

Seeking gender-affirming medical care: A phenomenological inquiry on skillful coping with transgender and non-binary adults in the United States Midwest

Katie Heiden-Rootes,¹ Dixie Meyer,¹ Renata Sledge,¹ Bryce K. Davis,² Theresa Drallmeier,¹ Whitney Linsenmeyer,³ Samantha Levine,¹ Michelle R. Dalton¹

Correspondence: Katie Heiden-Rootes, Department of Family & Community Medicine, Saint Louis University, 3700 Lindell Blvd., Ste 1100, St. Louis, MO 63108, United States.

Tel.: 3149778196.

E-mail: Katie.heidenrootes@health.slu.edu

Key words: Transgender; gender-affirming healthcare; qualitative research; phenomenology; coping.

Contributions: Study conception, design, data collection, analysis, interpretation, and manuscript preparation by KHR; study conception, design, data collection, analysis, interpretation, and manuscript preparation by DM; data collection, analysis, interpretation, and manuscript preparation by RS; data analysis, interpretation, and manuscript preparation by BKD; interpretation, and manuscript preparation by the remaining authors: TD, WL, SL, and Michelle R. Dalton. All authors reviewed the results and approved the final version of the manuscript.

Conflict of interest: The authors declare no potential conflict of interest, and all authors confirm accuracy.

Ethics approval: The Ethics Committee of Saint Louis University approved this study. The study is conformed with the Helsinki Declaration of 1964, as revised in 2013, concerning human and animal rights.

Informed consent: All patients participating in this study signed a written informed consent form for participating in this study.

Patient consent for publication: Written informed consent was obtained from a legally authorized representative(s) for anonymized patient information to be published in this article.

Availability of data and materials: All data generated or analyzed during this study are included in this published article.

Received: 22 May 2023. Accepted: 19 November 2023.

Publisher's note: All claims expressed in this article are solely those of the authors and do not necessarily represent those of their affiliated organizations, or those of the publisher, the editors and the reviewers. Any product that may be evaluated in this article or claim that may be made by its manufacturer is not guaranteed or endorsed by the publisher.

[©]Copyright: The Author(s), 2023 Licensee PAGEPress, Italy Qualitative Research in Medicine & Healthcare 2023; 7:11485 doi:10.4081/qrmh.2023.11485

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial International License (CC BY-NC 4.0) which permits any noncommercial use, distribution, and reproduction in any medium, provided the original author(s) and source are credited.

¹Department of Family & Community Medicine, Saint Louis University, St. Louis, Missouri; ²Clinical Psychology Program, Department of Psychology, Saint Louis University, St. Louis, Missouri; ³Doisy College of Health Science, Department of Nutrition and Dietetics, Saint Louis University, St. Louis, Missouri, United States

ABSTRACT

This study sought to understand how transgender and gender non-binary (TGNB) individuals skillfully cope with healthcare services and to explore how childhood experiences impact expectations, habits, and meaning-making when utilizing healthcare services. Using an interpretive phenomenological approach, we sampled 17, White TGNB adults in the United States, ages 19 to 57, using semi-structed interviews about childhood experiences with healthcare utilization and adult experiences seeking genderaffirming healthcare. Analysis identified one main theme—Anticipate the worst in healthcare and be pleasantly surprised—and three subthemes: i) contrast between positive childhood and negative adulthood experiences in medical care; ii) coping practices for the worst; and iii) finding your unicorn doctor and medical staff for pleasant experiences. Results indicate participants experienced a disruption and acquisition of new coping practices in healthcare settings and the cultivation of a radical imagination for a more liberated medical world for TGNB people. Implications for providers and medical offices for empowering TGNB adults are described.

Introduction

Gender dysphoria, experienced by many transgender and gender nonbinary (TGNB) people, is improved through a social and medically-assisted gender transition because it brings the body into alignment with gender identity (Becker et al., 2016; Van De Grift et al., 2017). Medically-assisted gender transitions can include hormone therapy, commonly called "gender-affirming hormone therapy" (GAHT), to produce masculine/feminine characteristics, as well as masculinizing or feminizing top, bottom, facial, and vocal surgeries (Coleman et al., 2022). GAHT can be performed by an endocrinologist or primary care provider who has training in transgender healthcare (Coleman et al., 2022). Accessing medical care for GAHT can be difficult in certain regions of the United States of America, such as the Midwest and South, and globally, where there is less social acceptance and protection in place for TGNB people (MAP, 2023).





Most (70%) of TGNB adults in the United States report negative healthcare experiences (James et al., 2016) that increase the odds of negative mental health outcomes (Levine et al., 2022). Negative experiences have included provider refusal to touch TGNB patients or provide care, inappropriate touching or handling, provider use of harsh/abusive language, and/or assigning blame to the patient for health problems (Legal, 2010; Levine et al., 2022; Shires & Jaffee, 2015). Fear of these experiences creates a barrier to seeking healthcare. According to Levine et al. (2022), negative healthcare experiences for TGNB people were significantly associated with higher rates of healthcare avoidance and poorer mental health outcomes.

Adverse experiences in medical care are often grounded in a lack of provider knowledge about TGNB people and their healthcare needs (Chisolm-Straker et al., 2018; Fix et al., 2020) and provider transphobic attitudes among providers (Baldwin et al., 2018). Attitudes and biases against TGNB people vary greatly based on political ideology, gender (Riggs & Sion, 2017), religious beliefs, and contact with TGNB people (Ali et al., 2016; Brown et al., 2018; McGeorge et al., 2014). Recent studies with graduate students, medical students, and residents show predominantly positive attitudes and enthusiasm towards learning about TGNB patient needs and treatment (Ali et al., 2016; Johnston & Shearer, 2017); however, this change in trajectory will likely be slowly realized and fail to mitigate continued poor experiences for TGNB patients in the present and near future.

Skillful coping

TGNB people cope with a stigmatizing medical world. Coping is a common psychological construct for describing human efforts towards managing life stressors and stigma experienced by TGNB people (Budge et al., 2017). In phenomenological philosophy, "skillful coping" refers to the everyday, embodied, taken-for-granted ways people move through their worlds (Dreyfus & Hubert, 1991). Skillful coping lacks reflective thinking and is an "absorbed coping" that is not concerned with success, but rather, a sense of "being drawn towards an equilibrium" (Dreyfus, 2014, p. 3). Dreyfus (2014) identifies five stages of skill acquisition: novice, advanced beginner, competent, proficient, and expert. At each stage, individuals develop more sophisticated ways of understanding and responding to situations, allowing them to act more fluidly and effectively within their respective practice or activity.

Acquisition of new coping practices occurs through experience after something goes awry in familiar situations or in response to novel situations or settings. Recognizing that prior ways of coping no longer suffice in such circumstances, individuals develop new coping skills through reflection, trial and error, or from peers who have gained relevant coping skills/expertise. Eventually, new coping practices are absorbed into one's repertoire and can be shared with others (Dreyfus, 2014).

For many patients, healthcare is a foreign world awash with scientific language, bureaucratic rules, and technological imperatives. For patients who are TGNB, their medical world loses its familiarity as well when they seek to obtain GAHT. Where they once were able see a physician for routine care (e.g., wellness visits, flu shots, illness, etc.), seeking GAHT introduces new unknowns about provider attitudes, bias, and readiness to treat TGNB patients (Chisolm-Straker et al., 2018; Jaffee et al., 2016; Stroumsa et al., 2019). Coping with this new world requires developing practices for identifying providers who will meet their needs while mitigating or coping with anticipated stigma and harm in medical settings (Levine et al., 2022). Eventually, patients who are TGNB become experts in skillfully coping with GAHT medical care may expect and plan for stigma and have ready habits for emotional selfcare after visits.

Current study

To better understand how TGNB patients acquire new coping practices and mitigate stigma in medical settings, this study followed a hermeneutic phenomenological approach with one overarching research question: What are the everyday coping practices of TGNB patients seeking gender-affirming hormone therapy? The aims of the study were twofold: 1) to describe everyday healthcare experiences of TGNB adult patients seeking and receiving GAHT and 2) to describe practices for facilitating skillful coping acquisition of TGNB patients seeking GAHT.

Materials and Methods

Study design and theoretical framework

This study utilized a hermeneutic phenomenological, qualitative approach based on an ontological view of being in the world. Humans relate to their world through everyday, embodied activities where skillful coping with the social world is needed (Dreyfus & Hubert, 1991; Heidegger, 2002). A phenomenological approach was ideal to answer the research question, given its emphasis on understanding the conscious experience of everyday life and ordinary experiences (Merriam & Tisdell, 2016).

Setting, participants, and data collection

This study took place in a Midwestern state that holds no anti-discriminatory protections for TGNB people. This creates a unique context for understanding skillful and acquired coping practices of TGNB adults in medical settings and for informing improved clinical care provided to TGNB patients (Benner, 1994). Upon IRB approval from the research team's university, we conducted semi-structured interviews with 17 TGNB adults (see Table 1 for demographics). Participants were predominately racially





White, partnered, employed either full or part time, had some college education, and identified as transgender male or female.

Data were collected in 2019 and 2020 as part of a larger research project (thus, delaying this publication). Inclusion criteria required each participant to i) be aged 15 years or older, ii) have visited a physician in the past two years, and iii) be actively seeking, receiving, or using hormone therapy for a gender transition. Recruitment relied on convenience and snowball sampling methods with flyers at area family medicine and mental health or group psychotherapy agencies. Participants signed a written consent document and re-

viewed it at the beginning of the interview. Interviews lasted between 44 and 75 minutes. (See Table 2 for the interview protocol.) These were conducted in person or by telephone and then transcribed by research assistants or a professional service. Pseudonyms were assigned when transcripts were corrected, removing identifying names and information. All participants received a nominal gift card as incentive.

Data analysis

Thematic analysis followed the six phases outlined by Braun and Clarke (2006): i) familiarizing the team with the

Table 1. Participant demographics.

Pseudonym	Age	Education	Employment	Relationship	Sexuality	Sex assigned at birth	Gender	Income	Mental health utilization
Colton	32	High school diploma	Fed. disability	Significant other	Don't know	Female	Male	1,000-9,000	Currently
Avery	53	Grad/prof degree	Full time	Single	Bi/pan*	Female	Male	40,000-59,000	Never
Jon	31	Some college	Full time	Cohabitating, engaged to significant other	Bi/pan	Female	Male	75,000-99,000	Currently
Esther	34	Some college	Full time	Single	Bi/pan	Male	Female	20,000-39,000	Currently
Rylee	21	Some college	Part time, Full time student	Single	Bi/pan	Male	Female	40,000-59,000	Currently
April	57	High school diploma	Disabled	Single	Heterosexual	Male	Female	1,000-9,000	Currently
Steven	26	College degree	Full time	Married/partnered	Gay	Female	Male	75,000-99,000	Previously
Cameron	19	Some college	Part time, Full time student	Single	Bi/pan, queer	Female	Gender fluid	20,000-39,000	Previously
							ransmasculine		
Isaac	25	College degree	Full time	Divorced	Bi/pan, queer	Female	Male, nonbinary	20,000-39,000	Previously
Elliot	26	Grad/prof degree	Part time	Married/partnered	Queer	Female	Nonbinary, gender queer	40,000-59,000	Previously
Robin	23	Grad/prof degree	Part time	Cohabitating with significant other	Bi/pan	Female	Male	10,000-19,000	Currently
Lincoln	37	College degree	Full time	Married	Heterosexual	Female	Male	>100,000	Previously
Rachel	36	College degree	Full time	Single	Bi/pan	Female	Nonbinary	20,000-39,000	Currently
Ashley	34	Grad/prof degree	Not employed	Significant other	Queer/lesbian	Male	Female	1,000-9,000	Currently
Morgan	34	Some grad school	Full time student	Cohabitating with significant other, divorced	Bi/pan	Male	Female	1,000-9,000	Currently
Mary	30	High school diploma	Not employed	Significant other	Bi/pan	Male	Female	1,000-9,000	Currently
Joey	20	Some college	Part time	Single	Bi/pan	Female	Male	75,000-99,000	Currently

^{*}Bi/pan refers to bisexual or pansexual.

Table 2. Interview protocol.

- 1) Tell me your story about gender identity (includes prompts about childhood exploration, coming out, and family/social reactions)
- 2) Tell me about who in your life supports you now (includes prompts about changes in family relationships since coming out and childhood)
- 3) Tell me about seeing a healthcare provider (e.g., pediatrician) as a child
- 4) Tell me about your general impression of seeking gender affirming medical care
- 5) As you think about the present time, tell me about a positive and then a distressing experience with a healthcare provider (this could be any experience in healthcare from ER to routine visits)
- 6) Have you ever sought counseling or therapy? If so, tell me about your experience there including positive and distressing experiences





data, ii) generating initial codes, iii) searching for themes, iv) reviewing and refining themes, v) defining and naming themes, and vi) producing reports of the themes. The first author began by organizing and then orientating the analysis team to the data. Then, inductive coding of verbatim transcripts was completed by three research assistants and the first author while listening to the audio recordings. Coders paid attention to vocal inflection and tone for providing added meaning to the language. Each interview was independently coded twice by different researchers as a practice of trustworthiness in the analysis process (Colorafi & Evans, 2016). Searching for themes occurred through a team-based approach to collapsing codes followed by the first author developing larger categories that highlighted the shared meaning across multiple codes. Notetaking and commentary about connections and diverging experiences between participant stories were documented in the categories and discussed in analysis team meetings.

All transcripts with coding and commentary was returned to participants for member checking. Fifty percent of the participants returned their transcripts with added commentary via email to the first author. Member checking thus aided in refining codes, drawing meaning, and finalizing themes as participant responses either showed concordance with our findings or provided suggestions where we could more accurately capture the experience of the participants.

Final codes and categories were then gathered into a codebook and organized by initial goals of the study set by the researchers. Final themes were presented to the analysis team and co-authors for choosing quotes and adding commentary and interpretations. We aimed to use participants' language wherever possible for constructing final themes (Benner, 1994).

This manuscript reports on one theme and three subthemes associated with healthcare experiences. Two other themes related to family and coming out are reported on in another published manuscript by the authors (Figure 1) (Heiden-Rootes et al., 2023). This was done because the authors identified two different professional audiences—medical professionals and family scientists—who would benefit from the two manuscripts reporting in their respective journals.

Trustworthiness and credibility

Trustworthiness and credibility were addressed in multiple ways (Morse, 2015). First, all participants agreed to participate in member checking at the time of the interview, and 50% returned feedback. This process informed corrections to our initial coding and deepened our understandings. Next, all interviews were coded by two team members. Team meetings compared stories, coding, and reflected on our interpretations, given our own social contexts. In addition, team meetings allowed us to discuss redundancy we were seeing across participants' experiences for establishing saturation of the data (Hennink et al., 2017). Saturation was met by interview 15; however, we attempted to recruit

"Anticipate the worst" and be "pleasantly suprised

Positive childhood experiences in medical care as backdrop to new fears and negative experiences in adulthood

Coping practices for "the worst"

Finding your "unicorn doctor" and medical staff for pleasant experiences

Avoidence of healthcare

Self advocacy as protection

Figure 1. Meta theme, major themes, and subthemes.





five more participants and were able to interview and consent two of those.

Researcher reflexivity

Eliminating prejudicial bias is impossible; however, it is imperative that researchers are able to identify it to insure that the meanings of the participants are given preference (LeVasseur, 2003). The research team contained cisgender and TGNB researchers and graduate research assistants. Most of the co-authors have training and experience in providing medical and mental healthcare to TGNB people. Two of the authors have extensive experience in qualitative research and education with the TGNB community which aided in identifying bias and increasing researcher humility for privileging the voices of TGNB participants. Two of the authors provide medical care to the TGNB community. Finally, the first author conducted an audit trail by reviewing intake forms for missing data, completion of coding across interviews, a check for inclusivity of experiences in quotes and coding, and completeness of theme development.

Results

Our results are derived from our interpretation of the experiences of our sample and member-checking supporting our interpretation of the findings. Thematic analysis of codes revealed one theme, *Anticipate the worst in health-care and be pleasantly surprised*, and three subthemes.

Theme: Anticipate the worst in healthcare and be pleasantly surprised

The theme describes new expectations in healthcare settings as an TGNB person seeking GAHT and the need to develop practices for managing new fears in medical care. Three subthemes describe the "breakdown" that led to the need for new practices for coping with healthcare as a TGNB person: i) positive childhood experiences in medical care as backdrop to new fears and negative experiences in adulthood; ii) coping practices for the worst, and iii) finding your "unicorn" doctor and medical staff for pleasant experiences.

The themes and subthemes move along a developmental timeline from childhood, to being openly TGNB and experiencing mistreatment in healthcare (i.e., the breakdown), to acquisition of new coping practices, to finding medical care that met their needs and was positive because of the new coping practices. Old ways of coping with medical encounters no longer worked for obtaining the care needed as they faced misgendering, stigma, and mistreatment by medical providers and their office staff. The loss of known practices in medical encounters required acquisition of new coping practices for TGNB patients, including anticipations (or new expectations), self-advocacy, and self-protection for any medical encounter. Skillful coping in medical encounters became an all-encompassing phenomenon that de-

fined the lived world of TGNB patients in medical care: *Anticipate the worst and be pleasantly surprised.* It also became a community process where the support of other TGNB people and family and friend advocates were key to skill acquisition and successful coping.

Subtheme 1. Contrast between positive childhood and negative adulthood experiences in medical care

All participants described either positive or neutral experiences in childhood with physicians and medical providers. Almost all participants (16 out of 17) identified negative experiences in healthcare as an adult. Negative experiences as adults contrasted sharply with largely positive childhood expectations. Participants described families who regularly sought pediatric care in childhood that led to trust in the medical system. In some cases, participants spoke warmly about childhood physicians: "I had a good experience with medical care as a kid. I was never afraid to go to the doctor or anything like that. I mean, especially when he's my doctor and chaperone on the [school] field trip" (Colton). This was both an indicator of family socioeconomic status (e.g., White, middle-class upbringings) and family practices in seeking routine medical care for their children, yet this may also reflect that when our participants were children, their TGNB identity was not openly expressed.

This changed after being out as a TGNB person. Negative, and in some cases abusive (e.g., transphobic comments, examining and touching genitals when unrelated to the reason for seeking care, refusal of care, voyeurism among physicians and residents, misgendering or misnaming, etc.) experiences with providers and medical staff. Negative experiences changed expectations for care in medical settings: "When you go in [for a medical appointment], you must anticipate the worst. And just, always after that, be pleasantly surprised" (Steven).

The patient world of the TGNB participants now included "the worst" possibilities. They needed to be ready for and anticipating negative and abusive experiences in medical care, and they could no longer predict what to expect in medical care: "It's like you never know how it's going to be if you go somewhere [new]" (Jon). The negative experiences taught participants to always be on guard as a means of skillful coping. As Steven shared: "I'm more afraid of you [provider] than you are of me." Positive childhood experiences that initially created patient expectations and practices were no longer useful now as openly TGNB adults.

One participant, Carter, said that he now expected more abuse and could not pretend or hope for anything different. Instead, he said, "It's [abuse and mistreatment in medical settings] going to happen again. It just is." To be TGNB is to have many negative and some abusive experiences in healthcare: "We've all had some kind of terrible experience with the medical community. Most have many over the years" (Carter).



Explanations by participants for why the "the worst" experiences will continue to occur included the religious affiliation of a hospital, lack of education on the part of the medical staff and physicians, ongoing discrimination due to transphobia, and cultural, gender-binary stereotypes and biases: "I have nothing against religious people. I have something against those people who block my access to healthcare because of their religious beliefs" (Robert).

Subtheme 2. Coping practices for the worst

Many participants indicated their childhoods included religious involvement and living in religious, small, rural communities. Participants described knowing early in their lives that being lesbian, gay, bisexual, transgender, and queer (LGBTQ) was "wrong" or "bad," and their experiences in healthcare settings, now as adults, mirrored previous messages and experiences of rejection in their families and communities. As a visibly TGNB person in healthcare, participants needed new practices for obtaining needed care, given that the worst was always possible and would happen again.

Participants described developing new practices through advice and support of TGNB communities located online and through friendships. Initially, most talked about being warned of the worst and were given some guiding rules to follow for finding GAHT, routine, and emergent or urgent care. Guiding rules eventually became everyday practices used routinely and with new providers as needs arose (surgery, pregnancy, etc.).

Two learned practices commonly utilized for coping with the worst emerged from the data: i) avoidance of healthcare and ii) self-advocacy as protection.

Avoidance of healthcare

The most common practice mentioned was avoidance of healthcare all together. About half of the participants described managing new fears of being TGNB in medical care by going years without seeing a physician and avoiding healthcare whenever possible. Esther, for example, described avoidance, even after a car accident:

At that point, I hated doctors. I just didn't want to go. Honestly, unless I was terribly, terribly, terribly ill, and even then.... I had a car accident, and I was able to walk away from it. I am in the ambulance, and I'm just like, "Nope. I'm going home," and they're like, "But you've just been in a major accident." I'm like, "Yeah. I walked over to this ambulance, and I crawled out of my car, and you looked me over. You don't see broken bones. There's a bruised knee. I'm going home." I just didn't like doctors, and I didn't like being around a lot of that.

Avoidance of medical care thus allowed the participants to avoid harm and their own body's fear responses including anxiety and panic attacks when going to a medical visit or when calling to make appointments: "For the visits, most of the time, I almost had panic attacks even before I got in [to the office]" (Steven). With time and practice, Isaac described developing a bulk scheduling approach to necessary medical visits—GAHT, dentist, and primary care provider. He described medical appointments as very nerve wracking and wanting to get them over in one or two days.

Self-advocacy as protection

Despite their hesitancy, participants found themselves in need of medical care for GAHT or other emergent or primary care needs. The coping practices of *self-advocacy as protection* revealed distinct needs of autonomy and safety if engagement with medical care was necessary. This subtheme seems to define the situated freedom (Leonard, 1989) available to TGNB patients in medical care where autonomy and safety are dependent experiences. Autonomy was required for making decisions and accessing the kinds of medical care needed for gender-body congruence. Participants emphasized that TGNB people are not a monolith and have different desires or needs for GAHT and/or surgeries. Participants also described providers who sometimes had stereotyped ideas about feminine and masculine ideals, requiring advocacy for themselves, for instance:

Every transgender person and every person, they experience gender in a different way. And so, every trans person, they're going to have different expectations for their transition, and different things that will make them feel happy and comfortable with their body, whether that be, you know, no surgery, no hormones, to hormones and every surgery under the sun. (Joey)

Joey's comment reflects the need for providers to engage GAHT as a TGNB patient-led experience. To Joey and other participants, "self-advocacy" meant educating providers about TGNB identities, gender expressions, and diversity. It also included screening and researching providers prior to encounters via the web.

Participants described shared lists of possible providers within online TGNB communities, researching providers via web and social media to look for political and religious affiliations, being persistent in trying out and getting in with providers who were known as trans advocates, managing (and limiting) interactions with medical and pharmaceutical staff, and correcting providers when misgendered and about the science of hormone therapy. Some emphasized a sense of empowerment when they were able to autonomously select a provider, see providers respond to their feedback (e.g., seek education and be open to new information), and access GAHT.

Participants described testing those who answered the phones at medical and pharmacy offices or staff, e.g. medical assistants and nurses, to see if they were affirming and supportive. This allowed participants to gauge the degree





of openness to TGNB patients while keeping a safe physical distance:

I called ahead of time, and I spoke to the nurse, and I said, "Look [laughter], I don't want there to be any surprises. But here's the situation," and she was like the third or fourth person. It took a long time to actually get to her. But I did, and she was very nice and handled all my questions. (Avery)

Medical staff routinely misgendered some participants, even when obvious markers of gender were changing due to social expression (e.g., hair style/growth) and hormone therapy (e.g., body changes due to GAHT). In some cases, self-protection and advocacy required leaving and seeking a new physician:

The first office, the people were nice, but it still made me uncomfortable that the whole office all gendered me female. I think for a while, I was just like, well, I was new to being trans, new to getting medical care as a trans person, and I kind of told myself like, "Oh well, this what you gotta put up with sometimes. People are learning." But after a while, I was just like, this is ridiculous. When I started to really look male, and my voice is super deep, and I've changed my name legally, and you're still calling me by female pronouns. (Lincoln)

At other times, participants talked about learning who was affirming in the medical office and being strategic about interacting with them. This included front desk staff and other medical staff such as medical assistants and nurses:

I've been going there [medical office] for a couple of years. I know which nurses and which front desk people are very good about validating, which ones aren't as accepting, and so I try to go to those...because there's usually two or three people that are at the front desk to help people. So, I do try my best to kind of...pick my own adventure when I go into the doctor's office to make it as validating as possible. (Joey)

Self-advocacy as protection also included knowing the current TGNB research on hormone therapy to advocate for GAHT with physicians. Correcting physicians about the science and safety of hormone therapy was a common experience. Most participants did not receive positive responses by physicians when corrected, though two did note that the physician shared their own need to learn and grow in this area, accepting information and correction.

Participants worked with physicians who wanted to provide hormone therapy who did not have much education and experience, but were open to learning, as described by Robin:

I saw it in an OBGYN who had previously had experience with male to female transitions and hormones, but I was going to be her first female to male for the hormones, so I was kind of her guinea pig.

Robin's story for obtaining GAHT includes learning to work with an inexperienced medical provider. Robin also shared the need to endure negative side effects because the provider was still learning and unsure what dosages were appropriate. Robin described needing to advocate for changes to the dosage when side effects became debilitating.

A few participants brought printed peer-reviewed articles or written self-studies and summaries to their medical appointments:

I had looked up several published studies that said the same thing: Once testosterone is out of your system and reproductive organs start back up, it is probably not a big deal. And so, my husband and I, being weird nerdy engineers, calculated the half-life of testosterone in the blood and did a huge.... I even wrote a study and published it, not in a legit thing, but wrote it all up to explain it. Here is where I started, here is what I did, here is where I am today. There is barely any testosterone in my system. So, BOOM." (Isaac)

Others spoke up immediately when physicians recommended changes to dosage or types of hormone therapies. Colton, for example, described clear opposition to his physician's recommended changes out of self-protection for himself:

When my doctor suggested a different form of testosterone, I voiced my opinion, and I was like, "No, I think this will be the best for me." I was like, "If I'm wrong, I can find out that I'm wrong on my own."

Subtheme 3: Finding your unicorn doctor and medical staff for pleasant experiences

The worst experiences contrasted sharply with the very good experiences that were unexpected, what one participant called finding "a unicorn doctor." The *unicorn doctor* experiences were full of emotion during the interviews—happiness, surprise, relief, and excitement. Participants talked about finally experiencing safety, respect, being believed or trusted, having their correct names and pronouns used, and being in the care of educated medical providers and staff. This culminated into straightforward access to GAHT where participants did not need to educate, avoid, or convince providers of the treatment needed.





Rylee, for instance, recalled, "My most positive single moment was back when the endocrinologist was, like, 'Yep, here's your prescription for hormones,' and I'm like, 'Wait. What?'" Rylee's story highlights confusion and surprise upon receiving GAHT without self-advocacy as the physician completed the needed assessments, was adequately trained, and was ready to fulfill her needed prescription for GAHT.

An exemplar of *unicorn doctor* experiences was the story Isaac told of giving birth as a transgender man. He described a nurse who advocated for him and his partner from initial contact with the hospital to aftercare, all the while seeing Isaac as a whole, dignified person. This included overt communication of advocacy and introducing Isaac and his partner to the entire hospital staff in the delivery unit during a visit prior to delivery: "She was like—'I am going to fight for you guys, and you are going to stay here. I am going to take care of you.' She was going to overstep so we got what we needed carewise."

After the baby's delivery, the nurse maintained routine visits with Isaac, his partner, and the baby inquiring about Isaac's work life:

She could have just asked "How's the baby?" and all, but she reached out even further than the walls of the hospital and was, like, "How is the school [Isaac's employer] handling this? Is there anything we can do for you guys?" And that's just something you don't see.

The provider was able to see Isaac (and his baby and partner) as patients who needed intentional care. This stood out as an unusual experience, even among the *unicorn doctor* stories, because of how far the nurse went to address the known mistreatment risks for TGNB patients in healthcare.

Almost all the very good healthcare experiences occurred with providers who were recommended to participants by another TGNB person, an LGBTQ organization, or an online TGNB community. An informal network of providers was being documented and shared to ensure collective safety and promote what one participant called, "trans joy" (Rylee). Lincoln shared an experience of obtaining a referral for top surgery through the informal network of provider names that led to intentional care, highlighted issues of insurance, and also manifested as respectful treatment of his partner by staff:

This surgeon came highly recommended from my group through [trans org name]. Several of the guys had gone to get their top surgeries with this surgeon. She operates out of an office in [city name] but they [TGNB online community] were telling me, "Look it's worth the drive. This is your body, you know. It's permanent." So, to have this surgeon who came that highly recommended and, again, the office staff

[was] amazing, respectful, worked with me on making sure everything would get processed through my insurance the right way which was really great. It's not just about the surgery itself, but how it's going to be covered. The surgery itself, everybody made sure I was comfortable. They were really respectful to my wife through the whole process. The surgeon gave me her personal cell phone number and was like, "Look, the staff is going to take care of you, but if anything goes wrong, you have a way to contact me directly." (Lincoln)

Coping practices changed with unicorn doctors when responsibility for advocacy shifted to the provider. Participants noted feeling listened to, receiving active responses from their provider, and seeing their provider as educated about the effects of hormones on their bodies. The providers were prepared to take action to fulfill care needs, rather than the patients having to educate their providers: "I'm very happy that I have found medical professionals that have been willing to really take my view and my, my desires, my life into account." (Joey)

While listening may seem like a simple task, the participants described it as unusual and surprising. Most participants who talked about being listened to described it as respectful and, in one case, lifesaving:

Interviewer: Can you say a little bit about what made her [physician] so lifesaving for you? Ashley: Yeah! Um.... She listened.

Discussion

This study described the experiences of TGNB adults who sought GAHT and developed new skillful coping practices for creating a sense of safety in an unpredictable medical world. Our findings add to the growing research investigating how TGNB people cope within a stigmatizing medical and social world (Bhattacharva et al., 2021; Budge et al., 2017; Budge et al., 2013; Riggs et al., 2020). It is tempting to depict TGNB people and our participants as resilient, given their persistence in developing coping strategies to access GAHT and medical care. Our findings illustrate a radical imagination of a liberated medical world for gender-affirming care. "Radical imagination" refers to a hope and vision for a more just and free future that does not yet exist, and yet, the TGNB community persists in attempting to actualize it through culture and practices (Haiven & Khasnabish, 2014). Embedded in their coping practices are efforts to create (through education and selfadvocacy)—or find a unicorn doctor who embodies—the imagined possibilities of a liberated medical world. Radical imagination, then, provides a situated freedom for participants' hopes, meanings, and possibilities for the future to germinate. It is an inner, imagined community space that cannot be taken from them as a collective, but, instead, can





be enacted when it is shared by others in existent healthcare contexts.

Our sample, though, is racially White and well-educated within the USA. The study is missing important voices from the TGNB community including racial, geographic, global, and educational diversity for creating a fuller picture of how radical imagination for TGNB people can embody liberation from racism and other kinds of discrimination. Emerging research on the experiences of TGNB people from historically marginalized racial groups within the USA is beginning to articulate the needed skillful coping practices for navigating both racism and TGNB stigma (Goldenberg et al., 2019; Sherman et al., 2022).

Experiences described by our participants spanned the past 20 years, with the most recent experiences in healthcare being the most positive. This is noteworthy, suggesting some providers are becoming better trained to be inclusive and gender-affirming. It is also possible TGNB people are becoming more skilled at advocating and navigating the healthcare system. TGNB health is not a required part of medical or mental health education in the U.S. or most countries (Korpaisarn & Safer, 2018; Obedin-Maliver et al., 2011). Finding unicorn providers may be particularly difficult in some regions where support for religious freedom allows for healthcare discrimination (Perone, 2020) and new state legislation restricts access to gender-affirming healthcare (Kraschel et al., 2022). Therefore, progress is uneven, and more effort is needed at the national level to mandate standards and improve provider education.

Skillful coping (Dreyfuss, 2014) dictates the need for traditional methods or ways of navigating the world to meet present day experiences. TGNB elders have needed to trailblaze to create new methods of interacting within a sometimes hostile medical environment. As a community, the skillful coping practices of TGNB elders become the explicit rules shared with newly out, young TGNB patients. In this way, skillful coping is a shared endeavor that is shaped by the medical and social contexts of TGNB patients and enhances community connection. Coping practices such as how to connect with TGNB organizations for guidance and how to locate safe provider referral lists are essential in navigating the healthcare system (Lewis et al., 2019). This is especially true in rural communities, where elder TGNB individuals share their coping practices (Scott & Cornelius-White, 2022).

Implications for medical practice and education

The medical system needs to become a system of unicorn providers, inclusive of doctors, nurses, medical staff, and other providers. This study highlights the varied medical contexts, beyond GAHT, TGNB patients find themselves across specialties. Mistreatment should be intolerable within medical culture given the Hippocratic Oath ("do no harm"). TGNB people need routine, urgent, and gender-affirming care, and providers and medical staff who are trained to "pleasantly surprise" and liberate TGNB patients. Practically, while it may be challenging to find a gender-affirming physician, finding an affirming presence in other healthcare providers such as medical staff, nurses, and mental health professionals may give TGNB persons hope, as now, they have a partner in actualizing gender-affirming healthcare.

Despite medical guidelines from the World Professional Association for Transgender Health that emphasize the informed consent model for the provision of GAHT (WPATH, 2022), many medical providers may still require that their patient's gender dysphoria and identity development is documented in a letter of support from a mental health professional. The letter of support creates "proof" for the medical provider to become the unicorn provider, though this can also create an additional burden and financial cost for TGNB patients traversing a complex and hostile healthcare system (Brown et al., 2020). Based on this study and others, the experiences of TGNB patients could be changed dramatically if all providers and medical staff fostered their own comfort in talking to TGNB people (Johnston & Shearer, 2017) in order to facilitate the informed consent model for GAHT. Provider education could include training on reducing microaggressions in healthcare (i.e., misgendering and overemphasizing pronouns), improving bias reflexivity is needed (Munro et al., 2019), and real-world interaction with TGNB patients is needed for improving comfort (Linsenmeyer, Heiden-Rootes, Drallmeier, Rahman, Buxbaum, Rosen, et al., 2023; Linsenmeyer, Heiden-Rootes, Drallmeier, Rahman, Buxbaum, Walcott, et al., 2023). This could facilitate a more collaborative and safe experience where medical staff and physicians seek to know, understood, and advocate with and for TGNB patients.

Second, providers and medical staff should expect TGNB patients to be on-guard and cautious, considering past negative and abusive experiences in medical care. Building rapport and trust is central and inclusive of the entire healthcare team. All members of the healthcare team can create a welcoming environment across the healthcare visit. Several practices can be gleaned from Linsenmeyer, Heiden-Rootes, Drallmeier, Rahman, Buxbaum, Rosen, et al. (2023). For example, subtle affirming practices such as LGBTQ magazines in the waiting room, all front desk staff inquiring about and using appropriate pronouns and preferred names, and recognition of Pride celebrations within the office can change the culture of the medical office to support inclusivity. Medical offices can serve their patients by maintaining referral lists of other gender-affirming providers and services in the areas of mental health professionals, primary care, hair and nail salons, and photography. Finally, providers should collaborate with communitybased organizations and social media groups that serve the TGNB community, given the word-of-mouth culture for vetting the safety of healthcare providers.





Limitations and future research

Our findings inform specific clinical actions or lines of inquiry for continued study (Benner, 1994). While our sample was racially White and recruited from Midwestern suburban and urban areas, we offered one vantage point to gain in-depth descriptions and understandings from those raised in middle class, rural, and White families. Additionally, participants nearly universally reported positive or neutral childhood experiences with healthcare. Given a different recruitment site or a focus on a minoritized racial group, the stories would likely change and offer different insights specific to their contexts. Finally, our results need to be understood in the context of the generation of our participants. Our participants were young (mean age 31.6) and part of a growing TGNB population that is living openly in the United States (CDC, 2023). Our participants have access to national and local organizations focused on TGNB advocacy (e.g., The Trevor Project, American Association for Marital and Family Therapy's Queer & Trans Advocacy Network, and Human Rights Campaign). Given the age of our participants, maybe our participants do not feel as alone as older TGNB people.

Future research could sample purposively from other racial groups and those living in specific regions for assessing needs and identifying needed systemic interventions. Future research may also explore the experiences of TGNB individuals who began their gender transition during childhood or adolescence and how this impacted their experiences with healthcare into adulthood.

Finally, our study only included TGNB adults seeking GAHT. Many TGNB people do not seek medical care for gender-affirmation, yet still interact with the medical world for other healthcare needs. Future research should consider their unique experiences as they elicit different reactions and treatment.

Conclusions

Childhood experiences in medical encounters are often contrasted with experiences of being out and visible as TGNB adult patients. TGNB people "anticipate the worst" and are "pleasantly surprised" in healthcare, developing necessary coping practices of avoidance and self-advocacy as protection as they seek the unicorn doctor who will provide competent and needed GAHT. Results suggest TGNB people must skillfully cope to obtain autonomy and safety in healthcare through vetting, educating, correcting providers, and establishing community networks of referrals. All healthcare providers including physicians, physician assistants, nurses, medical staff, and mental health providers can better serve TGNB patients by actively improving their comfort and advocacy for TGNB patients within the healthcare setting.

References

- Ali, N., Fleisher, W., & Erickson, J. (2016). Psychiatrists' and psychiatry residents' attitudes toward transgender people. *Academic Psychiatry*, 40(2), 268-273.
- Baldwin, A., Dodge, B., Schick, V. R., Light, B., Schnarrs, P. W., Herbenick, D., & Fortenberry, J. D. (2018). Transgender and genderqueer individuals' experiences with health care providers: what's working, what's not, and where do we go from here? *Journal of Health Care for the Poor and Under*served, 29(4), 1300-1318.
- Becker, I., Nieder, T. O., Cerwenka, S., Briken, P., Kreukels, B. P., Cohen-Kettenis, P. T., Cuypere, G., Haraldsen, I. R. H., & Richter-Appelt, H. (2016). Body image in young gender dysphoric adults: a European multi-center study. *Archives of sexual behavior*, 45(3), 559-574.
- Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 99-127). Sage Publications.
- Bhattacharya, N., Budge, S. L., Pantalone, D. W., & Katz-Wise, S. L. (2021). Conceptualizing relationships among transgender and gender diverse youth and their caregivers. *Journal of family psychology: JFP: journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, 35(5), 595–605.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101.
- Brown, H. M., Rostosky, S. S., Reese, R. J., Gunderson, C. J., Kwok, C., & Ryser-Oatman, T. (2020). Blessing or BS? The therapy experiences of transgender and gender nonconforming clients obtaining referral letters for gender affirming medical treatment. *Professional Psychology: Research and Practice*, 51(6), 571.
- Brown, S., Kucharska, J., & Marczak, M. (2018). Mental health practitioners' attitudes towards transgender people: A systematic review of the literature. *International Journal of Transgenderism*, 19(1), 4-24.
- Budge, S. L., Chin, M. Y., & Minero, L. P. (2017). Trans individuals' facilitative coping: An analysis of internal and external processes. *Journal of counseling psychology*, 64(1), 12.
- Budge, S. L., Katz-Wise, S. L., Tebbe, E. N., Howard, K. A., Schneider, C. L., & Rodriguez, A. (2013). Transgender emotional and coping processes: Facilitative and avoidant coping throughout gender transitioning. *The Counseling Psycholo*gist, 41(4), 601-647.
- CDC. (2023). Youth Risk Behavior Survey: Data Summary & Trends Report. Available from: https://www.cdc.gov/healthyyouth/data/yrbs/pdf/YRBS_Data-Summary-Trends_Report2023_508.pdf
- Chisolm-Straker, M., Willging, C., Daul, A. D., McNamara, S., Sante, S. C., Shattuck II, D. G., & Crandall, C. S. (2018).
 Transgender and gender-nonconforming patients in the emergency department: what physicians know, think, and do. *Annals of emergency medicine*, 71(2), 183-188. e181.
- Coleman, E., Radix, A., Bouman, W., Brown, G., De Vries, A., Deutsch, M., Ettner, R., Fraser, L., Goodman, M., & Green, J. (2022). Standards of care for the health of transgender and gender diverse people, version 8. *International Journal of Transgender Health*, 23(sup1), S1-S259.
- Colorafi, K. J., & Evans, B. (2016). Qualitative descriptive meth-





- ods in health science research. *HERD: Health Environments Research & Design Journal*, 9(4), 16-25.
- Dreyfus, H. L. (2014). Skillful coping: Essays on the phenomenology of everyday perception and action. OUP Oxford.
- Dreyfus, H. L., & Hubert, L. (1991). Being-in-the-world: A commentary on Heidegger's Being and Time, Division I. Mit Press.
- Fix, L., Durden, M., Obedin-Maliver, J., Moseson, H., Hastings, J., Stoeffler, A., & Baum, S. E. (2020). Stakeholder perceptions and experiences Regarding access to contraception and abortion for transgender, non-binary, and gender-expansive individuals assigned female at birth in the US. Archives of sexual behavior, 49, 2683-2702.
- Goldenberg, T., Jadwin-Cakmak, L., Popoff, E., Reisner, S. L., Campbell, B. A., & Harper, G. W. (2019). Stigma, gender affirmation, and primary healthcare use among Black transgender youth. *Journal of Adolescent Health*, 65(4), 483-490.
- Heidegger, M. (2002). On time and being. University of Chicago Press.
- Heiden-Rootes, K., Meyer, D., Levine, S., Dalton, M., & Rich, Q. (2023). "Testing the Waters" in a "World That Refuses to Make Space": Development and Coming Out with Transgender and Non-Binary Adults. *Journal of Feminist Family Ther*apy, 1-21.
- Haiven, M., & Khasnabish, A. (2014). The radical imagination: Social movement research in the age of austerity. Fernwood Publishing.
- Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code saturation versus meaning saturation: how many interviews are enough? *Qualitative health research*, 27(4), 591-608.
- Jaffee, K. D., Shires, D. A., & Stroumsa, D. (2016). Discrimination and delayed health care among transgender women and men. *Medical care*, 54(11), 1010-1016.
- James, S., Herman, J., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. a. (2016). The report of the 2015 US transgender survey. Available from: https://transequality.org/sites/default/ files/docs/usts/USTS-Full-Report-Dec17.pdf
- Johnston, C. D., & Shearer, L. S. (2017). Internal medicine resident attitudes, prior education, comfort, and knowledge regarding delivering comprehensive primary care to transgender patients. *Transgend Health*, 2(1), 91-95.
- Korpaisarn, S., & Safer, J. D. (2018). Gaps in transgender medical education among healthcare providers: A major barrier to care for transgender persons. *Reviews in Endocrine and Metabolic Disorders*, 19(3), 271-275.
- Kraschel, K. L., Chen, A., Turban, J. L., & Cohen, G. (2022). Legislation restricting gender-affirming care for transgender youth: Politics eclipse healthcare. *Cell Reports Medicine*, 3(8), 100719.
- Legal, L. (2010). When Health Care Isn't Caring: Lambda Legal's Survey on Discrimination Against LGBT People and People Living with HIV. https://www.lambdalegal.org/sites/default/ files/publications/downloads/whcic-report_when-health-careisnt-caring.pdf
- Leonard, V. W. (1989). A Heideggerian phenomenologic perspective on the concept of the person. Advances in Nursing Science, 11(4), 40-55.
- LeVasseur, J. J. (2003). The problem of bracketing in phenomenology. *Qualitative health research*, 13(3), 408-420.
- Levine, S., Heiden-Rootes, K., & Salas, J. (2022). Associations between healthcare experiences, mental health outcomes, and substance use among transgender adults. *The Journal of the American Board of Family Medicine*, *35*(6), 1092-1102.
- Linsenmeyer, W., Heiden-Rootes, K., Drallmeier, T., Rahman, R.,

- Buxbaum, E., Rosen, W., Gombos, B., & Otte, A. (2023). Advancing Inclusion of Transgender and Gender-Diverse Identities in Clinical Education: A Toolkit for Clinical Educators. *Health Promotion Practice*, Online. https://doi.org/10.1177/15248399231183643
- Linsenmeyer, W., Heiden-Rootes, K., Drallmeier, T., Rahman, R., Buxbaum, E., Walcott, K., Rosen, W., & Gombos, B. (2023). The power to help or harm: student perceptions of transgender health education using a qualitative approach. *BMC Medical Education*, 23(1), 836.
- MAP. (2023). *Snapshot: LGBTQ Equality by State*. Retrieved December 1 from https://www.lgbtmap.org/equality-maps
- McGeorge, C. R., Carlson, T. S., & Toomey, R. B. (2014). The intersection of spirituality, religion, sexual orientation, and gender identity in family therapy training: An exploration of students' beliefs and practices. *Contemporary Family Therapy*, *36*(4), 497-506.
- Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation* (4th ed.). Jossey Bass.
- Morse, J. M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative health research*, 25(9), 1212-1222.
- Munro, L., Travers, R., Woodford, M. R. (2019). Overlooked and invisible: Everyday experiences of microaggressions for LGBTQ adolescents. *Journal of Homosexuality*, 66(10), 1439-1471.
- Obedin-Maliver, J., Goldsmith, E. S., Stewart, L., White, W., Tran, E., Brenman, S., Wells, M., Fetterman, D. M., Garcia, G., & Lunn, M. R. (2011). Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *JAMA*, 306(9), 971-977.
- Perone, A. K. (2020). Protecting Health Care for Transgender Older Adults Amidst a Backlash of US Federal Policies. *Journal of Gerontological Social Work*, 1-10.
- Riggs, D. W., Bartholomaeus, C., & Sansfaçon, A. P. (2020). 'If they didn't support me, I most likely wouldn't be here': Transgender young people and their parents negotiating medical treatment in Australia. *International Journal of Transgender Health*, 21(1), 3-15.
- Riggs, D. W., & Sion, R. (2017). Gender differences in cisgender psychologists' and trainees' attitudes toward transgender people. *Psychology of Men & Masculinity*, 18(2), 187.
- Sherman, A. D., Balthazar, M., Klepper, M., Febres-Cordero, S., Valmeekanathan, A., Prakash, D., Cimino, A. N., Wharton, W., Allure, K., & Kelly, U. (2022). Approach and avoidant coping among black transgender women who have experienced violence: A qualitative analysis. *Psychological Services*, 19(S1), 45.
- Shires, D. A., & Jaffee, K. (2015). Factors associated with health care discrimination experiences among a national sample of female-to-male transgender individuals. *Health & social work*, 40(2), 134-141.
- Stroumsa, D., Shires, D. A., Richardson, C. R., Jaffee, K. D., & Woodford, M. R. (2019). Transphobia rather than education predicts provider knowledge of transgender health care. *Medical education*, 53(4), 398-407.
- Van De Grift, T. C., Elaut, E., Cerwenka, S. C., Cohen-Kettenis, P. T., De Cuypere, G., Richter-Appelt, H., & Kreukels, B. P. (2017). Effects of medical interventions on gender dysphoria and body image: a follow-up study. *Psychosomatic Medicine*, 79(7), 815.
- WPATH. (2022). Standards of Care for the Health of Transsexual, Transgender, and GenderNonconforming People (8th Version). Available from: https://www.wpath.org/soc8

