

"Trans broken arm": Health care stories from transgender people in rural areas

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Douglas Knutson, Julie M. Koch, Tori Arthur,

T. Andrew Mitchell, Meredith A. Martyr

Abstract

According to scholars, transgender and gender diverse individuals suffer disproportionately from health-related concerns such as: depression, anxiety, psychological distress, and HIV infection. Scholars have also found that transgender people experience high rates of homelessness, harassment, violence, and unemployment. These challenges may ultimately affect the physical and emotional health of transgender individuals. Recently, calls for health-related research among LGBT individuals have intensified and scholars and practitioners have begun to focus more heavily on provision of health care to transgender and gender diverse individuals. These efforts have been directed in part by general guidelines produced by national professional organizations. However, little is known about the health-related experiences of transgender people in rural and remote areas of the United States, where individuals may face unique issues and barriers. Thus, the present study was designed to provide rich qualitative data illustrating encounters between rural transgender people and health professionals, as well as, how the rural or remote location of participants plays a role into their health care experiences and access. We used semi-structured interviews to assess the health care related experiences of 10 transgender and gender diverse individuals in rural and remote areas of the U.S. Our analysis resulted in 4 main categories with 12 domains. We present these results and include quotes and vignettes to further illustrate the experiences of our participants. We also present recommendations from participants for providers including suggestions about outreach and training for providers. In the discussion, we highlight ways this study relates to guidelines offered elsewhere.

Keywords

Transgender, rural, health, qualitative

Introduction

In 2016, the National Institutes of Health (NIH) designated the LGBT community a health disparities population (Pérez-Stable, 2016). In its Strategic Plan to Advance Research on the Health and Well-being of Sexual and Gender Minorities (NIH, 2015), the NIH acknowledged important gaps in the literature especially in

regard to LGBT subpopulations (e.g., racial and ethnic groups, small or easy-to-miss demographics). One population of concern may be transgender people in rural and remote areas of the United States. Here, we use the term *transgender* as an umbrella term to encompass a variety of gender diverse people who may or may not *transition* from their gender assigned at birth to their true gender (WPATH, 2011). In general, society is un-

derstood to impose a *gender binary* or a categorization system that forces one to identify as either male or female (WPATH, 2011). Transgender people may or may not pursue *transition(s)* or may take steps to outwardly or socially present their gender identity (WPATH, 2011). Individuals who endorse a gender identity that is the same as the gender they were assigned at birth are referred to as *cisgender* or *cis* (APA, 2015). One indicator of a person's gender identity is the pronouns they prefer to use (e.g., he, she, or they) (WPATH, 2011).

Scholars in a variety of disciplines (e.g., public health, psychology, the medical field) have offered insight into barriers to health care experienced by transgender people (Kitts, 2010; Koch & Knutson, 2016; Lombardi, 2001). Studies of challenges that impede access to health care among transgender people are both expository (Lombardi, 2001) and research-based (Kitts, 2010) and they highlight issues from the absence of adequate resources to the medical knowledge deficits among providers (Snelgrove, Jasudavicius, Rowe, Head, & Bauer, 2012).

Despite the existence of these largely urban-based studies, researchers have highlighted the dearth of information regarding provision of health care to transgender individuals in rural and remote areas (Horvath et al., 2014; Koch & Knutson, 2016). As explained by the NIH, LGBT individuals in rural areas may be difficult to reach because they may lack resources through which they may be identified (NIH, 2016). Scholars have offered preliminary recommendations to health care providers based on case study

data and on localized studies of health care provider attitudes (Knutson & Koch, 2016; Willging, Salvador & Kano, 2006). These scholars call for greater attention to quality service provision and offer best practices with transgender individuals (Koch & Knutson, 2016; Willging et al., 2006).

It is likely that the NIH move to reclassify LGBT groups as a health disparities

There's this thing called 'trans broken arm,' right? You know, where someone might come into the doctor with a broken arm and if you're cis or not presenting in a way that's confusing for people, it's a broken arm, but if you're presenting as trans, there's this whole other layer of, 'Okay, so did you get the broken arm because you're trans?' I know that's kind of a ridiculous statement, but there are layers that go on top of that [identity] that...you have to navigate. (Bailey)

population will lead to an additional increase in literature and research addressing the health-related needs of LGBT people since the amount of research has already increased over the past several years (Coulter, Kenst, Bowen, & Scout, 2014). Professional organizations such as the American Psychological Association (2015), the American Counseling Association

(2010), and the National Association of Social Workers (2015) have provided recommendations and competencies to guide general work with transgender clients that include direction not to pathologize gender diversity and to affirm diverse gender identities. These guidelines are helpful, but they primarily govern work in the mental health fields and do not address specific needs and challenges that may impact health care access among transgender individuals in rural and remote areas.

Likewise, the World Professional Association for Transgender Health (2011) publishes Standards of Care (SOC) for medical treatment of transgender individuals, but little is known about how frequently these guidelines are followed, and so far, the guidelines are recommendations and not enforce-

able. Furthermore, these broad guidelines may not address the nuanced challenges experienced by transgender people in rural areas. In other words, the Standards of Care may not buffer or alter anti-transgender bias held by health care professionals in remote areas of the U.S. (Eliason & Hughes, 2004).

What we know about transgender health so far does not provide an adequate picture of health care provision for rural transgender people. Furthermore, it is unknown what effect, if any, rural location has for transgender individuals. So far, research has been limited in its geographical scope regarding transgender populations (NIH, 2015). The little we do know from studies that have included LGBT individuals in rural areas, is that transgender people in rural areas may receive treatment that is of a lower quality than the care received by cisgender people (Willging et al., 2006). Given the disproportionate health issues experienced by transgender relative to the general U.S. population, this possible trend of inadequate health care provision is troubling.

Researchers have demonstrated that members of the transgender community suffer disproportionately from elevated rates of depression, anxiety, substance abuse, and suicidal ideation relative to the general U.S. population (Clements-Nolle, Marx, Guzman, & Katz, 2001; Clements-Nolle, Marx, & Katz, 2006; Hughes & Eliason, 2002; NIH, 2016). Scholars have indicated that these challenges to transgender health may stem from gender-based discrimination and minority stress (Clements-Nolle, Marx, & Katz, 2006; Meyer, 2003). Meanwhile, nationwide surveys have also pointed to high rates of homelessness, psychological distress, and HIV infection among transgender individuals relative to the general population (James, Herma, Rankin, Keisling, Mottet, & Anafi, 2016).

Given the high need for quality health care among transgender people and the potential that health care provision in rural areas may be subpar, we reached out to members of the transgender community to assess their experiences accessing health care. This qualitative, exploratory study represents an exploration of the health care related experiences of transgender people in rural areas through rich description of their stories. We interviewed participants using a semi-structured interview protocol that focused on health care access in rural locations. The research questions that informed the study were: “What are the experiences of transgender people living in a rural area in regard to accessing health care?”, “What are examples of specific encounters with health care professionals from the perspectives of transgender people?”, and “What are recommendations or insights that may be offered by transgender people to health care providers?”

Methods

We asked participants to self-identify their gender and sexual/affectual orientation. Participants were 10 transgender and gender diverse identified individuals above the age of 18 who lived in rural and remote areas of the United States. As is common in qualitative research, we utilized homogenous sampling to obtain “*information-rich* cases for study in depth” (Gleisne, 2006, p. 34). As recommended by Patton (2002) we used purposeful selection criteria to guide our recruitment of participants who identified as transgender or gender diverse, were older than 18 years old, and lived in rural or remote areas. Given the homogenous composition of our sample in regard to gender identity and location, our sample size of 10 participants is considered adequate for the

phenomenological qualitative analysis we used (Glesne, 2006; Hill, 2012).

Participants represented a broad range of sexual/affective orientations. Their ages ranged from 23 – 59 years old ($M = 36.2$ years). Participants identified as White (7), Multi-Racial (2), and American Indian or Alaskan Native (1). For additional demographic information see *Table 1*. Considering the qualitative nature of our study, we allowed participants to self-identify as residents of rural and/or remote areas of the U.S. We included questions about participant location in our demographic form and we automatically excluded prospective participants who reported living within the city limits of large urban centers. We also included a question about participant rurality in our semi-structured interview script and we found that participants described their locations based on a variety of markers. For example, two participants stated that their town featured only one or two stoplights while two other participants talked about their proximity to other residents using undeveloped roads. A primary characteristic shared among participants was their perception of being distant from urban centers or nested in a remote area of the U.S.

Throughout the conduct of this study, we were guided by broader phenomenological research methods outlined in Glesne (2006) and more specifically organized by Hill (2012) in her Consensual Qualitative Research approach. Central to Hill's (2012) methodology is an inductive approach through which participant responses give rise to the results, open-ended interview questions, and small sample sizes, among other components. We indicate adherence to phenomenological methodological approaches with in-text citations throughout the following text.

Participants were recruited nationally

through LGBT organizations, professional list-servs, and Facebook groups. IRB approved recruitment materials included a list-serv email and a flyer which were distributed both physically and electronically. Interested participants who contacted the primary investigator were emailed a link to a Qualtrics-based survey with three parts: an informed consent form, a basic demographic questionnaire, and a scheduling matrix that allowed participants to indicate their availability for the approximately one-and-a-half-hour interview. After participants completed the Qualtrics survey, the primary investigator contacted them via email to confirm an interview date and time.

We conducted interviews using a 15 item, semi-structured interview protocol created using CQR guidelines and general phenomenological interviewing techniques (Glesne, 2006; Hill, 2012). We drafted interview questions based on our knowledge of the literature. The interview protocol was designed to begin with general questions and build to more specific and personal questions in order to facilitate rapport and openness (Glesne, 2006). The interview included questions about transition, their location, and healthcare experiences.

As interviews were conducted, they were transcribed either by the PI or by a third-party transcriber. Audio files were transcribed verbatim and were cross-checked for accuracy by research team members (Hill, 2012). Transcripts were thoroughly de-identified.

The research team included five members, all of whom identified as White and cisgender: a gay, male doctoral student; a pansexual, female doctoral student; a heterosexual, male doctoral student; a queer, female doctoral student (the auditor); and a queer, female faculty member. The research team first met to discuss biases and expectations as recommended in Consensual Qual-

itative Research (CQR) (Hill, 2012). By highlighting and recording their biases and expectations for the study, the team sought to hold each other accountable during the coding process. Also, team members read articles on structured phenomenological qualitative approaches in preparation for the study (Hill, Knox, Thompson, Williams, Hess, & Landany, 2005; Hill, Thompson, & Williams, 1997). Several of the research team members conducted CQR and other qualitative studies before, and were familiar with coding, auditing, and research team procedures.

Research team members shared a pre-existing bias that rural areas are averse places for transgender people to live, and that transgender people in rural areas have fewer resources. We also held in common a desire to advocate for better treatment for gender diverse individuals. A few research team members who identified as sexual minorities shared their own stories of being misdiagnosed and/or mistreated by medical professionals. As a group, we expected that participants would share stories about harassment and rejection by health care professionals. Throughout data collection and analysis, we held each other accountable for these pre-existing biases and expectations and used our external auditor to check any potential assumptions about participant experiences that were showing up in our coding scheme.

Data Analysis

As recommended by Glesne (2006), the researchers utilized multiple files in order to organize and analyze the interview data. These included a domain table, separate files for each interview, quote documents, and frequency tables. These files were created and updated throughout the process of data analysis. For the first transcript, the core research

team met and dialogued about possible codes that could be used to organize the “fat data” of the text into more manageable units for analysis (Glesne, 2006, p 151). These codes were then applied to subsequent transcripts, renegotiated, and refined. Beginning with transcript two, researchers coded the documents separately and then met to work to consensus in groups of three (Hill, 2012). After the sixth transcript, the research team submitted all data and the most recent domain table to the outside auditor for review. This auditor had not been in attendance at consensus-building coding meetings and was, therefore, able to provide a more unbiased critique of coding decisions and code definitions (Hill, 2012). Audit results were processed by the research team and were resolved through dialogue with the auditor before the established domain list was applied to the remaining four transcripts.

After we coded all transcripts and reconciled differences of opinion through consensus, we calculated the frequency of participant statements for each code (*Table 2*) (Glesne, 2006). Significant quotes were also highlighted and collected into separate documents by research team members. Through a process of negotiation and inductive analyses of the transcripts, the researchers created broad categories to capture overarching components of the participants’ experiences. These categories were further deconstructed into sub-codes called domains (Hill, 2012). Some domains were even further dissected into qualifiers as to whether the domain was experienced by the participant positively, negatively, or as neutral (*Table 2*).

Results

The four large categories that took shape as the research team analyzed the data were:

Transitions, Providers, Social, and Recommendations. *Transitions* contains information about participants' gender identities and their experiences with visibility and/or different transitions (physical, social, etc.) within their rural locations. The *providers* category includes content regarding the experiences and interactions of participants with providers and their staff. *Social* encompasses information about ways that participants have pushed for better health care in their rural locations and the *recommendations* category includes direct suggestions from participants to providers about ways that service provision may be improved.

We break each of these categories down further into major domains below and offer definitions, sample quotes, and anecdotes for each category. We provide a narrative description of results without sub-domains in order to increase accessibility of the narrative. These sub-domains were, however, retained for the frequency counts presented in *Table 2*. Stories and quotes have been extensively de-identified and some verbal fillers (e.g., um, uh, like) were removed to increase readability of the quotes. Because of the small number of participants, we will use gender-neutral "they/them/their" pronouns and pseudonyms for all participants to facilitate de-identification.

Transitions

The first category, *transitions*, arose from participant stories and reflections on factors directly related to their rural location and their gender identity and/or process of transition. This category contained three subdomains, the *process*, *experiences*, and *resources*, which we discuss in further detail below.

The process. Participants discussed a variety of dimensions pertaining to their identities as transgender individuals in ru-

ral and remote areas. Much of the content in this domain was descriptive and related to thoughts, reflections, and other variables involved in transitions. For example, consistent with other participants, Sam highlighted the role of the internet in their identity development:

"...I knew that I was different since I was younger. I've always kind of known this. I just kind of blew it off because I didn't know what to do between family and everything. So, we didn't have the internet until I was like seventeen or eighteen and that's when I started searching, 'Why I feel like a girl?' The kind of phrases I would look up and stuff."

This internet theme resurfaced when we asked participants how they found health resources in their area later in the interview. As rural areas offer few encounters with other transgender people, the internet plays an important role.

Experiences. Similar to statements included in *the process*, participants offered direct information about their physical, emotional, and behavioral reactions to health care experiences. This domain differed from *the process* because content related more to participants' specific medical needs involved in transition.

Participants described a wide range of emotions resulting from health care encounters. Arguably, the most noteworthy among these were statements about feeling dehumanized or isolated by negative treatment from health care providers. For example, Sage stated:

"I get the feeling that the medical professionals in my town do not consider me a priority. They don't ... they don't understand and they don't want to understand. And it makes me feel very isolated. And it makes me feel ... abnormal."

Later, they said:

"I think that the cis-people in my area can expect to have medical care that includes a basic understanding of their physiology and

what type of care they require. Being trans has given me the feeling that I'm a medical oddity and that I do not belong here."

As indicated by Sage's story above, negative emotions and encounters with providers were connected with behaviors such as avoidance of medical care and postponement of treatment. Bobbie shared, "Well, actually up until this past few months I've ... kind of put several things related to my health on the back burner. Things like ... seeing an eye doctor, dealing with a sleep disorder ..." In the context of rural areas where transgender people may feel unwelcome, feelings of being a "medical oddity" or of being out of place in the health care system may add to concerns about accessing vital services such as mental health support.

Resources. The final domain in the *transition* category is *resources*. *Resources* refers to access to or use of assets such as time, money, transportation, medical specialists, insurance, and other items or commodities, particularly related to the rural or remote location.

Participants talked about the dearth of resources and providers in their immediate rural area. Bryn stated:

"I think that ... a lack of access to health education and lack of access to health services is a hardship of the area that I live in. I participate in a PFLAG group and we do educational meetings...and one of the things that we wanted to educate our group on was HIV awareness. And it was almost impossible to find someone in this area who knew anything about HIV awareness. And so that's the kind of thing, you know? People in a rural area ought to have just as much access to that kind of education and care as people in an urban area. But we couldn't find someone to come in and talk about HIV education because of where we live. We finally asked someone to drive in from [a large city] to do it for us."

Ash shared a disappointing challenge that resulted when competent providers

were not available:

"... without the support of somebody local who is at least, you know, 'Look, maybe we need to look into this, because there is a significant amount of symptoms that indicate that this is a problem.' And there is some very possibly life-threatening issues here that need to be addressed. And, without somebody that's local even acknowledging any of this, I can't possibly justify going and ruining what little bit of a life that we have chasing down what could well be just another dead end."

Reflecting on the distance some of them are forced to drive in order to access services in urban areas, participants listed a variety of demands that their rural location places on their resources. These included: time, money, transportation issues, scheduling, time off from work, and other issues. Casey framed the issues well when they said:

"If I've got to drive to my endocrinologist, it's a whole day thing. I can't work that day because it takes an hour and a half to two hours to get there, I'm usually there for two hours and then it takes another two hours to get back. It's not just a run down the street. It takes a whole day of planning to go to this endocrinologist."

Providers

The next major category included experiences related specifically to interactions with and behaviors of health care providers. This category included the four domains: *provider behaviors*, *perception of providers*, *relationship with providers*, and *provider training*.

Provider Behaviors. Participants talked about specific provider behaviors that ranged from extreme forms of mistreatment to supportive acts of advocacy. This domain captured both specific actions performed by providers and when providers refused to take action.

Negative provider behaviors included reports of misrepresented test results, malprac-

tice, neglect, withholding of information or treatment, tendency to conflate gender identity with unrelated presenting concerns, and mistreatment from supporting staff such as receptionists. For example, Ash reported being told at a medical center, “Get out of here. We’re not going to help you. We can’t help you. You need help, but not from us.” Ash went on to say, “And I’ve heard that time and time, again. ‘There’s something wrong with you, but we can’t help you.’” It was not uncommon for participants to be told that they could not be helped or for them to be asked to leave a facility. When searching for medical services, Jesse said they would call to check about whether or not a given doctor would see them. Jesse stated:

“And I would say, ‘OK, do you think the doctor would want to see me or would you check to see?’ And some of them would say, ‘I’ll check.’ And then some of them would say, ‘I know he won’t. Don’t come here. You’ll get thrown out.’”

Likewise, Bobbie reported being “turned away” by 15 doctors before they found one who was willing to provide hormone treatment. Kennedy told a story about a therapist who “took one of my hands and compared it with his own hands to see if my index finger was longer than my ring finger to determine if I was gay.”

Both Ash and Jesse spoke about times that their medical records had been lost or misplaced. Jesse said:

“And I’ve had this issue at [hospital omitted] on several occasions. I had it when I was going to see a rheumatologist about my arthritis. I had a whole-body X-ray that was ordered and I go and I get the test done and...it took six weeks to find those X-rays. They misfiled 20 X-rays? They’re digital f--ing X-rays! How do you misfile them? It’s not like somebody says, ‘Hey Ethel, let’s go out for coffee’ and you drop them in the wrong drawer. So, I have to question if those X-rays were lost because somebody just really wanted to say, f-- it. I really be-

lieve a lot of this is intentional prejudice.”

Participants indicated that some of the doctors who would see them charged more for their services or demanded that they pay in cash. Bryn shared:

“The fact that these doctors are aware of how unique they are, they often charge more. So that’s a part of the burden also. Some of them don’t file insurance on your behalf, because they’re aware of how unique they are and they know they can get away with that. And so they’ll charge you full price and then you have to file your insurance on your own afterwards. So, yeah, there are definitely some financial impacts, because, I mean you know, there are two or three doctors in a 150-mile radius, and they know they’re the only ones who do this. And so they ... they kind of take advantage of it.”

Participants also shared examples of altruism on the part of medical professionals. Participants spoke about counselors who empowered them and about doctors who provided referrals for life-saving treatments. As mentioned earlier, Bryn worked through a list of 15 doctors before they “finally found one and she referred me to my doctor [in a large urban area].” Likewise, sometimes providers made a large impact on participants simply by using a participant’s correct name and pronouns. Bryn casually stated, “...then they were nice when the appointment happened, because like I said, they scratched out and put my name on the [intake] paper.” For participants, the fact that many of these doctors were in rural areas added to the impact of their kindness.

Perception of providers. Some participants described an overall feeling or perspective on rural providers that was not tied to a specific behavior or incident. For example, some participants described feeling as if certain rural providers were generally unhelpful, wrong, or incompetent when it came to transgender issues. Others perceived their

providers to be incorrect about health care decisions. Some participants tended not to trust doctors in rural areas. For example, Bobbie said, “For transgender [health care], I would recommend going to a bigger city, personally. I wouldn’t recommend a rural doctor period.” Sage shared similar sentiments when they said, “I get the feeling that the medical professionals in my town do not consider me a priority. They don’t ... they don’t understand and they don’t want to understand.”

These perspectives and experiences caused participants to set low expectations for rural health care. When asked to give recommendations for providers to improve services, Sage expressed difficulty believing medical sensitivity to transgender individuals could increase. They stated:

“One thing that has made me feel not being able to find easy access to transgender health in my area, it’s ... sort of conditioned me to accept the bare minimum from medical professionals. And I can’t even imagine a medical professional going above and beyond for someone ... for a transgender person around here.”

Campbell shared a negative view about the attitudes of rural doctors when they said:

“So the first doctor that I went to see about my transition, I was referred to them by the therapist that I was seeing...and some other transgender people. So they have been used to trans patients, but frankly they weren’t very good. Um, they weren’t very friendly. They were just like, ‘Ugh, another one.’ Like they were willing to do it, but they didn’t really give a lot of care and consideration to their patients.”

However, when rural medical providers were perceived to be competent and caring, participants were energetic in their praise of the services they received. Campbell shared:

“So she [a psychiatrist] can take care of the physical health and the mental health aspects, which has been really great. Because for me, a lot of my symptoms physically

have actually been related to the stress and everything else everything I’ve been going through psychologically. And so it’s been really great to have somebody that’s knowledge in both areas.”

Relationship with providers. Participants spoke about interpersonal dynamics between themselves and their rural providers. These dynamics were marked by either trust and warmth or mistrust and discomfort.

Some participants reported difficulty communicating with rural providers due to mistrust and a lack of comfort or ease around the provider due to the participants’ gender identity. Other participants felt completely misunderstood. For example, Bailey shared:

“I mean that was one of the things when I was in the hospital. You talk to a lot of therapists...who may not have any experience with trans people that they know of and so you get people who...say, ‘Just thinking in terms of your marriage’ because I was married for [number of years omitted], ‘sex isn’t everything and you know you need to be able to move on.’ And it’s like, ‘I don’t think you understand. This really has nothing to do with my sexuality. This is an identity thing, but you’re conflating them.’”

Casey shared, “I mean, I just try to deal with the doctors as little as I can.” Sage shared having “the feeling that I can’t really, truly rely on medical professionals in a complete way.”

Concerns among participants about how they would be treated by rural health care professionals impacted the way that participants prepared for their medical visits. Ash shared a fear of showing up at the doctor’s office “all scatterbrained” although they stated that, for all of their preparation, “we don’t ever get anywhere.” Participants also shared how difficult it can be to establish a relationship with a new provider. Bryn said:

“Especially if it’s somebody new that I’m seeing. If I get referred to somebody and I’ve never met them before or if I know that

I'm going to have to explain, 'Well, I've had this surgery and this surgery and I have this part and not this part and that's because I'm trans.'"

Some participants described the process of coming to terms with the necessity of coming out to doctors and medical professionals. They also indicated, based on their experiences with providers that attitudes toward transgender people may be improving. Sage shared, "It's gotten a lot better over the past few years. Now, I'm not so nervous about having to say that I'm transgender [at the hospital]." Sam stated that correct pronoun use indicates to them that the provider is "trying" and that this effort produces positive emotions and validation.

Provider Training. Participants discussed the level of knowledge and information that rural providers seemed to have about transgender issues. This category included reports of misinformation or a need for education among rural providers.

Participants regularly talked about the need to educate rural providers. Jesse shared, "Then I had to go through teaching a doctor about cross-gender hormones and what tests did they need to do with me and what drugs they needed to prescribe for me and provide them with all of the stuff." Bryn described this dynamic in terms of a hardship:

"There's the hardship then of me having to do the education in the health care setting. And I felt that way when I started my transition. There were several providers that I went to and I had to teach them what transgender was. And that's a hardship. It shouldn't be my responsibility to educate my healthcare provider."

Jesse said, "You know, I've had people that have no f--ing idea what that [transgender] was. I had to explain it."

Sage further elaborated on the lack of training and on a perceived lack of motivation among rural doctors to self-educate.

"It honestly feels as if medical professionals have made a point to not educate themselves about trans health, even though they are aware that transgender people exist. I understand that transgender people are rare in my area, but I'm also aware that even rarer medical issues are covered in basic healthcare training at least cursory level. If someone were to come in with a rare type of cancer, to their primary care physician in this area, I imagine... the doctor would at least know where to refer the patient to so they can receive care. Or if they don't know, they make a point to find out. For care related to trans issues, it's been the exact opposite to me. Doctors don't know and don't care to know."

Social Dimensions

Some participants shared experiences of *social* or interpersonal experiences in their interviews. While these stories were powerful and we included them in our coding, most did not directly relate to health care provision. Still, our participants shared important examples of ways they became involved in advocating for better rural health care.

Self-advocacy. The data provided narratives of steps that participants had taken to care for themselves and to increase the quality of rural services for others. Casey seemed to put it best when they said:

"Um, I would tell them [other transgender people] that it's going to be some of the most difficult situations in your life that you're going to be in that you could lose friends or things over this but you have to you know, you have to take care of yourself."

A number of participants told us that they were participating in this study as a form of advocacy for themselves and for their communities. An example of this self-advocacy was offered by Jesse who said, "...whenever I see a [intake] form like that, I will talk to the staff, get a blank form, and write in edits on it and suggestions to change it..."

Two of our participants had been in-

volved in creating lists of competent, transgender affirmative providers in their local rural areas. Another of our participants had the resources to be seen outside of their local area for health care, but they chose to be seen by local doctors so that those doctors would have experience with a transgender person that they could use to treat others with fewer resources who could not seek care outside of their community. Yet another participant in a remote area hosted gatherings and pool parties where attendees could enjoy a harassment free environment.

Recommendations for Providers

The final theme included *recommendations* offered by our participants. In general, participants highlighted the demand that their rural location places on resources such as time, money, and transportation. They also highlighted a need for rural providers to educate themselves about transgender issues and for urban providers to be more sensitive to the needs of rural consumers.

Advertising, resources, and transportation. Participants highlighted the need for providers to have referral lists and awareness of resources. Bryn said, “There need to be resources available in doctor’s offices. I would like to see pamphlets put out in doctors’ offices that provide this information.” Kennedy also encouraged providers to have “more awareness of what services are out there...” Participants highlighted the need for case managers who can help with transportation, networking, and information about navigating insurance issues. As noted by participants, transportation is a significant issue for transgender people in rural areas.

Outreach and remote services. Participants highlighted that transgender people would benefit from the extension of urban services into rural areas. Bobbie suggested

that urban providers offer satellite support groups in rural areas. Bryn highlighted the importance of free testing services. Casey also suggested that medical professionals attend a support group or meeting for a transgender organization. Jesse asked providers to “...do outreach...look for transgender support groups and then call them and say, ‘Hey, I’m Dr. so and so. I provide this service. Would you put me on your list?’”

Additional education. Participants expressed frustration that rural medical providers were not taking more initiative to educate themselves about transgender issues. As Casey stated, “Google should be your best friend, I mean, it takes just a second. If you haven’t heard of something, just look it up.” Campbell said, “You need to know about us before we get to you.”

Bryn noted, “The health care system ought to be doing this for us, but here we are doing it for them.” Bryn went on to say:

“I get calls from hospitals, from nursing staffs at doctors’ clinics asking me to come teach them about transgender people. I think that’s great that they want to learn, but why aren’t they getting that as part of their preparation to be doctors and nurses?”

Jesse went a step further by asking providers to “join WPATH.”

Participants noted that they are often diagnosed based on their gender identity. P1 stated, “They [medical providers] need to quit making up their minds about people before they even listen to what they have to say.” Bryn added, “...that’s something that I think that more medical providers need to get is that you don’t have to have all the answers, but you do have to have a measure of respect for people.” Participants highlighted this necessity for rural providers who may be more susceptible to stereotypes and assumptions since they may have less experience with transgender individuals.

Facility design. A few participants not-

ed that even urban facilities that are more transgender affirmative, may come across as cold and anxiety provoking. When waiting rooms are small, transgender individuals may be forced to sit close to cisgender patients who are visibly uncomfortable. Campbell suggested, “My biggest thing would be to make it as calm and comfortable as possible: comfortable chairs, calming colors, some nice photos.” Participants stated that rural offices may be more inviting and cozy whereas urban offices maybe daunting for rural residents if they present a more clinical, sterilized feel.

Support staff. Jesse said, “I have found more discrimination coming from non-health care personnel in a medical environment than I have from nurses and doctors.”

Jesse went on to note:

“You don’t get to talk to the doctor. You get to talk with the office staff. The doctor doesn’t call you with your test results, the office staff does. The doctor doesn’t schedule your follow-ups; the office staff does. So educating that office staff is as important as a doctor knowing what the hell to do once you get back there on the table.”

Bryn recommended:

“Just make sure that there is some kind of policy or procedure in your office when someone calls and says ‘I’m trans or non-binary and I want to get health services at your office’ so that the front office staff doesn’t stutter and flutter and wonder what to do with this person. Make sure that they know exactly how to handle it, how to gender them correctly, how to handle their name if they have a name they use that’s different from the name that’s going to be on their insurance card – a procedure in place automatically.”

Pronouns. Sage offered, “A pronoun is basically the foundation of all of it.” Sage went on to encourage medical providers to rethink their medical forms. They asked providers to “have a box for you [the patient] to fill in what pronouns you want. That

would probably be a good, tangible way for them to try to figure out what pronouns a person wants instead of assuming them.” Sam shared how important pronoun use was to them when they were transitioning and hinted at the negative impact of being misgendered by health care professionals. Kennedy also mentioned the importance of correct pronoun use.

Discussion

The aim of this project was to provide insight into the experiences of transgender people in rural areas as they engage with the health care system through a qualitative exploration of their stories. Our qualitative analysis resulted in four major categories with twelve domains. In addition to vignettes and stories, our participants offered recommendations for providers who wish to provide more competent services to transgender people in rural areas.

As has been indicated in prior studies, we found that our participants face a myriad of challenges and that some of the negative emotions reported by transgender people, such a depression and anxiety (Clements-Nolle et al., 2006; NIH, 2016), were tied to health care experiences for our participants. Health care related negative emotions and personal struggles were captured in our *transitions* category. As a result of their interactions with health care providers, our participants reported negative emotions, misdiagnoses, and interactions with professionals that exacerbated, rather than reduced, the difficulties faced by these participants. When our participants did report finding resources, they generally indicated that they found sources of care through social networks, the internet, and through their own efforts rather than through their health care providers.

These findings are congruent with indications that the overall quality of rural care may be of diminished quality (Willging et al., 2006). Our *providers* category contains a variety of stories about negative or even negligent behavior on the part of health care professionals. Our participants directly linked their experiences to their rural location and clearly expressed feelings that providers in urban areas have more experience with treating transgender people. Participants repeatedly called on providers to seek continuing education in the area of transgender health.

In addition to providing more insight into health care access in rural areas, our findings add to the existing indications from scholars that transgender people in rural areas face additional barriers to treatment such as limited resources, transportation issues, and exposure to providers who may possess deficits in knowledge regarding transgender health concerns (Snelgrove et al., 2012). Our *resources* domain highlights issues with transportation, access, financial resources and employment reported by our participants. These resource and access issues certainly reflect nationwide trends (James et al., 2016). However, there is little quantitative data with large samples to indicate whether the issues faced by our participants outpace national statistics.

Given these deficits, it is worth noting that our participants offered recommendations that align with the many of the guidelines that have been offered by scholars and professional organizations (ACA, 2010; APA, 2015; Koch & Knutson, 2016; Lombardi, 2001, WPATH, 2011). In other words, our participants advised providers to use appropriate pronouns, more accurately assess gender identity on intake paperwork, and obtain continuing education on transgender health. These best practices are already encouraged by professional organiza-

tions and scholars (ACA, 2010; APA, 2015; Koch & Knutson, 2016; Lombardi, 2001, WPATH, 2011). Our findings may offer preliminary indications that these guidelines are not being followed in rural areas, despite their wide circulation and increasing visibility. This may be due to the fact that current guidelines are aspirational and generally unenforceable. One major place this lack of adherence to best practices may show up is in relationships with providers (Kitts, 2010; Snelgrove et al., 2012) as captured in our *providers* category.

In addition to bolstering existing guidelines and recommendations, our participants emphasized two additional dimensions of rural experience: the role of support staff and the importance of pronouns. Participants noted that support staff are often the first point of contact for a consumer, and that the staff's behavior can significantly impact one's experience regardless of the attitude or training of the providers themselves. Additionally, participants reinforced the need for medical forms to take into account gender variance and to demonstrate sensitivity to the identity of gender diverse individuals.

We also wish to highlight a major finding of this study regarding the resilience and self-advocacy of our participants that was captured in our *social dimensions* category. Our participants told powerful stories about creating resource lists, staying in their rural locations to obtain health care in an effort to educate their physicians, and of creating social support networks through which resources and information were shared. For all of the negative implications of this study, we wish to highlight and invite more study of the strengths and positive potential within the transgender community.

Finally, we believe that our findings offer important awareness and opportunities for the health care community. Based on our

results, we strongly encourage medical providers and educators to further incorporate information about transgender health care into training and educational curricula. We are aware that wonderful guidelines exist, but these best practices are only beneficial when they are implemented. Additionally, our findings further support calls for research into the unique struggles faced by transgender people in rural areas. Broader studies with larger sample sizes are needed in order to further highlight disparities that may exist between transgender individuals in different areas of the U.S. and elsewhere.

Limitations

As a qualitative study, this project was subject to the limitations of qualitative data. Recruitment of transgender people who were in rural or remote locations was very challenging and the majority of participants were recruited through Facebook groups. This means that people without internet access and/or who are not involved in social media may have been excluded. Access to email was imperative since all communication with participants was conducted via email. Additionally, interviews were conducted by phone or via skype. Individuals without consistent access to phone and/or internet were excluded from participation in this study. Furthermore, due to challenges obtaining participants, we conducted interviews over a 15-month period beginning in September, 2015 and ending in November, 2016.

Prospective participants may have been dissuaded from participation by the fact that the study was being conducted by mental health professionals and scholars through a university. The scholarly perspective of the research team may have impacted results as well. All research team members had con-

ducted studies and had engaged in therapeutic work with LGBT individuals. In addition to the strong sense of advocacy expressed by research team members at the beginning of the study, prior knowledge may have impacted the way that transcripts were coded. The research team worked hard to reduce the impact of biases on the project: we discussed biases at the beginning of the project, we consulted with an auditor, and we coded transcripts through consensus with attention to possible preconceptions.

Conclusions

Our participants reported a variety of experiences accessing health care as residents of the U.S. in rural and remote areas. These issues may guide and inform practitioners as they expand their services to include support for transgender individuals. Our work may also form the basis for future studies in this area. Additional research is needed with larger samples to assess the quality of health care experiences and to provide additional guidance as to how services may be improved ■

Address correspondence to:

Douglas Knutson, Oklahoma State University, School of Applied Health and Educational Psychology, 434B Willard Hall, Stillwater, OK, Email: douglas.knutson@okstate.edu

References

- American Psychological Association (APA). (2015). Guidelines for psychological practice with transgender and gender nonconforming people. *American Psychologist*, 70, 832-864. doi: 10.1037/a0039906
- American Counseling Association. (2010). American Counseling Association competencies for counseling with transgender clients. *Journal of LGBT Issues in Counseling*, 4, 135-159. doi: 10.1080/15538605.2010.524839
- Clements-Nolle, K., Marx, R., & Katz, M. (2006). Attempted suicide among transgender persons: The influence of gender-based discrimination and victimization. *Journal of Homosexuality*, 51, 53-69. doi:10.1300/J082v51n03_04
- Clements-Nolle, K., Marx, R., Guzman, R., & Katz, M. (2001). HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health intervention. *American Journal of Public Health*, 91, 918-921. doi:10.2105/AJPH.91.6.615
- Coulter, R. W. S., Kenst, K. S., Bowen, D. J., & Scout. (2014). Research funded by the National Institutes of Health on the health of lesbian, gay, bisexual, and transgender populations. *American Journal of Public Health*, 104(2), 105-112. doi:10.2105/AJPH.2013.301501
- Eliason, M. J., & Hughes, T. (2004). Treatment counselor's attitudes about lesbian, gay, bisexual, and transgendered clients: Urban vs. rural settings. *Substance Use & Misuse*, 39, 625-644. doi:10.1081/JA-120030063
- Glesne, C. (2006). *Becoming qualitative researchers: An introduction* (3rd ed.). Boston: Pearson Education, Inc.
- Hill, C. E., Thompson, B. J., & Williams, E. N. (1997). A guide to conducting consensual qualitative research. *The Counseling Psychologist*, 25, 517-572.
- Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology*, 52, 196-205. doi: 10.1037/0022-0167.52.2.196
- Hill, C. E. (Ed.). (2012). *Consensual qualitative research: A practical resource for investigating social science phenomena*. Washington, DC: American Psychological Association.
- Horvath, K. J., Iantaffi, A., Swinburne-Romine, R., & Bockting, W. (2014). A comparison of mental health, substance use, and sexual risk behaviors between rural and non-rural transgender persons. *Journal of Homosexuality*, 61, 1117-1130. doi:10.1080/00918369.2014.872502
- Hughes, T. L., & Eliason, M. (2000). Substance use and abuse in lesbian, gay, bisexual and transgender populations. *The Journal of Primary Prevention*, 22, 263-298. doi:10.1023/A:1013669705086
- James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). *Executive summary of the 2015 U.S. transgender survey*. Washington, DC: National Center for Transgender Equality.
- Kitts, R. (2010). Barriers to optimal care between physicians and lesbian, gay, bisexual, transgender, and questioning adolescent patients. *Journal of Homosexuality*, 57, 730-747. doi: 10.1080/00918369.2010.485872
- Koch, J. M., & Knutson, D. (2016). Transgender clients in rural areas and small towns. *Journal of Rural Mental Health*. doi:10.1037/rmh0000056
- Lombardi, E. (2001). Enhancing transgender health care. *American Journal of Public Health*, 91, 869-872. doi: 10.2105/AJPH.91.6.869
- Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin*, 129, 674-697. doi: 10.1037/0033-2909.129.5.674
- National Association of Social Workers. (2015). *Policy statement: Sexual orientation change efforts (SOCE) and conversion therapy with lesbians, gay men, bisexuals, and transgender persons*. Retrieved from http://www.socialworkers.org/diversity/new/documents/HRIA_PRO_18315_SOCE_June_2015.pdf
- National Institutes of Health. (2015). *Strategic plan to advance research on the health and well-being of sexual and gender minorities: FY 2016 – 2020* (Federal Register Document Citation: 80 FR 59169). Retrieved from <https://www.federalregister.gov/documents/2015/10/01/2015-25026/the-national-institutes-of-health-fy-2016-2020-strategic-plan-to-advance-research-on-the-health-and>
- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1, 261-283. doi: 10.1177/1473325002001003636
- Pérez-Stable, E. J. (2016, October 6). Sexual and gender minorities formally designated as a

health disparity population for research purposes [Web log post]. Retrieved from <https://www.nimhd.nih.gov/about/directors-corner/message.html>

- Snelgrove, J. W., Jasudavicius, A. M., Rowe, B. W., Head, E. M., & Bauer, G. R. (2012). "Completely out-at-sea" with "two-gender-medicine": A qualitative analysis of physician-side barriers to providing healthcare for transgender patients. *BMC Health Services Research*, 12(110), 1-13. Accessed from <http://www.biomedcentral.com/1472-6963/12/110>
- Willging, C. E., Salvador, M., & Kano, M. (2006). Pragmatic help seeking: How sexual and gender minority groups access mental health care in a rural state. *Psychiatric Services*, 57(6), 871-874. doi:10.1176/appi.ps.57.6.871
- World Professional Association for Transgender Health (WPATH). (2011). *Standards of care for the health of transsexual, transgender, and gender nonconforming people* (7th version). Retrieved from http://www.wpath.org/uploaded_files/140/files/Standards%20of%20CARE,%20V7%20Full%20Book.pdf