consequences

Utilizing an intersectional framework is critical in consideration of how LGBTQ people experience and conceptualize health related to access, and how that translates to culturally exclusive barriers to accessing healthcare. For BIPOC and immigrant populations alike, race and ethnicity are frequently conflated without accounting for nuance or heterogeneity, and Latinx and Asian populations in particular often become amalgamated into ethno-racial singularities; with this, there is often little-to-no consideration of how variation in language impacts access to health care outside of ethno-racial subgroupings that are (a) presented as homogenous, and (b) typically omit LGBTQ narratives. However, access and barriers to health care are critical to consider for LGBTQ people whose first or only language is not English. Over one-third (35%) of participants spoke more than one language, and findings on health as access highlighted language- and culture-based disparities in service inclusion. This is a vital consideration for LGBTQ access to healthcare: certain languages lack inclusive terminology for gender and sexuality, and even when such terms exist, interpreters and translators often do not have the linguistic resources needed to incorporate them.

Furthermore, language is significantly informed by culture: a key consideration when examining findings utilizing an intersectional framework. E.g., participant N030's conceptualization of health, particularly as inclusion of services in different languages, should be understood in light of his experience moving through the world as a (self-described) poor, gay, Hispanic male. To understand intersecting axes of oppression based in poverty, sexuality, Latinidad, and masculinity, we must recognize broader cultures of machismo and "caballerismo" – not only as they vary within different Hispanic/Latinx/e cultures, but also as they present within white American hegemonic norms specific to masculinity (as all participants resided in the U.S. at the time of interview). In recent conversations within research, machismo has not been exclusively restricted toxic masculinity within Hispanic/Latinx/e communities: studies have expanded understandings of machismo to "caballerismo," understood to embody more positive entities such as emotional connectedness and family values (Arciniega et al., 2008; Rivera et al., 2021). However, when examining machismo (especially in contrast to caballerismo), research has indicated machismo as a predictor of (a) negative mental health outcomes for LGBTQ Latinx/e men, and (b) prejudice towards Latinx/e gay men living in the United States (Hirai et al., 2018; Noyola et al., 2020).

This has significant implications for health research that examines access to, and willingness to engage in health care, and is reflective of findings in the broader sample. Contrasting findings regarding health conceptualized as access (the fewest participants among the four themes) versus health as survival (the largest among the four) may indicate ways that health systems are not built for or by LGBTQ individuals, especially BIPOC, disabled, poor LGBTQ communities. Instead, these communities often rely on informal care and mutual aid systems – something heavily represented within the theme of health as survival. This holds particicular cultural and community significance for LGBTQ people, as illustrated in section 4.1.

Findings specific to socioeconomic status provided insight into how institutional paradigms may influence LGBTQ concepts of health, and by extension, impact access and willingness to engage in health care. Poor and low-income participants, who comprised 55% of the sample, were *the significant majority* for health as medicine (68.8%), access (83.3%), and survival (70.6%). However, only half of those who conceptualized health as mind, body, and spirit – opting to deprioritize institutional paradigms in favor of more holistic health conceptualizations – were poor and low-income. The contrasting, higher proportion of working- and middle-class LGBTQ people within this theme may suggest that, if poverty-related healthcare needs are met (even to some small extent), there may be increased capacity/ability to perceive health more holistically.

These implications are all the more significant when considering the work of health scholar and sociologist Mildred Blaxter, who indicates the relationship between poverty and illness as mutually reinforcing: "poverty can certainly make people sick, but equally sickness can make people poor (Blaxter, 1991, p. 88)." Integrating intersectional analysis into Blaxter's understanding of this cyclical relationship deepens implications for poverty, particularly as compounded by disability. Income caps for disabled individuals exist nationwide, and if disabled people surpass these limits, they cannot maintain eligibility for disability and health care programs that are essential to their daily living and survival (Barbarin, 2023). Moreover, federal legislation not only sanctions paying disabled individuals subminimum wage, but explicitly associates the practice with productivity contingent upon (dis)ability (Barbarin, 2023, U.S. Commission on Civil Rights, 2020). As such, the reciprocal relationship between poverty and illness becomes trifold when integrating considerations of disability. This is an essential consideration for healthcare access, and one that is markedly significant for BIPOC and LBGTQ populations who are both poor and disabled.

Finally, geographic context within the United States is an additional and essential consideration re: access and willingness to engage in healthcare. While all participants lived in NYC at the time of interview, several participants had relocated to NYC from states like Alabama and Texas. These participants predominantly relocated in pursuit of improved access to (a) *trans*-affirmative healthcare and (b) less stigmatized and more accessible HIV care. However, the expectation that NYC, as a prominent urban setting, would offer better access to LGBTQ-affirming healthcare did not come to fruition for several participants. For example, one participant felt uneasy about some Atlanta HIV clinics due to their lack of discretion and prominent locations, unlike the more discreet provision of HIV services in their previous state of Louisiana. As such, academics must exercise caution in making assumptions in research that too, presume that LGBTQ people living in urban environments will invariably encounter more affirming and accessible healthcare experiences.

4.4. Study limitations

This study still holds limitations concerning the use of an "LGBTQ aggregate." Despite utilizing an intersectional framework to examine diverse perspectives within the sample regarding age, gender, sexuality,

(dis)ability, socioeconomic status, race and ethnicity, and language(s) spoken, LGBTQ subgroups must be examined to discern any distinctive or additional themes that may be specific particular subsets within LGBTQ populations. This is not to imply singularity of experience within LGBTQ subgroups; rather, a sample that more closely examines subgroup experience(s) can provide further insight into how interlocking oppressions inform concepts of health. Doing so can provide insight regarding any potential commonalities or differences in concepts of health, along with any potential reasons behind said variations. This is especially important to consider as many of these subgroups have been pushed to the margins of already-marginalized communities, simply by nature of experiencing intersecting forms of marginalization and oppression.

Further, methodological strategies intended to specifically enhance qualitative rigor would have enhanced the study. Specifically, reviewing interpretations with participants through a process of member-checking would have helped clarify and enrich our findings; multiple engagements with participants, as well as their input on study questions and analysis, would have added to the trustworthiness of the study. Considering the use of intersectionality as a grounding theoretical framework, the latter is especially important to take into account. It is essential to prioritize the perspectives of multiplicatively marginalized LGBTQ individuals, as we have endeavored to in this study; however, even as LGBTQ researchers who share many of these experiences of marginalization, it is imperative that we still engage in collaboration and coordination with community members to enhance our methodological strategies and broader research. Notwithstanding our own multiplicatively marginalized identities, as researchers, we still possess a significant influence over our participants and over how our participants' narratives are portrayed in research. As such, future research would benefit from a more participatory approach to research investigating meaning-making and beliefs about health and related implications for health and well-being.

4.5. Implications and Recommendations for future research

This study's findings have significant implications for health professionals and health scholars. Incorporating people's concepts of health into how we understand health more broadly is critical for each stage of accessing health care, and should enter the process at the beginning, if imagined as linear. This applies not only to LGBTQ concepts of health, but is significant for all underrepresented and systemically marginalized populations.

For practitioners, patient conceptualizations of health should inform patient-centered care and shared decision making, which ought to be premised upon a mutual, shared, explicit understanding of health beliefs and health related goals. Providing space for discussion of health beliefs opens a learning moment and educational opportunity for practitioners to meet any gaps in a patient's clinical health knowledge, and to meet any gaps in provider knowledge about the patients' health literacy, priorities, values, strengths, and more.

In research, integrating and substantiating LGBTQ people's self-determined concepts of health contributes to the development of intersectional health paradigms that incorporate a multi-faceted, people-first understanding of health. Incorporating both intersectional analysis and consideration of LGBTQ concepts of health in research is key: while there are natural limits to the depth of exploration within a study sample, we cannot underestimate the significance of homogenizing the diverse and multiplicitous experiences of individuals within LGBTQ communities, particularly for multiplicatively marginalized LGBTQ individuals who are more susceptible to invisibilization and amplified stigmatization. The aggregation of these experiences into an LGBTQ monolith is a notable trend and limitation within broader research, and one that emphasizes the importance of utilizing intersectional analysis, both as a theoretical framework and research paradigm.

The implications of such can be seen in the findings of this study. For example, four participants in this study identified as heterosexual. However, research and practice often construct heterosexual as non-LGBTQ, a practice that invisibilizes heterosexual transgender people and conflates gender and sexuality for LGBTQ people. This invisibilization serves as a noteworthy form of exclusion: we cannot begin to understand, in research and more broadly, those whom we cannot see. The implications of said invisibilization are salient at intersecting axes of domination and oppression *within* transgender communities – an important consideration for transgender women's experiences of transmisogyny. Transgender women (particularly transgender women of color) experience ostracization both inside and outside of LGBTQ communities, and face compounded discrimination and transmisogynistic violence more broadly (Arayasirikul & Wilson, 2019; James et al., 2016).

As such, this study's findings hold additional implications regarding the reification of racialized transmisogyny, as all heterosexual participants in this study were African American/Black and Latina transgender women. Transmisogyny has been understudied in health, particularly for transgender women of color (Arayasirikul & Wilson, 2019), and transgender women/transfeminine people face significant barriers in accessing healthcare (James et al., 2016; Vidal-Ortiz, 2008). Thus, moving towards a more inclusive approach – particularly in consideration of transgender/gender expansive concepts of health – allows us to broaden how we understand health beliefs, and can create a more comprehensive picture of LGBTQ concepts of health. Such considerations are key to how both researchers and practitioners holistically understand health, as understandings of health within research shape broader healthcare practices.

5. Conclusion

It is essential to move past cisheteronormative, institutional paradigms and prioritize integrating intersectional LGBTQ concepts of health in order to radically reimagine inclusive health frameworks. Inclusion of LGBTQ people's concepts is not solely a matter of representation, it is integral to all conversations on broader, holistic healthcare, and should not be relegated to a subspecialty or sub-topic specific to sexual health and risk/disease. This perspective may be broadened to all marginalized populations within health research and health care. Disregarding the health beliefs of systemically minoritized communities not only limits our broader understanding of health, but also reifies myriad barriers to access within a significant portion of healthcare.

Thus, if we are to comprehend health beyond dominant, institutionalized discourse that excludes and pathologizes LGBTQ people, we must re-imagine health as grounded in self-determination for LGBTQ people, wherein they have the agency to conceptualize and define their own health. Empowering LGBTQ people to conceptualize their own health has the capacity to profoundly shape healthcare access, health research, health policy, and beyond, benefiting all marginalized and underserved communities, and all intersections therein.

CRediT authorship contribution statement

Jacqueline Cosse: Conceptualization, Formal analysis, Project administration, Visualization, Writing – original draft, Writing – review & editing. **Kimberly Hudson:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Writing – original draft, Writing – review & editing. **Meghan Romanelli:** Data curation, Investigation, Project administration, Validation, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence

the work reported in this paper.

Appendix

A1.

Note: Categories for sexual orientation, gender identity, racial-ethnic identity, and SES utilize participants' own language.

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